

TESTIMONY

ON

COMMUNITY AND FAMILY LIVING AMENDMENTS OF 1983

S. 2053

Respectfully Submitted

BY

Association for Retarded Citizens-U.S.

Witness:

Dee Everitt
President, ARC-U.S.

Monday, August 13, 1984
Minneapolis, Minnesota

The Association for Retarded Citizens-U.S. is a national organization of volunteers - parents, educators, professionals in the field of mental retardation, self-advocates and others. The ARC has been in existence for 35 years. Currently, our membership consists of approximately 200,000 individual members, over half of whom are parents of retarded children. We are the largest organization in this country representing and promoting the rights of persons with mental retardation and their families. As President of the ARC-U.S. and as the parent of a daughter who is severely retarded, I want to thank you for this opportunity to express the views of the ARC.

We are in a new age in the field of mental retardation. Parents with young disabled children no longer consider sending their child away to receive care, training and education. Indeed, the passage of Public Law 94-142, the Education for All Handicapped Children Act, and the availability of educational and certain other services within community settings have practically erased the word "institution" from the vocabulary of these parents. The use of institutions is not, and will never be, a desired option for them.

With families keeping their disabled children at home, there is now a growing demand for sophisticated, stable services systems within our communities. New experiences, new knowledge have created very different expectations from those of the past. It is time to let go of the old models and ideas and embrace the new ones. And it is the responsibility of the federal government to respond to these new experiences and this new knowledge and promote better services, better practices and better lives for our nation's mentally retarded and other disabled citizens. Your presence here today indicates the depth of your understanding of the situation in which disabled individuals and their families find themselves. I must commend you for holding this field hearing and thank you for your concern, openness and

willingness to listen, and then to act.

Mental retardation is a life-long handicapping condition. Many retarded people continue to reside in large institutions where services are often primarily custodial in nature. The Association for Retarded Citizens believes that custodial care is a waste of human resources as well as dollars. We believe it is in the public interest to develop and maintain in every state and community a stable, but not static, system of community services which disabled persons may tap as needed to help them learn and maintain the skills to be as independent as possible.

Although the ARC has formally adopted a policy of working toward the eventual phase-out of institutions, we have not yet set a target date because we see the waning of institutions as a likely, inevitable consequence of our more immediate goals which are: 1) to implement community services which encourage and assist families to maintain their children in their home by alleviating the extra financial, emotional and practical burdens to which families may be subject; and 2) to establish arrays of family and community living arrangements and services which support the developmental and social needs of individuals with disabilities, and enable them to experience a life style that is as close to normal as possible.

Movement toward expanded home and community-based services and away from the use of institutions is already well underway. The census of public institutions for retarded people peaked in 1968. What is less well known is that the number of certified beds in Intermediate Care Facilities for the Mentally Retarded has also peaked. The 1981 total of approximately 196 thousand declined to about 132 thousand in 1983. The public component was 106 thousand in 1982 and is falling. In 1982 10,660 of these ICF/MR beds were in 1,157 facilities for 15 or fewer residents. You may be interested to know that one-fifth of all these people were in Minnesota, [Janicki, M.P., Mayeda, T., Epple, W.A.; "A Report on the Availability of Group Homes for Persons with Mental Retardation in the United States," November, 1982.

Another figure that is interesting is that twenty-eight institutions have closed or been scheduled for closing in the last four years. Braddock, D., Weller, T.; "The Closure of the Dixon Developmental Center: A Study of the Implementation and Consequences of a Public Policy," March, 1984. During the same time period there has been an increase in state funds allocated to home and community services as well as the enactment of the Medicaid waiver program for such services.

In short, a movement is underway. However, this movement is somewhat erratic and lacks cohesion because states have been so dependent on federal incentives and requirements, most of which are at cross purposes to the growing trend for home and community services.

It is time for the federal government to get in step with the new age in the field of mental retardation. There is a new generation of families who have no use for institutions, there is an older generation who still have their adult disabled children at home, often without needed services, and there are those in institutions who need to be returned to our communities. S. 2053, the Community and Family Living Amendments of 1983, would eliminate the current biases for institutional care under the Medicaid program and support those services and programs for severely disabled people which are consistent with the new policies in the disability field which have emerged over the past two decades.

