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[Free Hand Press Letter Regarding Americans with Disabilities] [loose]

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Free Hand Press

- publishers of Mouth magazine
the voice of disability rights

January 5, 1995

George Stephanopolous, Office of Policy and Strategy
The White House
1600 Pennsylvania Avenue NW
Washington, DC 20500

Dear Mr. Stephanopolous,

We are people with disabilities. For all of the years that good-hearted advocates have spoken on our behalf, a great deal has been accomplished and a great deal has been lost as well.

Point of fact: Today 2.4 million Americans with disabilities are held, most of us against our will, in nursing homes, state schools, county hospitals, and so-called "facilities" of various kinds — largely at taxpayer expense. Please get these two things straight:

- (1) no American is consigned to a care facility unless they have a disability
- (2) what transpires in long-term care facilities is not *care* but captivity.

The operators call us "guests" or "residents." In truth we are only hostages, held for a ransom of taxpayer dollars in this proud country which purports to lead the worldwide fight for freedom.

This is not a question of "where a few people want to live," as Governor Tommy Thompson put it. Freedom is the issue here — the *only* issue. We have resolved that the "care" industry will not claim more generations of our people. We will speak for ourselves and determine our own destiny. *You Choose* is the first public raising of our voices toward that end.

Twelve thousand copies of *You Choose* are in the hands of people with disabilities who are hand-delivering them to federal and state legislators and the press as we speak and over the next eight weeks. We hope that you and the entire Clinton administration will stand with us against those who speak not for us but for our captors.

The facts, figures and the faces of reality we have published here may be of use to you as well in holding the line on Medicaid entitlements and the federal management of Medicaid. Without that much, we are surely lost.

Most sincerely,

Lucy Gwin, editor

61 Brighton St. Rochester New York 14607-2656
telephone (716) 473-6764 - fax (716) 442-2916



What
would
you
choose
for
child?



National average annual cost to
taxpayers of housing one person
in a state institution for persons
with developmental disabilities

\$82,228

*In 1994, 77,618 children and adults
lived in America's state-owned
institutions for people with mental
retardation and developmental
disabilities. Most of the families and
individuals served in this way did not
have a choice.*

In 1994, most states offered assistance to families and individuals with developmental disabilities under Medicaid Home- and Community-Based Services waivers. Those waivers, which help keep children and adults with developmental disabilities out of institutions, were available to 157,180 people at an average annual \$27,649 taxpayer cost per person served nationwide.

State waiting lists for qualifying families are as long as ten years.



In 1992, 7,538 adults with developmental disabilities in some states received supports known as Personal Assistance Services so that they might live in the community. The average cost per person served was \$1,753. 14,779 others received Supported Living services in some states at an average annual taxpayer cost per person so served of \$7,569.

**This figure includes both people who require 24-hour support and people who require fewer services.*

National average annual cost to taxpayers of the most expensive support services for a developmentally disabled person living at home

