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NATIONAL ASSOCIATION OF STATE MENTAL RETARDATION PROGRAM DIRECTORS, INC.

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December 2, 1988

LEGISLATIVE SPECIFICATIONS

REVISIONS IN H.R. 5233, THE "MEDICAID QUALITY SERVICES TO THE MENTALLY RETARDED AMENDMENTS OF 1988"

Short Title

A Provisions of the Existing Bill. Section 1 cites the title of the bill as the "Medicaid Quality Services to the Mentally Retarded Amendments of 1988."

the Present Language. It is generally accepted practice in the disability field to avoid the use of potentially demeaning labels, such as "the mentally retarded", "the mentally ill" and "the physically handicapped". In re-writing disability-specific legislation over the past few years (e.g., the Developmental Disabilities Act, the Vocational Rehabilitation Act, and the Education of Handicapped Act), Congress generally has substituted "people first" language.

Proposed Revision. Modify the short title of the bill to read: the "Medicaid Quality Services for Persons with Mental Retardation and Related Conditions Amendments of 1989." [N.B., No attempt will be made to note other conforming changes that are needed in the text of the bill; but, it would be advisable to use "people first" language consistently throughout the revised measure.]

D. Programmatic Implications. While altering statutory references to persons with mental retardation and related conditions will not change the substantive effects of the legislation, it will exhibit Congressional sensitivity to the underlying aims of the bill and the aspirations of persons with severe disabilities.

E. Cost Implications. None.

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Title I - Optional Expansion of Community-Based Services

A. Definitions.

1. Provisions of the Existing Bill. Section 101(a) of H.R. 5233 contains a revised definition of the term "habilitation services", as it currently appears in Section 1915(c)(5) of the Act. This revised definition would: (a) add the word "community" as a modifier of the existing term "habilitation services"; (b) make it clear that such services may be designed "to assist individuals in participating in community or other activities"; (c) decouple eligibility to participate in prevocational, education or supported employment services from the individual's former status as a resident of a skilled nursing or intermediate care facility (including an ICF/MR); (d) condition receipt of federal Medicaid reimbursement for such services furnished in "supervised residential settings" to those settings which meet regulatory standards promulgated by the Secretary of Health and Human Services; and (e) explicitly define the types of room and board costs that would be excluded from Medicaid reimbursement.
2. Problems with the Present Language. In general, the revised definition contained in Section 101(a) of the bill would be a distinct improvement over the current statutory definition. However, in order to avoid administrative conflict between HCFA and the states over the meaning of particular elements of the definition and to make it clear that the states would be authorized to claim Medicaid reimbursement for a variety of types of supportive services, as well as direct training activities, the following additional modifications in the definition are proposed.
3. Proposed Revisions. Include the following specific changes in the definitions of "community habilitation services", as it appears in Section 101(a) of the bill.
 - a. Optional Service Title. Insert the words "and supportive" after "habilitation" and before "services" on line 10, page 2 of the bill

Justification. The purpose of this change is to underscore the fact that various types of supportive services may qualify for Medicaid reimbursement under the new state plan option (see further discussion under 3(f) below). The title of the proposed, new optional service, therefore, would be "community habilitation and supportive services".
 - b. Adjunctive Activities. Redesignate subparagraph (B) of Section 1915(c) (5) (lines 8-14, page 3) as subparagraph (C) and subparagraph (C) as subparagraph (D); then add a new subparagraph (B) reading as follows:

(B) includes such activities as are necessary to ensure the effectiveness of training or to promote participation in community activities, including related program management functions, maintenance of staffing to assure individual access to assistance, and other related functions or activities.

Justification. The intent of this new subparagraph is to make it clear that the provision of direct training or assistive services often involves a variety of adjunctive activities that may be treated as Medicaid-allowable costs. Such activities are an integral part of accomplishing person-centered objectives, but, nonetheless, may not take place at the same time and place as the direct client contact/service intervention. For example, a community residence that is responsible for the welfare of persons who are incapable of self-preservation in a fire emergency or otherwise in need of round-the-clock supervision may be required to maintain "overnight" staff, awake and on-duty. If so, the costs of such staff should be viewed as a component part of the

overall cost of providing such individuals with community habitation and supportive services. Similarly, the costs of developing and maintaining individual program plans on recipients of community habitation and supportive services should be treated as an allowable Medicaid expenditure, even though portions of such activities will not involve direct, one-to-one interaction with the affected individual.