As you have acknowledged, Senator Chafee, S. 2053 is not perfect as currently written. The ARC has studied each and every provision of the bill, listened to the concerns expressed by those who oppose the bill in its current form and developed several modifications which we recommend be incorporated, into the legislation. Each of our proposals is described in Attachment 1. While there is not time today to discuss in detail our suggested changes, let me point out one very important suggestion which directly responds to input from ARC members and to testimony given on February 27 at the hearing held by the Senate Subcommittee on Health. This

particular suggestion takes into consideration the political realities in Congress as well as the views of those concerned about the total withdrawal of federal Medicaid funds from institutions as called for in S. 2053.

As introduced, S. 2053 requires a 100 percent withdrawal of the federal share of Medicaid money from large institutions within fixed periods of time, 10 years for some institutions, 15 for others. The federal funds would be withdrawn from large institutional facilities and become available for community-based services. Under the ARC modification, 85 percent, rather than 100 percent, of the federal funds would be withdrawn from the large institutions. The ARC revision clearly mandates that community services be included in each state's Medicaid plan.

In addition, this percentage phase out is combined with a plan to provide financial incentives for community placement. The incentive would reduce federal matching dollars in the institution while maintaining the federal match for community-based services. For example, if state X currently has a 50:50 federal-state match, the percentage of the federal match for institutions would decrease from 50 percent over a given period of time. Conversely, the 50 percent match for community services will remain the same. Thus, it would be increasingly more attractive for states to fund community services. An ARC proposal regarding the percentage and time schedule is nearing completion and will be shared with you in the very near future.

Finally, the Secretary of Health and Human Services would be required to periodically assess the progress of the states in accomplishing the national goal of providing community-based services. The Secretary also would be required to make a comprehensive report to Congress, two years before the end of the 10-year period, concerning the states' progress. It is hoped that the Secretary's report will trigger Congressional hearings on the state of the art of community and other services in order to determine how the Medicaid funds should be used in accomplishing the

national goal of community-based services for all people with mental retardation.

Certainly; I and other ARC volunteers and staff are available and ready to meet with you and/or your staff to discuss in greater depth the ARC proposals.

Under S. 2053 funds now used for care in institutions will be made available for community services. It is anticipated that many of those Medicaid certified facilities which cater primarily to eligible severely disabled persons will (1) become smaller, (2) close, or (3) be converted to other uses; the extent and scheduling of such a phase down or out and the sizes, types and locations of facilities, if any, to be maintained will be determined by state planning and priorities. States will continue at all times to be free to fund people and settings with state dollars and/or dollars available from other federal sources as appropriate. Providing states such decision making authority and flexibility allows them to respond to the specific situation and circumstances within the state and should result in the smoothest transition possible.

The ARC strongly supports those provisions of S. 2053 which require individual program plans and community services plans; the participation of clients, parents, guardians and others, as appropriate, in the interdisciplinary teams; the appeal procedures for clients, parents and others; the requirement for individual case management; the size limitation of not more than three times the average family household size within the particular community; and the accreditation of programs.

The ARC looks forward to working with Congress to refine and improve S. 2053 and to its early enactment. Again, I commend you for holding this field hearing and would like to close with the following quote from a letter by Thomas Jefferson to a friend:

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

That is what S. 2053 is about - keeping pace with the times.

ARC-U.S. RECOMMENDS

CHANGES TO S.2053

"COMMUNITY AND FAMILY LIVING AMENDMENTS OF 1983"

April 17, 1984

On November 4, 1983, Senator John Chafee introduced S. 2053, the "Community and Family Living Amendments of 1983." The Association for Retarded Citizens of the United States helped with the drafting of the bill and strongly supports its intent. Since that time the ARC, as well as Senator Chafee, has sought input from around the country in order to improve the provisions in S. 2053. A hearing was held on February 27 before the Senate Subcommittee on Health. ARC President Dee Everitt has continued to request that ARCers concerned about S.2053 communicate to her their suggestions for change.