\$27,649*

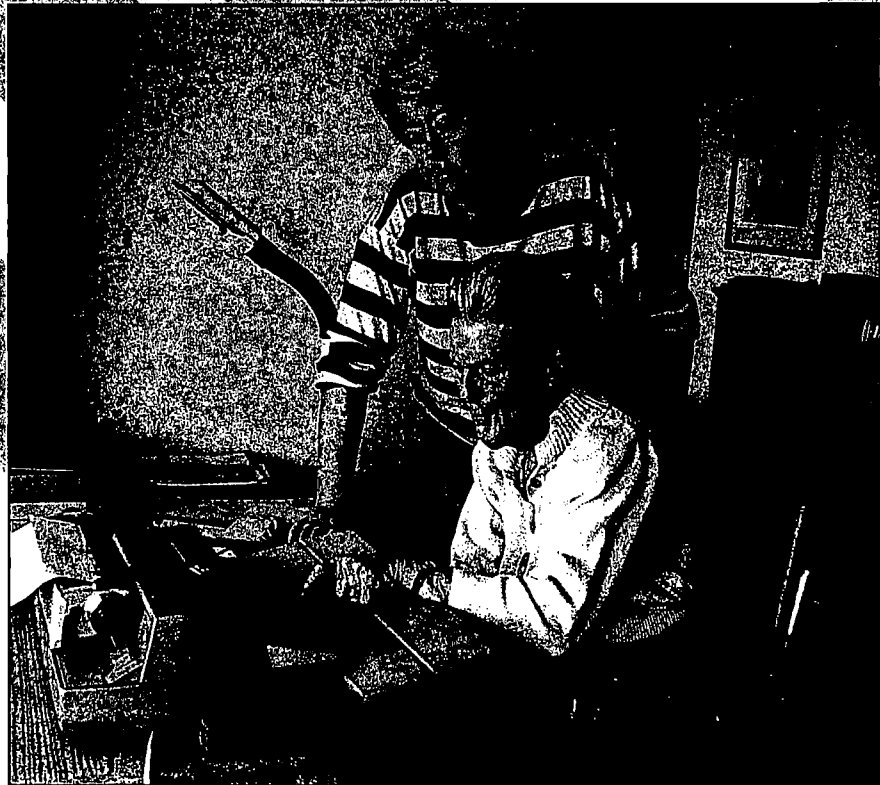


1.9 million Americans with disabilities have no choice but to live in nursing homes. Taxpayers provide 63% of nursing home funding. Very few tax dollars are allocated for home- and community-based services.

National average annual cost
to taxpayers of housing one
aging and/or disabled American
in a nursing home

\$40,784

the old
spaghetti
factory



Some states make Medicaid waiver funds available so that a small number of people with disabilities may live in their own homes, not nursing homes. The waiver funds pay for attendant services: assistance with a range of activities of daily living, such as transferring from bed to wheelchair, shopping for and preparing meals, grooming, and toileting.

**This figure includes both people who require 24-hour support and people who require fewer services.*

National average annual cost to
taxpayers of providing Medicaid
Personal Care to one disabled
American in her own home

