

the people." the quote isn't accurate, but the number are!

If you wish to see the Medicaid ICF/MR/DD program continue to serve only 10% of the estimated number of persons with severe disabilities in need of "long term" support services, then you can continue to be a spectator of citizenship in action. If, however, you believe that future new Medicaid expenditures must be directed to the 90% of individuals with severe disabilities currently living at home or in the community, then you must become actively involved during the next 120 days. If you have been involved, please hang in there for the final "full court press" of 1988.

Current Status As we go to press, 40% of the members of the United States Congress—38 Senators and 173 Representatives—are cosponsors of the Medicaid Home and Community Quality Services Act, S 1673 and H.R. 3454. The Senate held a hearing on March 22nd. No dates have been set for a full Senate Finance Committee "mark-up" of the bill. On the House side, no date has been set for a hearing in the Energy and Commerce Subcommittee on Health and the Environment. This landmark legislation could die when Congress is expected to adjourn its 100th Session in early October unless each of us becomes active during the next 120 days.

Background The Medicaid Program began in 1965 as Title XIX of the Social Security Act. The "medical assistance program" is an entitlement program for individuals of low income and limited assets. In the case of persons with disabilities, entitlement to Medicaid is a direct benefit of receiving Supplemental Security Income (SSI) except in 7 states which have more

stringent financial eligibility requirements for the state/federal Medicaid program. Medicaid is a state/federal program with each state controlling and defining the extent and scope of all services, (including the ten mandated "medical" services), eligibility for services for optional groups of individuals, which (if any) of the 23 optional services it will provide and the rates of payment to providers. The federal government provides open-ended matching funds to each state on a percentage rate. The rate can be from 50 to 80% based on the state's average per-capita income.

The ICF/MR Program In 1971, as a result of rampant abuse and deplorable conditions in large public facilities, the Congress enacted an amendment to the Medicaid program to establish as an optional state service—the Intermediate Care Facility for Persons with Mental Retardation and Related Conditions (including cerebral palsy). The ICF/MR program now exists in all states except Wyoming and Arizona. In 1985, the total federal and state Medicaid ICF/MR expenditure was \$5.2 billion. **ICF/MR Reform** In 1981, the Congress enacted the Medicaid Home and Community Based Waiver program as a state option to develop an array of home and community support services as an alternative to "institutional" services for persons who were eligible for, at risk of placement into, or desirous of leaving a facility. Although the waiver has assisted 35 states to expand community services, the limits on its use and the rigorous federal application, renewal and cost containment procedures, and institutional eligibility standards, do not make the waiver in current law viable for expansion. **Substantive Medicaid Reform** The current Medicaid reform legislation represents the 3rd generation of a bill originally introduced by Senator John Chafee (R.I.) in 1983. S. 1673 and H.R. 3454 are endorsed by 24 national organizations. This legislation represents a consensus of seven lead organizations including UCPA, whose

progress of the human mind. As that becomes more developed, more enlightened, as new discoveries are made, new truths discovered, and manners and opinions change, with the change of circumstances, institutions must advance also to keep pace with the times. We might as well require a man to wear still the coat which fitted him when a boy as civilized to remain ever under the regimen of their barbarous ancestors."

Thomas Jefferson

Opposition To Reform The well organized and vocal opposition to the bill is coming from three constituencies: parents of sons and daughters residing in state facilities and large, private ICFs/MR; state employee unions; and some private providers. These groups are being very effective! **Votes Needed** It takes 51 votes in the Senate and 218 in the House to enact a bill into law. We have 38 and 173 cosponsors respectively and a number of members who are not cosponsors have indicated they will vote for the bill on the floor. It takes 11 votes to move a bill out of the Senate Finance Committee; 9 members of the Committee are cosponsors. It takes 21 votes to move a bill out of the House Energy and Commerce Committee; 14 members of the Committee are cosponsors. We need your continued involvement to reach our goal.

Action Steps

1. Become knowledgeable about S. 1673 and H.R. 3454.
2. Check to see if your Senators and Representatives are cosponsors.
 - A. If your elected official(s) is a cosponsor, write him/her a letter of thanks including your personal involvement (consumer, parent, advocate, professional) and if-
 - i. a Senator, urge him/her to contact Senator Lloyd Bentsen (TX) Chairman of the Senate Finance Committee to conduct a **full** committee "mark-up" and to move the bill to the Senate floor for a vote early this summer; **ii.** a Representative, urge him/her to

"I am not an advocate for frequent changes in laws and constitutions, but laws and institutions must go hand in hand with the

contact Representative Henry Waxman (CA), Chairman of the House Subcommittee on Health and the Environment to conduct a hearing on H.R. 3454 early this summer. B. If your elected official is not a co-sponsor, write him/her stating your personal involvement, support for the bill, urging co-sponsorship and contracts with Senator Bentsen or Representative Waxman as an **i** and **ii**.