Definition of Prevocational Services. Add a new subparagraph (F) to Section 1915(c)(5) (after line 25, page 4) that reads as follows:

(F) the term prevocational services means services aimed at assisting an individual in securing employment at a wage rate equal to or above 50 percent of the federal minimum wage over a sustained period of time. Such services may include:

(i) assisting an individual to acquire and maintain generalized basic work and work-related skills necessary to secure and retain employment;

(ii) providing instruction in skills related to a specific job for which the individual is being prepared, or ongoing instruction in such skills to assist the individual in retaining such employment;

(iii) furnishing the individual with assistive devices and aids integral to securing employment or helping the individual to overcome impediments to employment; and,

(iv) providing transportation between the person's place of residence and the work place or work training site.

Such service will be furnished in accordance with written objectives contained in the individual's service plan, prepared in accordance with Section 1924(j)(4), which shall describe how such services will assist the person in securing and maintaining employment, but shall not be conditional upon securing such employment within any specified period of time. Persons participating in prevocational services shall be compensated in accordance with applicable state and federal laws. Such services may be furnished at specialized training sites or at worksites in which the majority of persons are not disabled. Such services do not include vocational rehabilitation services which otherwise are available to the individual through a program funded under Section 110 of the Rehabilitation Act of 1973 (29 U.S.C. 730).

Justification. Present HCFA policies governing the provision of home and community-based waiver services use the same measure of earning capacity to distinguish prevocational services - i.e., 50 percent of the federal minimum wage - as proposed in HCFA regulations on June 1, 1988 (53 FR 19950). The proposed language, however, departs from the HCFA's definition in that it would explicitly allow services aimed at assisting an individual to secure specific employment, rather than simply being trained in general work behaviors. HCFA's definition prohibits a state from classifying a service as "prevocational" if it is intended to result in employment in a specific job or if the individual might be expected to gain employment within a year. These provisions are absolutely contrary to the expressed intent of the bill - "to [promote] the individual's capability of engaging in major life activities with other individuals including employment...". A wage-based test represents the most equitable and objective means of distinguishing between "prevocational" and "vocational" services.

- i Definition of Supported Employment. Add a new subparagraph (G) to Section 1915(c)(5) (after line 25, page 4) that reads as follows:

(G) the term "supported employment" means services designed to assist an individual in securing and maintaining integrated, paid employment when sustained competitive employment at or above the federal minimum wage is unlikely in the absence of the provision of ongoing support services. Such services may include:

- (a) individual assessments and counseling;
- (b) individual job development and placement services;
- (c) training in work and work-related skills required to perform a specific job, including on-site training;
- (d) ongoing supervision and monitoring of the individual's performance on the job;
- (e) training in skills necessary to obtain and retain employment;
- (f) transportation between the individual's residence and place of training or work, including public transportation;
- (g) furnishing the individual with assistive devices and aids integral to obtaining and retaining employment; and,
- (h) such other services as are necessary to overcome direct or indirect obstacles to employment

Such services shall be furnished in accordance with objectives specified in an individual service plan, which shall describe how the services furnished will assist the person in securing and maintaining competitive employment, but shall not be conditional upon securing such employment within any specified period of time. Persons participating in supported employment services shall be compensated in accordance with applicable federal laws. Such services will be furnished at work sites in which the majority of persons are not disabled, except that services may be furnished off the job site, where appropriate, to meet specific individual service plan objectives. Such services do not include vocational rehabilitation services which otherwise are available to the individual through a program funded under Section 110 of the Rehabilitation Act of 1973 (29 U.S.C. 730).