\$9,692*

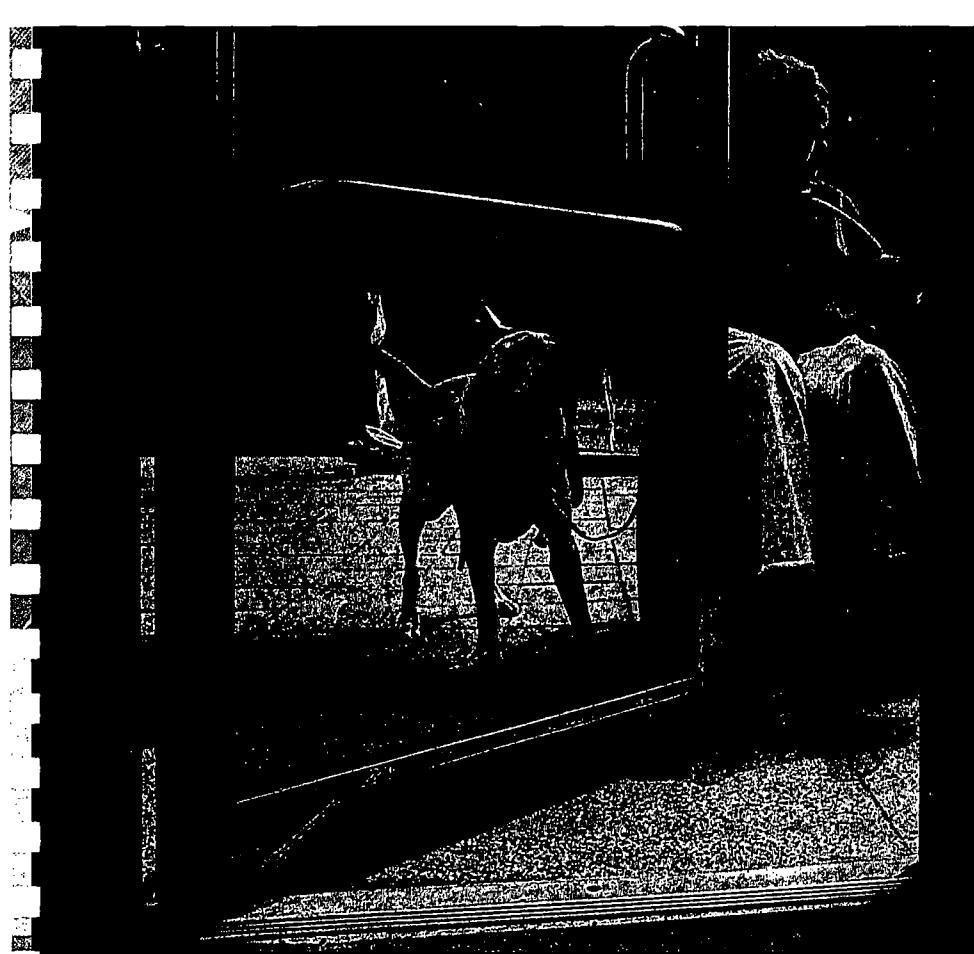


Although most nursing home residents are over the age of 70, some are as young as two years of age. Every nursing home resident has one or more disabilities. Not all require the services of nurses on a daily or even weekly basis.

Many people live in nursing homes only because they have no other choice. Medicaid does not, for the most part, fund home health services. Medicaid funds institutions.

National average annual cost
to taxpayers of housing one
aging and/or disabled American
in a nursing home

\$40,784



Some states offer attendant services to individuals with disabilities under the Medicaid Personal Care Option. We were unable to secure the US HCFA data on the number of people served in this way. Dollar averages shown here were gathered in 1988 by the World Institute on Disability from states operating Medicaid-funded Personal Care Option programs. Figures shown here are 1995 dollars.

Some people require a greater number of hours of service, thus their services are more costly. Some people require fewer hours of service. The dollar figures given here are averages spent at current allowance levels.



National average annual cost to taxpayers of state programs providing assistance services to one disabled American in her own home

\$9,692





150,257 American children and adults are living in tax-funded mental institutions at any given time. Most are there because home- and community-based services are not available to them. Taxpayer dollars fund institutions almost exclusively.

Average annual cost to taxpayers of housing one disabled American in a mental institution

\$58,569*

*Because insufficient community-based services for people with mental illness are funded by taxpayers, no reliable national number is available for comparison. Florida, one state where some such supports are available, is cited at right. Although national average tax dollar expenditures for institutions are far higher (\$83,573 per person served), Florida's figures are cited on this page.



There are insufficient support services in the community for the estimated 3.2 million American adult household population with the diagnosis of serious mental illness. (This is a 1992 estimate of the Centers for Disease Control.) Mental health support services are available in some locales from community organizations.

**In Florida in 1994, (see paragraph at left) 260,000 people received community support services at a cost of \$440.2 million taxpayer dollars.*