C. Write your own letters to Senator Bentsen and Representative Waxman, stating your personal involvement, support for the legislation and the actions in **i** and **ii** above.

D. The address for Senator Bentsen and Congressman Waxman are: Honorable Lloyd Bentsen, Chairman Senate Finance Committee, United States Senate, 703 Hart Building, Washington, DC 20510. Honorable Henry Waxman, Chairman Subcommittee on Health and the Environment, United States House of Representatives; 2418 Rayburn, Washington, DC 20510.

E. Join/form a coalition in your community/state and help spread the word to the following groups who will become involved in our **Call To Action** if they can learn what the legislation will do for them;

- i. parents of infants, toddlers, preschoolers, and school-age children who wish to have their children grow up at home and may need a variety of family support services;
- ii. school age youth (and their families) in the transition years (ages 14-21) who have expectations for adult community living, employment and support services. This bill provides an "entitlement" to such services;
- iii. high school graduates (and their families) currently on community service waiting lists of one to ten years duration as this bill provides an "entitlement" to basic adult services after three years of state implementation;

iv. families who are elderly whose

sons/daughters to continue living in their home community when their parents can no longer care for them; v. individuals (and their families) currently living in nursing homes and large ICFs/MR who wish to return to the community but are unable to do so because the "waiver" program is full.

F. Since this is federal legislation and involves billions of future tax dollars, spread the word to your coworkers, friends, neighbors, church/synagogue members, and your friends and relatives in other states who pay taxes and want their dollars to support this issue.

G. In all letters, be sure to include the following:

i. your return address; **ii**. the bill number (S. 1673, H.R.3454); **iii**. a request for a written response. H. Arrange personal visits with your elected officials when they return home for the weekend, holidays or other occasions (call their local offices for their schedules).

I. Do not give up! You do make a difference in our system of representative government. The future quality of life for children and adults with cerebral palsy and other severe disabilities depends on your individual and collective actions. United, active and together we can and will be victorious in seeing the enactment of this landmark legislation in 1988. The thousands of individuals and their families awaiting its benefits cannot wait until 1991, 1992, or 1993 as some pundits suggest it will take to resurrect the current level of momentum with a new Congress, new president, new Congressional and federal agency staff. J. THE TIME IS NOW TO SHAPE THE FUTURE K. For additional information, contact Allan Bergman or Fran Smith at 1-800-USA-5UCP.

Medicaid Long-Term Care Reform
Organizing Principles

Over the course of the last several months, six- national organizations have spent considerable time in an effort to achieve a consensus on major principles that should be in incorporated into any legislation designed to reform the Medicaid long-term care system as it affects persons who have developmental disabilities.

The organizations which participated in the development of the draft document were: The Association for Retarded Citizens (ARC), the National Association of Developmental Disabilities Councils (NADDC), the National Association of Protection and Advocacy Systems (NAPAS), the National Association of State Mental Retardation Program Directors (NASMRPD), The Association for Persons with Severe Handicaps (TASH), and United Cerebral Palsy Associations, Inc. (UCPA)

Following the organizing principles developed by the national organizations:

Category	Organizing Principles
Eligibility	<ul style="list-style-type: none"> o Medicaid long-term care benefits should be limited to otherwise eligible persons with substantial chronic disabilities originating in childhood. o Persons with disabilities originating in childhood that meet the SSI/Social Security test should be considered presumptively eligible for specialized LTC services. o Eligibility should be based on the individuals needs rather than on any presumptions about his/her level of care requirements or need for a particular residential setting (i.e., a Medicaid-certified LTC institution), as currently required under the HCB waiver program. o The legislation should avoid disenfranchising otherwise eligible persons in states with stricter criteria of disability than the federal SSI test (i.e., 209(b) states). o In recognition of the fact that a natural or adaptive family generally provides the optimal living environment for children with severe disabilities, federal legislation should remove financial hardships to families caring for such children at home. o The criteria governing income eligibility for specialized LTC services should permit coverage of optional categorically needy persons on the same basis as currently authorized for person in Title XIX-certified institutions and HCB waiver programs.

