GOVERNMENTAL AFFAIRS OFFICE OF THE ASSOCIATION FOR RETARDED CITIZENS SUITE 516 1522 K STREET, N.W., WASHINGTON, D.C 20005-1247 (202)785-3388

October 21, 1986

TO: All State ARC Units FROM:

Governmental Affairs Committee

SUBJ: Action Plan for Medicaid Reform (CFLA) at Close of 99th

Congress

As the 99th Congress comes to a close, the ARC may look back and take stock of the significant gains made toward Congressional approval of major reform in Medicaid long term care services for people who are mentally retarded. The Community and Family Living Amendments of 1985 (CFLA) acquired support of 85 Members of Congress: 9 Senators including lead-sponsor Senator John Chafee (R-RI) and 76 Representatives including lead-sponsor Rep. James Florio (D-NJ). In September, 1986, the Senate Finance Committee's Subcommittee on Health held a hearing on the Medicaid program and its impact on long term care services for persons with developmental disabilities. The majority of testimony presented at the hearing, including that of the ARC, urged the Committee to address the need for increased support for community and family based services. Senator David Durenberger (R-MN), Chairman of the Subcommittee, closed the hearing with a commitment that the Committee will address the issues raised by CFLA in 1987. However, as this Congress ends, a great deal of work is needed to maintain the momentum and build enough support for passage of major Medicaid reform legislation in the 100th Congress.

Enclosed you will find an "Action Plan for Medicaid Reform" outlining activities to be carried out at the state and local levels over the next few months. Please use the action plan and accomplish as many of the listed activities as possible. We would also like to hear about any additional efforts that your state/local unit undertakes. The activities outlined in the plan are geared toward renewing commitments and building momentum for serious Congressional consideration during the next Congress. While local and state units are building the base for future action, the ARC will be working at the national level in coalitions and with Congressional Members and staff of the House and Senate to develop improved legislation within the basic concepts and principles of CFLA.

(over)

Note that in any discussions or correspondence with Members/ staff, references should now be to the concepts of "reform or improvement of Medicaid long term care services for persons with mental retardation", "Medicaid reform along the lines of the Community and Family Living Amendments", or other general references. This is because CFLA bills S. 873 and H.R. 2902 are technically dead with the end of the 99th Congress. New bills introduced in the 100th Congress will carry new bill numbers and may carry new names. It is important, therefore, to stress our concepts and goals for reform during this interim period, rather than stressing the bills in their particular current forms. Of course, continue to refer to S. 873 and H.R. 2902 when discussing support during the 99th Congress and when necessary to illustrate the breadth and depth of the reforms needed in Medicaid. In your meetings, discussions, and correspondence you may also wish to stress: the need for increased family and community support services; waiting lists for those services in your state or area; and the concept that, although care may be needed over a lifetime, service needs for each individual are ever-changing and, to be effective, service systems must be flexible enough to meet individual needs.

Our goal is to get passage of Medicaid reform legislation during the 100th Congress. It will take a great deal of effort from people at all levels of the ARC. We must use the coming months to improve our base of support and to continue the growing momentum toward a consensus for change. We appreciate all your efforts in this direction.

N.B. - State units - Please forward this Alert to your local units.

# Action Plan for Medicaid Reform November, 1986 through January, 1987

#### Week of November 10

- o Send letters of appreciation to all CFLA cosponsors (final list attached) from, your area/state. For those who have been re-elected, stress your expectation of their continued support for similar Medicaid reform legislation in the 100th Congress, with the goal of passage of the legislation,
- o Notify the ARC Governmental Affairs Office of any particular problems or concerns which have arisen regarding CFLA in your state. This is a critical time for improvements to be included in drafts of a new bill, if possible.

#### Week of November 17

- o Write to all newly elected Members of Congress to make them aware of your concerns regarding Medicaid and your desire to work with Members and their staff regarding the needs in your state. Try to assess the new Member's level of knowledge of mental retardation and Medicaid issues, and begin to plan the activities necessary to educate the Member to the need for reforms in Medicaid long term care.
- o Write to other Members who will return to Congress but who did not previously co-sponsor CFLA. Discuss again the needs in your state/area and the concerns regarding Medicaid long term care reform. Urge their serious attention to this issue in the 100th Congress. Begin plans to meet with these Members while they are at home between Congressional sessions.