On March 31 and April 1, 1984, the ARC's national Governmental Affairs Committee met to decide what changes to S. 2053 should be recommended to Senator Chafee at this time based on the information provided in testimony at the hearing and in response to President Everitt's appeals for input from all those concerned. Mrs. Everitt has received many letters relative to S. 2053 and is extremely pleased with the constructive suggestions they contain.

President Everitt participated during the entire two day meeting of the Governmental Affairs Committee. The attached document describes each of the recommendations the ARC has endorsed and provides some explanation of these recommendations. A similar document has been shared with Senator Chafee. Final decisions on how best to modify S. 2053 probably will not be made for several weeks or months. Senator Chafee and the ARC are continuing to solicit input so that S. 2053 can be modified in the most beneficial manner for the mentally retarded and other disabled individuals affected by the bill.

ARC-U.S. RECOMMENDS

CHANGES TO S.2053

"COMMUNITY AND FAMILY LIVING AMENDMENTS OF 1983"

Recommendation

Explanation

Partial phase-out

Require an 85 percent, rather than 100 percent, withdrawal of Federal Medicaid funds from institutions.

Provide for a cost-of-living adjustment relative to the 15 percent of Federal Medicaid funds allowed for institutional care at the end of the 10-15 year time line.

Require the Secretary of the Department of Health and Human Services to periodically assess the progress of the states in accomplishing the national goal of providing community-based services. The Secretary would be required to make a comprehensive report to Congress two years before the end of the 10 year period concerning the states' progress.

The 85 percent withdrawal would occur over the 10-15 year time line contained in S. 2053, and would be based on the total amount of Federal Medicaid funds flowing into institutions in the state on a specific date (as yet unspecified). (Specific examples describing the effect of the proposed changes on a state's Federal Medicaid funds will be developed and available in the near future.)

The adjustment for inflation will mean that states have 15 percent in real dollars still available for institutional care at the end of the 10-15 years. Details on this adjustment have not been worked out yet.

It is intended that the Secretary's report to Congress will trigger Congressional hearings on the state of the art of community and other services in order to further determine how Medicaid funds should be used in accomplishing the national goal of community-based services for all people with mental retardation as well as other disabled populations.

A major advantage of the recommendations at left is that by retaining some amount of funds in institutions -there is a strong, direct basis for enforcement of federal standards for such environments.

Partial phase-out (Cont'd)

Recommendation

Explanation

The proposed 85% reduction is consistent with the Position Statement on Residential Services adopted by the ARC delegate body at its annual convention in November, 1983, and with the ARC Goals and Objectives adopted by the Board of Directors. It responds to input from ARC members, as requested by President Everitt, and to testimony given on February 27 to the subcommittee of the Senate Finance Committee. It takes into consideration the political realities in Congress and the views of developmental disabilities professional and advocacy organizations whose support of S. 2053 is important to its passage.

It is important to recognize that the goal of phasing out large institutions requires first and subsequent steps; under present circumstances, the ARC'S proposed modification enhances that goal. As stated above, the modification is based on practical and political reasons. The ARC does not believe that there is any segment of the mentally retarded population that needs institutional care on a permanent basis.

The Committee is convinced that this modification is consistent with the policy direction set by the ARC/USA. Accordingly the Committee foresees that it will not initiate other changes in the withdrawal provisions.

Financial incentives for community services

Eliminate the provision in S. 2053 which provides a 5 percent higher Federal match for home and community services to persons who were institutionalized for the first five years following their return to the community.

Add a provision which would reduce the Federal matching rate for institutional care while maintaining the Federal match for home and community-based services.

The proposed modification will provide a more meaningful fiscal incentive for states to plan for and provide family home and community services, and avoid placing undue emphasis on services for institutionalized persons returning to the community. Many fear that S. 2053, as currently written, emphasizes services for persons leaving institutions at the expense of those already in the community, and that lengthy delays will ensue for those living in the community and in need of services, including those needing to leave home.