The average annual cost to
taxpayers per person served with
community supports

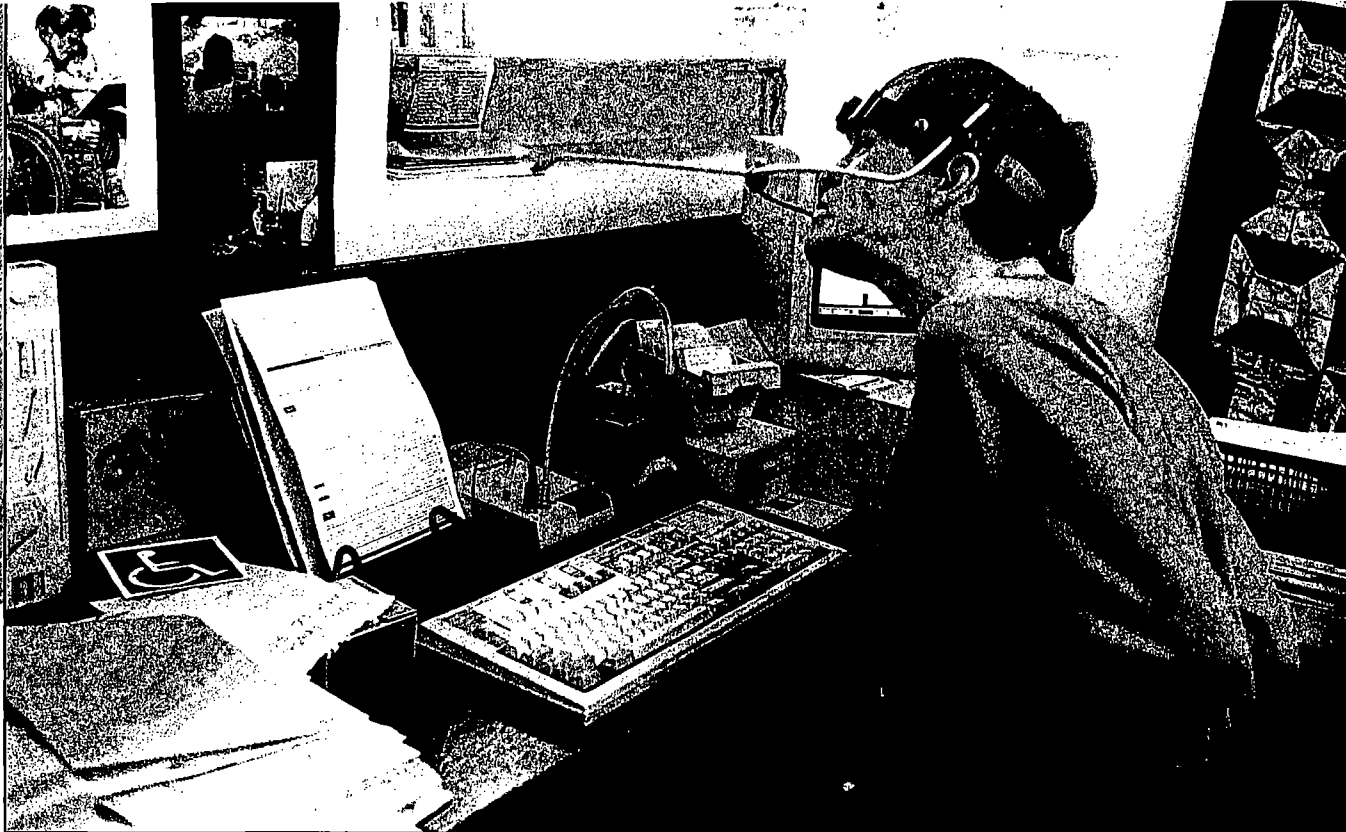
\$1,693*



1.9 million Americans with disabilities have no choice but to live in nursing homes. Taxpayers provide 57% of nursing home funding. Only one out of six long-term care tax dollars are allocated for home- and community-based services.

National average annual cost
to taxpayers of housing one
aging and/or disabled American
in a nursing home

\$40,784



Medicaid funds Personal Attendant Services (PAS) for a small percentage of people with disabilities. Such services are usually available only to people whose income is at or below the poverty level.



National average annual cost to taxpayers of providing attendant services to one disabled American at home through a Medicaid waiver

\$9,692



In 1994, the Veterans Administration's nursing homes and domiciliaries housed an average of 19,553 veterans on any given day. A larger number of veterans live in community nursing homes, most of them at Medicaid expense. Very few veterans with disabilities are given the choice of home- and community-based services.

National average annual cost
of housing one disabled
American veteran in a V.A.
nursing home