#### November 24 through December 19

- o Conduct meetings and tours with Members from your area/ state. Invite them to holiday events, conduct special tours, and arrange for them to meet with ARC members and experts from your area. Point out the -needs of families and the community and help them to understand how Medicaid long term care services are failing to address those needs.
- o Write letters to Representative Henry Waxman (D-CA), Chairman of the House Health and the Environment Subcommittee, stressing the needs in your state and urging that his Subcommittee seriously address Medicaid reform for long term care services. Mail letters to:

Representative Henry Waxman Chairman, Health and the Environment Subcommittee 2415 Rayburn House Office Building Washington, DC 20515 o Write letters to Senator David Durenberger (R-MN), Chairman of the Senate Health Subcommittee, stressing the same concerns and thanking him for his commitment (during the Senate Finance Committee hearing on September 19, 1986) to have the Subcommittee address Medicaid reform during 1987. Mail letters to:

Senator David Durenberger Chairman, Senate Subcommittee on Health 219 Dirksen Senate Office Building Washington, DC 20510

## January, 1987

o Develop concrete state and local plans for continued meetings and correspondence with Members from your state/area. Work with other supportive disability advocacy organizations in coalitions. Assess your state/unit needs regarding grass-roots activities and develop a structure and plans for carrying out activities over the coming year regarding major Medicaid reform. Plan how your system will respond to calls for constituent pressure, letter writing, and other types of assistance in the ongoing campaign for reform in Medicaid long term care services for persons with mental retardation.

### Co-Sponsors of S. 873

\*John Chafee (R-RI)

\*Daniel Inouye (D-HI)

\*Robert Stafford ((R-VT)
Claiborne Pell (D-RI)
Patrick Leahy (D-VT)
James Sasser (D-TN)
Jeff Bingaman (D-NM)
Orrin Hatch (R-UT)
Sam Nunn (D-GA)

# Co-Sponsors of H.R. 2902

\*James Florio (D-NJ) \*Tony Coelho (D-CA) \*Bruce Morrison (D-CT) \*Dean Gallo (R-NJ) \*Robert Torricelli (D-NJ) Chester Atkins (D-MA) Howard Berman (D-CA) Sala Burton (D-CA) John Conyers (D-MI) George Crockett (D-MI) Vic Fazio (D-CA) Tony Hall (D-OH) Augustus Hawkins (D-CA) Frank Horton (R-NY) William Hughes (D-NJ) James Jeffords (R-VT) Matthew Martinez (D-CA) Parren Mitchell (D-MD) Robert Mrazek (D-NY) Nick Rahall II (D-WV) Robert Roe (D-NJ) Gus Savage (D-IL) Larry Smith (D-FL) Olympia Snowe (R-ME) Arlan Stangeland (R-MN) FoFo Sunia (D-AS) Edolphus Towns (D-NY) Howard Wolpe (D-MI) Jim Cooper (D-TN) Thomas Foglietta (D-PA) James Oberstar (D-MN) Patricia Schroeder (D-CO) Walter Fauntroy (D-DC) Edward Markey (D-MA) Fernand St. Germain (D-RI)

Timothy Wirth (D-CO) William Boner (D-TN) Bernard Dwyer (D-NJ) Michael Lowry (D-WA) Bill Richardson (D-NM) James Traficant (D-OH) Steny Hoyer (D-MD) Andrew Jacobs (D-IN) William Gray (D-PA) Kenneth Gray (D-IL) John McKernan (R-ME) John Hammerschmidt (R-AR) Daniel Akaka (D-HI) Manuel Lujan (R-NM) Alan Mollohan (D-WV) Harley Staggers (D-WV) Thomas Foley (D-WA) Frank Guarini (D-NJ) James Howard (D-NJ) Nicholas Mavroules (D-MA) David Monson (R-UT) Douglas Bosco (D-CA) Barney Frank (D-MA) Earl Hutto (D-FL) Donald Pease (D-OH) Michael Barnes (D-MD) Paul Henry (R-MI) Thomas Luken (D-OH) Frank McCloskey (D-IN) Bob McEwen (R-OH) Peter Rodino (D-NJ) Claudine Schneider (R-RI) Martin Frost (D-TX) Glenn Anderson (D-CA) John Rowland (R-CT) Charles Hayes (D-IL) Gerald Kleczka (D-WI) Barbara Mikulski (D-MD) Robert Garcia (D-NY) Joe Kolter (D-PA) Bob Wise (D-WV)