Financial incentives for community services (Cont'd)

Recommendation

Explanation

Under the proposed change if state X currently has a 50:50 Federal state match, the percentage of the Federal match for institutional care would decrease from 50 percent over a given period of time. Conversely, the 50 percent match for community services will remain the same. Thus, it will be increasingly more attractive for states to fund family home and community services. The percentage decreases and time schedule have not yet been determined.

Temporary institutionalization

Alter the language of S. 2053 so that the provision for two year temporary institutionalization not include any stay in an institution which occurs prior to the 10-15 year withdrawal of 85 percent of the Federal Medicaid funds from institutions.

This change will provide more options and flexibility for the use of institutions following the withdrawal of 85 percent of the Federal Medicaid funds from institutions. Since 15 percent of the Federal Medicaid funds will remain available for institutional care the provision at left will only be relevant when the persons to be institutionalized trigger Federal Medicaid funding in excess of the 15 percent.

Eligible population

Define the eligible population as those severely disabled individuals who have a disability as defined in Section 223 of the Social Security Act which began before the age 50, except for individuals between the ages of 21 and 65 who suffer primarily from a mental disease.

Using the definition of the developmentally disabled with a higher age of onset has proven too confusing. The definition at left is based on the current definition of disability contained in the Social Security Act and will ensure that the definition of disability in S. 2053 is consistent with that used today to determine eligibility for Supplemental Security Income and Medicaid benefits.

Provide that any children or youth who are under the age of 21 when S. 2053 is enacted and who have a primary diagnosis of mental illness, retain their eligibility for family home and community services as they grow older.

Simplifying the definition in this way makes it clearer that to be eligible for Medicaid, and consequently S. 2053, one must usually be eligible for Supplemental Security Income.

Allowing mentally ill children who are eligible for services under S. 2053 to retain their eligibility as they grow

Eligible population(Cont'd)

Recommendation

Explanation

5. Options for those over 65

Alter language to allow either skilled nursing facility, intermediate care facility (not intermediate care facilities for the mentally retarded) or family home and community-based services for severely disabled persons over 65 years of age, regardless of their age at the onset of their disability.

older will mean these children will not be faced with the loss of appropriate services at age 21. By allowing mentally ill children and youth to continue eligibility into their adult years S. 2053 will be programmatically more appropriate for this population.

Because public policy for elderly disabled persons is not as certain as that for the non-elderly disabled, because the trend in services for this population appears to be in the same general direction as that called for in S. 2053, and because many persons feel that nursing homes are appropriate and "normal" for some elderly disabled persons, a recommendation is being made to allow either institutional (including nursing homes) or family home and community services for disabled persons over 65 years of age.

It is intended that the Secretary's comprehensive report to Congress (see recommendation 1 above) will clearly address best services practices for this population as a basis for future decisions regarding the use of Federal Medicaid funds to serve those elderly persons with severe disabilities.

6. Identification of eligible persons in nursing homes

Add specific language requiring states in their implementation agreements to undertake (i.e. make a commitment) to identify within one year and annually thereafter eligible severely disabled individuals who are living in skilled nursing facilities, intermediate care facilities, and board and care facilities having 16 or more beds and in which a significant number of recipients of Supplemental Security Income are likely to reside.

To strengthen the protections of severely disabled persons currently residing inappropriately in nursing homes states must be required to clearly commit to the development of a process for identifying eligible severely disabled individuals in SNFs, ICFs and board and care homes since such a process does not currently exist in many states and is essential for appropriate planning for the future.

Recommendations

Explanation

Protecting existing services

Add language stating that the amounts expended for community and family support services shall be in addition to any forms of medical assistance for which the individual would otherwise be eligible under the state's Medicaid program, except for Skilled Nursing Facilities, Intermediate Care Facilities, and ICF/MR services.

The recommended language will state explicitly that the services eligible for Medicaid reimbursement under S. 2053 would in no way jeopardize an individual's entitlement to other services under the state's Medicaid plan. For example, basic Medicaid services such as hospitalization and special services such as in-patient psychiatric care would clearly be retained as eligible Medicaid services under S. 2053.