Justification. The basic thrust of the above definition is essentially the same as the definition of supported employment contained in proposed HCFA regulations (53 FR 19950) implementing Section 9502(a) of COBRA (P.L. 99-272), although the suggested language delineating reimbursable activities under this service category is somewhat more explicit. The purpose of incorporating a definition of this term in federal Medicaid statutes is to make Congressional intent regarding the nature and scope of reimbursable services clear and, thus, help to avoid later disputes.

- e. Exclusion of Payments for Educational Services. Add the following phrase after the word "agency" and before the word "and" on line 20, page 3 of the bill, "except as specified in Section 1903(c) of the Act"

Justification. This technical amendment is intended to reflect a statutory change included in the Medicare Catastrophic Health Coverage Act of 1988

(P.L. 100-360). Under Section 411(k)(13) of P.L. 100-360, the Secretary is prohibited from establishing policies that deny Medicaid payments for covered services on the grounds that such services are "educationally-related" and covered in an eligible child's Individualized Education Program or Individualized Family Services Plan, as required under Parts B and H, respectively, of the Education of the Handicapped Act.

Definition of Other Supportive Services. Add a new subparagraph (H) to Section 1915(c)(5) (after line 25, page 4) that reads as follows:

(H) The term "other supportive services" means such services as the State determines to be necessary and effective in promoting the individual's capacity to engage in major life activities with other individuals, including participation in community activities. Such services may include:

- (i) transportation to community activity sites;
- (ii) therapeutic services, including the implementation of a routine regimen of services in accordance with a therapeutic program developed and monitored by a licensed therapist;
- (iii) individual assessments, specialized diagnostic tests, and such other evaluations as are necessary to support the development of the individual's service plan;
- (iv) prostheses, orthoses, supplies, appliances, adaptive equipment, communication aids and other functional assistive technologies and devices (including sensory aids) and rehabilitative technology services to evaluate, design, assemble, repair and maintain such equipment/aids/ devices/systems as are necessary to promote individual self-sufficiency or to overcome obstacles to participation in community life, and which are not otherwise covered under the state plan;
- (v) family counseling and training necessary to assure the continuity of habilitation services furnished in accordance with the individual's service plan;
- (vi) such health-related services as are not otherwise covered under the State plan or such supplementary payments for such services as may be necessary to take into account the special needs such individuals in accessing health-related services furnished under the State plan;
- (vii) respite care services furnished in order to provide relief for the individual's principal caregiver. Such services may be provided at the recipient's residence or at another site. The Secretary shall not promulgate regulations restricting the duration, frequency, or scope of such services;
- (viii) recreation or leisure time activities intended to promote the individual's participation in the community, provided that such services are furnished in locations or sites which allow interaction with non-disabled individuals;
- (ix) environmental modifications necessary to maintain the individual in the person's own home or a community residence; and,

(x) such other services as the state may deem appropriate to promote participation in community life or address obstacles to individual self-sufficiency.

Such services shall be furnished in accordance with objectives contained in the individual's service plan, as prepared in accordance with Section 1925(j)(4). The Secretary shall not be authorized to promulgate regulations that otherwise limit the duration, frequency, and scope of such services, nor shall the Secretary require that each service be specifically enumerated in the individual's service plan.

Justification. In general, the purpose of including an explicit definition of "other supportive services" in the bill is twofold: (a) to make it clear that a well-rounded array of community services must include a variety of special supportive services, as well as developmentally-oriented training services, if society is to effectively assist persons with severe disabilities to achieve enhanced levels of independence and community integration; and (b) to spell out the specific types of social supports a state may incorporate under its state Medicaid plan, in order to prevent HHS/HCFA from arbitrarily narrowing, through administrative rules and interpretations, the scope of allowable "community habilitation and supportive services". An illustration of the latter phenomenon can be found in recently proposed regulations issued by HHS/HCFA, which would restrict Medicaid reimbursement for respite care services to 30 days annually (53 FR 24103), even though there is no basis in statutory law or Congressional intent for such a limitation.