\$75,641

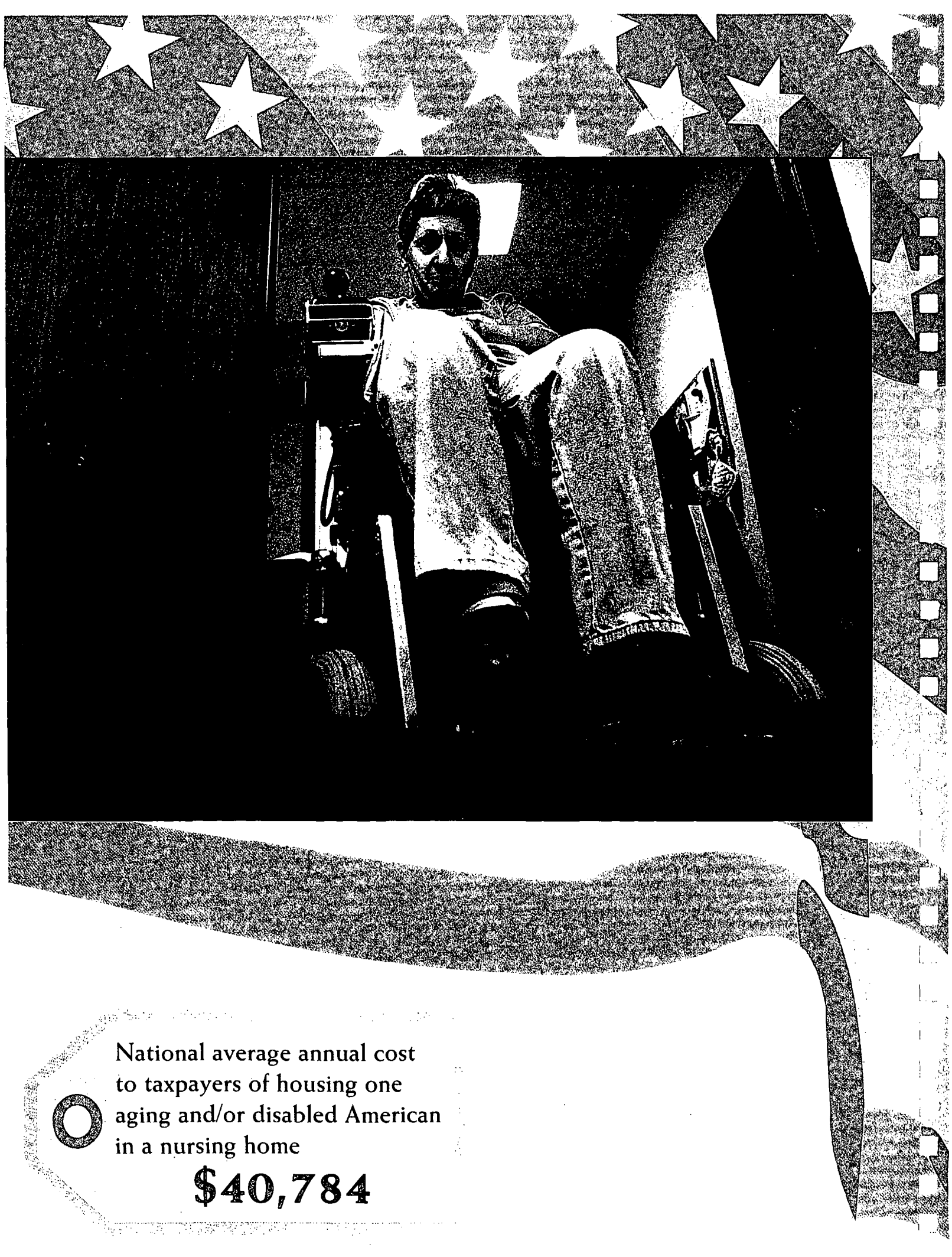
In 1994, the Veterans Administration's Homemaker/Home Health Aide Services, a pilot program, provided attendant services to approximately 1,500 people at an average cost of \$6,645 per person.

During that same year, 5,069 veterans or their dependents received services in their own homes and communities through the VA's Hospital-based Home Care Program. The average annual cost was \$8,132 per person served.



National average annual cost to taxpayers of providing necessary services to one disabled American veteran in his or her own home

\$8,132



National average annual cost
to taxpayers of housing one
aging and/or disabled American
in a nursing home

\$40,784



Attendant services are, in some instances, available to some Americans with disabilities under Medicaid waivers or state-funded programs.

Such services, while sometimes overseen by case managers or registered nurses, are often non-medical in nature and are performed by trained attendants. Examples of an attendant's work: range of motion exercises, feeding, grooming, housekeeping, toileting, dressing.



National average annual cost to taxpayers of providing the Medicaid Personal Care Option to one disabled American in her own home