Mandating and itemizing services

Require states to include in their Medicaid State plans an array of community and family support services for any severely disabled individuals who are entitled to medical assistance under the plan and who live in family homes or community living facilities. Language would be added requiring the array of services, when combined with other medical assistance available under the plan, to be sufficient in quality, extent and scope to assure the health, safety and effective habilitation or rehabilitation of such individuals.

To ensure that states provide appropriate family home and community services under S. 2053, such services should be itemized and mandated to the greatest extent possible. As appropriate under Medicaid law the provision to the left requires states to offer family home and community based services and allows states, for the most part, to select an array of services from those listed.

This array of services would be selected from the following list:

Several specific services were listed in response to input from concerned individuals. For example, supplies (meaning expenses incurred for such things as diapers, special diets, special play equipment, special clothing, tape, gauze, cushions, straps, ointments etc. that exceed those required for a normal person of the same age); adaption of equipment, vehicles or housing; personal guidance, supervision, counseling, representation or advocacy; special transportation services; specialized training for families or caregivers and preventive services.

- case management services;
- periodic interdisciplinary diagnostic and assessment services;
- personal assistance or attendant care;
- domestic assistance necessitated by the individual's disability;
- services to enable the individual to improve or maintain functional capacities;
- prostheses, assistive devices, supplies and appliances;
- adaptation of equipment or vehicles, or of housing or other space to be used by an eligible severely disabled individual;

Mandating and itemizing services (Cont'd)

Recommendation

- comprehensive outpatient rehabilitation facility services;
- personal guidance, supervision, counseling, representation or advocacy;
- adult day programs,
- services (other than board or lodging or basic foster care) provided to any severely disabled individual by a family with whom such individual is living;
- support services to families or caregivers including (i) specialized training and (ii) respite care in or out of home or usual residence;
- special transportation services;
- homemaker/home health services;
- chore services;
- crisis intervention;
- protective services;
- specialized vocational and occupational services that will enhance the independence, productivity, and community integration of a severely disabled individual, including employment training, support necessary to maintain the employment of such individual, and other training and therapeutic activities specified in the written plan of habilitation or rehabilitation developed with respect to such an individual;
- appropriate preventive services to decrease the needs of eligible individuals for future services;
- any other services identified by the State and approved by the Secretary as conforming with the purposes of this section; and
- amounts expended by any state agency or provider of services under this section to administer the provision of community and family support services shall be treated as administrative expenses of such plan.

Recommendation

Explanation

9. Room and Board

To permit no payment for room and board other than room and board provided for a period of not more than six consecutive weeks as an integral but subordinate part of a service funded under S. 2053, except that auxiliary payments may be made to cover extraordinary costs of food or housing attributable to the disabling condition(s) of a particular individual or individuals.

Concern has been expressed that open ended payments for room and board would foster "facility" or packaged models of care rather than individualized services. Other concerns were the potential confusion about the use of Supplemental Security Income payments (which are specifically intended for room and board) in conjunction with Medicaid payments for room and board, the possible duplication of the two funding sources, and the potential high cost of the room and board provision as currently written. The suggested change at left allows for room and board payments for respite care or emergency situations and **as** payments to supplement other funding for room and board, such **as** SSI, when necessary due to extraordinary or unusual food or housing expenses required because of the disabled person's condition (s). For example, costs in excess of the SSI payment which are due to special building or life safety code requirements for structures housing disabled people might justify a supplementary payment from Medicaid under S. 2053.

10. Mandated protective services:

Add language to require states to assure, as needed, the timely availability of protective services.

Require that these protective services as well as the mandated case management services be available to any severely disabled individual, even if his income or resources exceed the criteria set for eligibility under S. 2053.

Due to the recent Baby Doe situations it is increasingly important to establish state responsibility for a meaningful protective services system for severely disabled people, without regard to income or other assets.

In addition, individualized case management services continue to be viewed as the core for responsive, effective services in a community-based system of care and should be available to all persons determined to be severely disabled.

Recommendation

Explanation

11. Expanding grandfathering provision

Expand the grandfathering provision to include all existing facilities with up to 15 disabled residents (does not include staff living and/or working at the facility).