Eligibility
(cont.)

a A working individual with a qualifying disability should be permitted to retain a reasonable portion of his/her earnings (i.e., as opposed to having them recovered through mandatory contributions to the cost of his/her care).

Services

- o The legislation should encourage states to assign high priority to providing services either in the home of the individual's natural or adoptive family or in alternative family or foster living arrangements (i.e., as opposed to congregate care settings).
- o States should be allowed to select from among an array of service options in order to appropriately address the wide ranging needs among members of the target population.
- o Eligible persons who need specialized LTC services should receive an individually tailored service package without having to demonstrate a need for a comprehensive array of services (i.e., services should be "debundled").
- o Because the cost of room and board generally can be covered through other funding sources (i.e., notably SSI payments), such costs should not be considered Medicaid reimbursable services; persons otherwise eligible for SSI benefits, however, should be entitled to receive full monthly payments when living in out-of-home care settings, rather than only a reduced personal needs allowance.
- o Certain services for persons with severe disabilities should be available on a mandatory basis; others on an optional basis, under state Medicaid plans.
- o All LTC services for persons with severe disabilities should be furnished in accordance with the provisions of an individualized habilitation plan (IHP).
- o Persons with developmental disabilities who receive Medicaid reimbursable LTC services should retain their eligibility to all services generally available under the state's Title XIX plan, including coverage of hospital, physician and outpatient health-related services.

State Plan

- o The legislation should encourage states to exercise fiscal restraint in supporting specialised Medicaid-reimbursable services for persons with severe disabilities originating during childhood.
 - o Fiscal incentives should favor the expansion of community living/programming alternatives, while at the same time encouraging the states to control the overall growth in federal-state Medicaid outlays.
 - a One general aim of the legislation should be to facilitate the orderly transition of Medicaid dollars from institutional to community-based services.
 - o Reform legislation also should encourage states to expand community residential, day and support service alternatives for eligible individuals with qualifying disabilities residing at home or in other non-institutional settings.
 - o Access to community-based services should be available to every eligible person, on an equal basis, regardless of the severity of his/her disability or present place of residence.
 - o The existing institutional bias of Medicaid policy should be eliminated.
 - a Employees whose jobs are adversely affected by the phase-down or closure of larger Medicaid-certified LTC facilities should be afforded reasonable accommodations.
- States should be required to develop and maintain an adequate infrastructure to support the expansion and improvement of home and community-based service options for eligible persons receiving specialized LTC services, including the capability of providing staff training, technical assistance, and crisis intervention services.
- a Each eligible person receiving specialized LTC services should have access to individual service coordination services both within every program in which he/she participates as well as external to such programs. The external (or inter-organizational) services coordinator should be administratively independent of all providers of day and/or residential services.

- o A state should have a comprehensive management information system capable of: (a) tracking the progress of persons enrolled in Title XIX-funded programs/facilities; (b) identifying the service needs of unserved and inappropriately served persons for Title XIX LTC services; and (c) pinpointing systemic flaws or gaps in existing services, statewide, based on aggregated data.
- o The regular Medicaid state plan amendment process should be used by states in electing mandatory/optional LTC service coverages for persons with qualifying disabilities. However, the process of arriving at such determinations, and assuring adequate safeguards and protections, should provide an opportunity for public input.
- o Eligible persons and their families should be afforded due process safeguards, including the right to appeal program placement decisions.

Quality Assurance

- o The legislation should include explicit requirements governing the development and enforcement of program standards to assure that all persons participating in Title XIX-funded programs receive appropriate, high quality services. The vulnerability of the target population to abuse and neglect makes it particularly important that states establish adequate procedures for controlling program quality.
- o Responsibility for establishing and enforcing program standards should be shared by federal and state governments, with the federal government continuing to play a major role in setting and overseeing the enforcement of long-term care facility standards and the states playing a leading role in establishing and monitoring compliance with community service standards.
- o In designing and carrying out quality assurance program, increased emphasis needs to be placed on the effects of living environments and services on the individuals receiving assistance, including the expanded use of independent, third party monitoring and objective, valid and reliable methods for assessing such dimensions as the individual's developmental progress and integration into the community and survey of individual and family satisfaction.

Definitions

- a Certain key terms should be defined in the legislation, including "individual service coordination", "individual habilitation plan", "habilitation services", protective intervention services" and "community living facility".

Federal and State Administration

- o Any revised legislation should clarify and streamline administrative responsibility for managing Medicaid LTC services for eligible persons with developmental disabilities, at both the federal and state level.