\$9,692



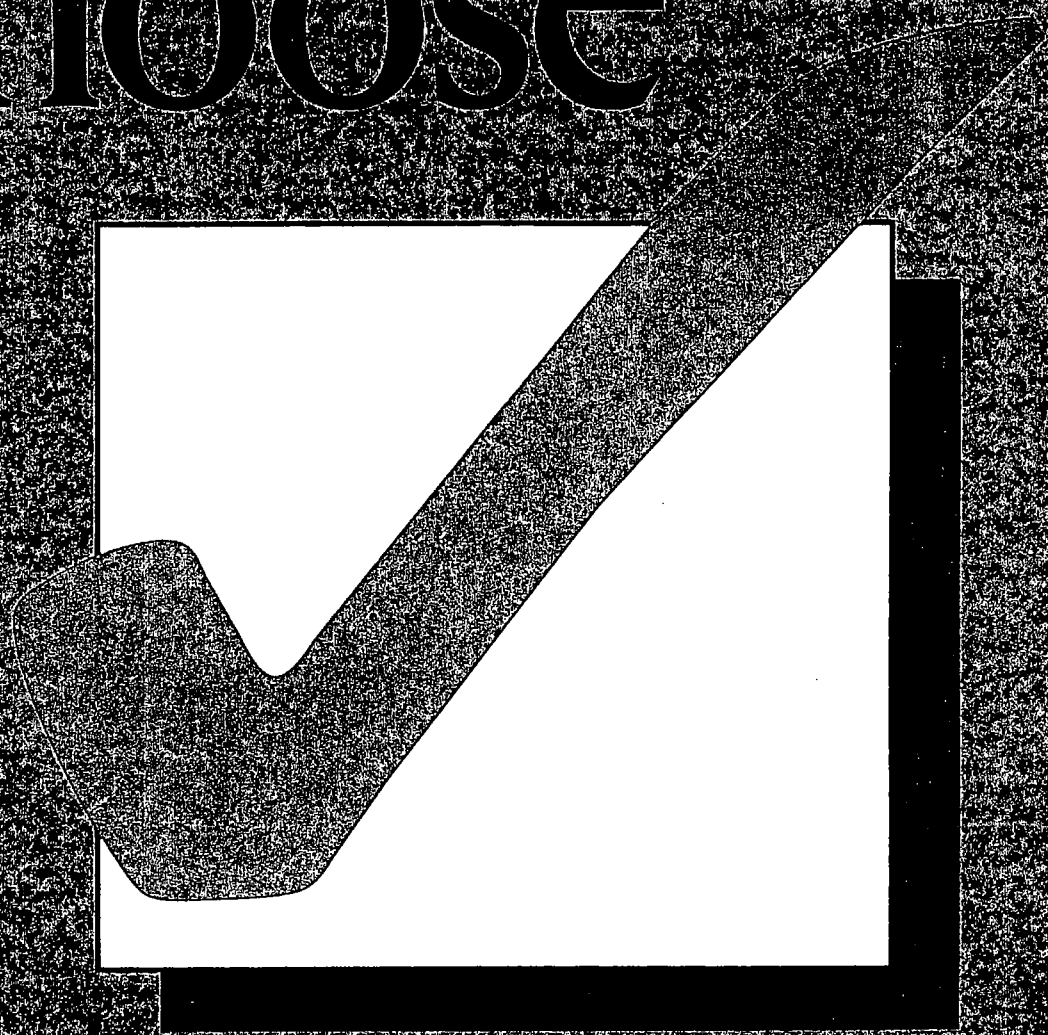


This information packet was produced by
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61 Brighton Street, Rochester, New York 14607

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Will any American child or adult be
forced to give up their freedom — their
own home — for a nursing home?

you
choose



© 1984 by the
American Association of
Nurses

*Who will do something about the waste and
inhumanity of America's long term care policy?*

**you
choose**



**ADAPT
P.O. Box 9598
Denver, CO 80209-9598**



I want a chance to choose.

Please send a packet of information on Community First
initiatives to give Americans choice in long term care.

Name _____

Address _____

City _____ State _____ Zip _____

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Long Term Care Policy -
It's Good To have the Facts when
You Choose

32pgs

Long Term Care Policy

It's good to have the facts when

**you
choose**

- *statistics*
- *sources*
- *a call to action*



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T E S T I M O N Y

"I was forced to stay
there. I had no other
choice. You keep
asking yourself,
'Is this America?'"

Jim B., Michigan

"The way they have it
planned, nobody gets
out of there alive."

Saundra H., California

"You think it can't
happen to you. Well,
it happened to me."

Lucy G., New York

"It's like kidnapping.
I had no freedom.
I had no life."

Jack U., Pennsylvania



I had to fight for my freedom

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Operating Manual for Elected Officials



cartoon by Jackie Urbanovic from "Making
Your Case" by the Minnesota Governor's
Council on Developmental Disabilities

**Americans with disabilities are counting on you.
Please get *You Choose* into the hands of people
who do choose.**

**Here's how to order more copies — but hurry!
Supplies are limited. First come, first served.**



You Choose

RE-ORDER FORM

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(Poor Folks edition not available in single-copy orders.)

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We ask, if you can afford it, that you purchase a sponsorship
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Mouth

the voice of disability rights

November-December 1995 \$3



Our homes or
nursing homes

you
choose

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MOUTH

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