In addition, add language that allows existing facilities with more than 15 residents which decrease their size to 15 or fewer residents at some time following the enactment of S. 2053, to have their residents (if otherwise eligible) receive services reimbursable under S. 2053.

As written S. 2053 only grandfathers facilities with up to 15 persons if they are certified as an intermediate care facility for the mentally retarded. It is not sound public policy to allow these facilities to continue funding under Medicaid while disallowing Medicaid reimbursement for services for individuals in other existing facilities of similar size simply because, at the time of enactment, they are not certified ICFs/MR.

In the same vein, it is appropriate to add language extending Medicaid reimbursement for S. 2053 services for severely disabled individuals in other existing facilities once these facilities reduce their resident population to 15 or fewer persons.

12. Training as a reimbursable item

Add language modifying current Medicaid law applicable to reimbursement for training (currently a 75:25 matching rate) to include the training of personnel skilled in the delivery of community and family support services needed by persons with severe disabilities, whether employed by a public agency or any agency under contract to the state to provide services under S. 2053.

Further, states would be required in their implementation agreements to include provisions to ensure that training is made available to natural, adoptive and foster parents of severely disabled persons as well as staff of community living facilities.

S. 2053 requires states to provide training but does not allow for Medicaid reimbursement of such training. It is evident that training is a critical factor in assuring quality services and has been a significant problem in many community service systems. Many advocates for S. 2053 have expressed a strong concern for the lack of funding for appropriate training including the training of natural, adoptive and foster parents.

13. Adequate fee levels

Add language to modify current law to require, to the greatest extent feasible, that states set fee levels, i.e. rates of reimbursement, for community and family support services that are reasonable and adequate to assure the provision of care and services which conform with applicable state and federal laws, regulations

A major problem in providing quality community services under the Medicaid program is that states often set fee levels too low to ensure such quality. While it would be inappropriate to mandate fee levels on a national basis the language at left will require, to the greatest extent possible, adequate rates of reimbursement for family home and community services.

Adequate fee levels (Cont'd)

Recommendation

and applicable quality and safety standards; to assure that severely disabled individuals eligible for medical assistance have reasonable access (taking into account geographic location and reasonable travel time for family and friends) to community and family support services of adequate quality; and to enlist enough providers so that these services are available to severely disabled recipients at least to the extent that services under the plan are available to the general population.

14. Equating income eligibility criteria

Add language to equate the income eligibility criteria established under Medicaid for institutional and community services. Such language may read: "if the state establishes a separate income standard for individuals who are in any medical institution, the state must establish the same separate income standard for all severely disabled individuals."

Explanation

Under current Medicaid law states may set a separate income standard for persons in institutional settings. Such a standard may allow an individual to have an income up to three times the federal Supplemental Security Income amount. This option is generally not allowed for disabled persons seeking Medicaid reimbursement for community-based services. The additional language at left will equate the income eligibility criteria.

15. Medicare gap

Add language stating that whenever an individual is receiving benefits under Title II of the Social Security Act as an adult disabled during childhood (ADC) and as a consequence of such Social Security income is found ineligible for SSI benefits, such individual shall be deemed to be eligible for services provided under S. 2053, i.e. treated as if he were an SSI recipient.

Concern has been expressed that persons whose benefits under the ADC program are too high to qualify them for SSI and consequently for Medicaid must wait two years in order to receive benefits under the Medicare program. The language on the left deems such persons eligible for S. 2053 services. However, the language goes further than covering services during the two year gap and allows ADC individuals to continue their eligibility for S. 2053 services even after they become eligible for Medicare.

It would not be good public policy to provide services under S. 2053 only to withdraw eligibility two years later. The fact is the Medicare program does not reimburse in any meaningful way services like those in S. 2053. It is important to note that the suggested language does not cover ADC persons who have income and resources other than ADC benefits which would cause them to be ineligible for SSI.

Recommendation

Explanation

L5. Maintenance of effort

Add language prohibiting states from suspending, reducing, discontinuing or terminating the medical assistance provided under their state plan because of any financial constraints created by the reductions called for in S. 2053.

In response to concern about the states maintenance of effort under S. 2053 the language at left was developed. However, it does not require that the total amount of state Medicaid matching funds currently used to provide services for retarded and other severely disabled persons, both institutional and community-based, be maintained, i.e. as services shift to the community the states are not mandated to maintain the same total amount of dollars for services to disabled people. Legal counsel suggests that such language would be inappropriate under Medicaid law and that the language to the left is more appropriate.

7. Fair employment standards for employees of private programs

Add language requiring states in their implementation agreements to assure the application of fair employment standards to workers in private programs and facilities offering care and services as described in S. 2053.

There is a great deal of concern in the field of mental retardation about the difference in salaries paid to public employees versus workers in private programs or facilities. The low wages in private programs are sometimes cited as a factor in high staff turnover and consequently, substandard care. The suggested language at left is aimed at helping alleviate this problem by requiring states to assure the application of fair employment standards to such employees.

While higher salaries will increase the cost of community services, salaries are only one factor (albeit an important factor) contributing to the generally more expensive institutional environments. For example, the division of labor, ie. specialized jobs, required in institutions is another factor contributing to institutional costs.

Recommendation

Explanation

18. Service requirements for community living facilities

Add language stating that community living facilities, in providing living arrangements, care and services to severely disabled individuals, must cooperate with other providers and with appropriate case managers in implementing a written plan of habilitation or rehabilitation for each individual.

Critics of S. 2053 have stated that as written the bill implies that community living facilities must themselves provide or be the focus of responsibility for all services to their residents. The suggested language on the left will clarify that such facilities must cooperate with other providers and the individual's case manager to assure the provision of appropriate services.

19. Private enforcement

Alter the language of the private enforcement provision to read as follows:

SEC. 5. (a)(1), Any person injured or adversely affected or aggrieved by a violation of this Act by a state agency administering a State Plan approved under section 1902(b) of the Social Security Act may bring an action to enjoin such violation.

(2) An Action brought under paragraph (1) shall be brought in the appropriate district court of the United States within the state in which such State Plan is in operation.

(3) Such party may elect, by so stating in the complaint filed at the commencement of such action, to recover reasonable attorney's fees and costs from the defendant in the event that such party prevails.

(b) (1) Upon filing a lawsuit under subsection (a), the complainant shall give notice by registered mail to the Secretary of Health and Human Services, the Attorney General of the United States, and the state agency administering the State Plan alleged to be in violation of this Act.

After obtaining legal advice it was felt that the private enforcement language in S. 2053 could be significantly improved and clarified. New language is presented at left. This language specifically states that aggrieved persons may sue the state agency administering the state Medicaid plan (rather than the plan itself), and may file to recover reasonable attorney's fees as well as costs. The fact that the Secretary approved the particular plan in question shall not bar action against the state agency. Previous language stating that "no action could be brought if, at the time the complaint is filed, the same alleged violation by the same state agency administering the plan is the subject of a pending action in any court of the U.S." was deleted because it was unnecessary.

Private enforcement (Cont'd)

Recommendation

Explanation

(2) The notice required under paragraph (1) shall state the nature of the alleged violation, the court in which such action will be brought, and whether or not attorney's fees and costs are being demanded in the event the plaintiff prevails.

(c) The approval of the State Plan, with reference to the provisions of this Act, by the Secretary shall not be a bar to the bringing of an action under paragraph (1) nor shall it constitute a defense to any such action.

20. Timelines for implementation

Require states to provide some family home and community services in the first year following enactment of S. 2053.

(Federal Medicaid matching dollars would be available for such services.)

Allow states two years following enactment to complete their implementation agreements. The 10-15 year time period for the withdrawal of 85 percent of the Federal Medicaid funds from institutions would not begin until completion of the implementation agreements.

To ensure an orderly, well-planned transition from institutional to family home and community services, states should be given two years to complete their implementation agreements. This allows time for the Federal government to develop and publish regulations implementing S. 2053, gives states time to complete the individual community services plans for institutionalized persons and to identify persons inappropriately placed in nursing homes and general ICFs. All of this information is necessary for states to develop a meaningful, data based implementation agreement.

While it is important to allow states sufficient time to complete their implementation agreements, it is equally important that states be required to begin providing appropriate home and community services in the first year following enactment so that the actual provision of such services is not delayed.

Delaying the beginning of the 10-15 year time line for the withdrawal of 85 percent of the Federal Medicaid funds from institutions until the third year following enactment (after completion of states' implementation agreements) in essence provides two additional years for the withdrawal to take place

Timelines for implementation (Cont'd)

Recommendation

Explanation

i.e., in reality, the 10 years would become 12 and the 15 would become 17.

21. Standards for non-certified institutional beds

Eliminate the provision in S. 2053 which would require that all institutions currently not certified as Intermediate Care Facilities for the Mentally Retarded comply with the federal standards for the ICF/MR program.

Under current Medicaid law states may chose whether or not to have each of their institutions certified as ICF/MR. Requiring states to bring all institutions into compliance with the Federal standards would mean a significant influx of Medicaid dollars into institutional environments. Such a requirement is not consistent with and is, in fact, at odds with the intent of S. 2053. Not requiring massive expenditures, primarily for capital improvements, in institutions does not mean that institutionalized persons should have less than the highest quality of services.

22. Client and advocate involvement in decision-making

Clarify language throughout S. 2053 to ensure the involvement of the disabled individual himself and, as appropriate, his advocate (in addition to his spouse, parent, guardian or appropriate family member) in all living arrangement and services decisions (and corresponding appeal procedures) for the disabled person.

It is important to make it clear that the disabled individual and, as appropriate, his advocate must be involved in all decisions (and corresponding appeal procedures) relative to the persons' living arrangements and services requirements.

23. Appeal procedure for persons in various community settings

Add language requiring an opportunity for an appeal and fair hearing before an impartial hearing officer for any individual (or his spouse, parent, guardian, appropriate family member or advocate acting on his behalf) who believes himself to be inappropriately placed or who is denied an appropriate placement or service, or who is being scheduled for transfer from one community living arrangement to another otherwise than on his own initiative.

S.2053 provides such an appeal procedure only for persons scheduled for transfer from an insitution to a community setting. It is equally important to have such an appeal process available to those living within the community.

Recommendation

Explanation

24. Deeming of resources for children

Add language to allow states to provide S. 2053 services to disabled children who, except for resources deemed to them, would be eligible to receive Supplemental Security Income benefits.

Under the Supplemental Security Income program disabled children are often found ineligible solely due to family resources which are deemed to be available to them. Denial or loss of SSI usually results in ineligibility for Medicaid. The language at left would allow states to choose to provide such children with S. 2053 services reimbursable under Medicaid.

OTHER DECISIONS/ISSUES IDENTIFIED

BY THE ARC

1. Start-up costs/capital construction - The Committee recognizes that such costs cannot be met under the Medicaid program. Other Federal and state programs which can provide start-up or capital construction monies were identified to be targeted for expansion. In addition, a recommendation will be made to Senator Chafee to require states to describe in their implementation agreements their plans for meeting such expenses.
2. Integration of S. 2053 language into existing law - The Committee endorsed the idea of integrating, to the greatest extent possible, the language of S. 2053 into existing law by using conforming amendments.
3. Clarifying audits, reviews, monitoring requirements - The Committee is further researching the most appropriate and effective audit, reviews and monitoring mechanisms to be utilized under S. 2053.
4. Intermediate size facilities- - The Committee made no changes in the size requirements in S. 2053. It was felt that, at this time, there is insufficient data to justify any expansion of S. 2053 coverage for facilities with more than 15 residents. This major issue is still open for further consideration. Key national organizations (e.g. National Association of Private Residential Facilities for the Mentally Retarded) and individuals have been requested to provide specific data and recommendations.
5. Expanding consumer involvement - The Committee is supportive of an expansion of disabled persons' involvement, when appropriate, in their services program, e.g., the selection, hiring and training of attendants, and is further researching the most appropriate language to accomplish this expansion.