The final paragraph of the definition attempts to strike a balance between the need to carefully plan services on behalf of an individual and recognize the fact that the overspecification of service plans creates needless paperwork. In the absence of such a statutory recognition, federal audits of Medicaid expenditures for community-based services may place federal financial participation in jeopardy in cases where discrete specifications of activities have not been spelled out in excruciating detail in the individual's program plan.

- g. Secretarial Standards. Delete subparagraph (F) of Section 1915(c)(5) and replace it with a new set of requirements, as described under B-3 a through c below.

Justification. The introduction of uniform federal standards governing the operation of Medicaid-supported community residences, as proposed in Section 1915(c)(5)(D) of the current bill, would have far-reaching ramifications. Recent experience with federal standard setting in the area of ICF/MR policy strongly suggests that the application of federal standards would result in: (a) a monolithic nationwide approach to delivering community residential services at a time when the emphasis in the field has shifted to creating a wider array of more individualized living and programming arrangements; and (b) a clinically driven model of services that ultimately would increase the cost of operating Medicaid-funded residential programs substantially, without necessarily achieving any measurable improvements in the quality and appropriateness of services provided to residents. To avoid these pitfalls, a different approach to quality assurance is needed - one which balances the legitimate interests of the federal government in assuring that recipients of Medicaid reimbursable services are adequately protected, while at the same time preserving reasonable latitude for the states to develop responsive service delivery networks. Such an approach is outlined under B-3 below.

4. Programmatic Implications. The additional definitional language suggested above would have two principal benefits. First, it would reinforce the growing trend toward organizing community-based DD services that include, not only developmentally-oriented training programs, but also the types of adaptations and supports which are necessary for individuals with severe disabilities to achieve meaningful, productive roles in American society. Second, by including more detailed definitional language, the proposed amendments would help to avoid later disputes concerning the precise scope of Medicaid reimbursable activities intended by Congress.
5. Cost Implications. Since the existing bill's basic, underlying precepts concerning the eligible target population and the circumstances under which such services could be covered under a state's Medicaid plan (i.e., as an optional service coverage) would not be affected by these proposed amendments, any additional federal costs associated with these proposals should be minimal. Some may argue that the greater specificity of definitional terms -- especially in the area of community supportive services -- would offer the states a firmer foundation for claiming Medicaid reimbursement for a wider array of community services and, consequently, would lead inevitably to higher federal costs. Experience with the Medicaid home and community-based waiver program (which is currently in operation in 38 states) provides little support for this argument. Although the HCB waiver authority provides states with considerable flexibility in designing appropriate community service arrays, the vast majority of waiver expenditures continue to be incurred for services rendered in small community residences and structured day programs — both of which would be covered under the bill's definition, with or without the proposed amendments. Indeed, where states have adopted new supported service approaches to delivery services (e.g., supported employment; supported living arrangements; etc.), the available evidence suggests that, over time, cost efficiencies are achieved.

B. Conditions of Optional Plan Coverage

1. Provisions of the Existing Bill. As a condition of covering optional community habilitation services under its state Medicaid plan, a state would be obligated, under Section 101(c) of H.R. 5233, to provide the Secretary with satisfactory assurances that certain fair and equitable arrangements would be made to protect the interests of employees affected by the coverage of such services under its Medicaid plan. The specific protections a state would be obligated to afford employees would be spelled out in a proposed, new Section 1925(j) of the Act, as added by Section 501(a) of H.R. 5233.

In addition, a state would not be permitted to claim Medicaid reimbursement for "community habilitation services" provided in supervised residential settings unless the particular facility/program setting met standards applicable to such a setting that were promulgated by the Secretary of Health and Human Services on or before October 1, 1989. These Secretarial standards would have to include provisions dealing with client rights and protections, case management, the use of comprehensive functional assessments, the process of developing, monitoring and revising individual program plans, the use of a uniform client performance accounting system, and the application of minimum health, safety, and sanitation rules (Section 1915(c)(5)(D), as added by Section 101(a) of H.R. 5233; (lines 1-11, page 4)).

2. Problems with the Present Language. H.R. 5233, as currently drafted, would impose conditions on a state's coverage of optional "community habilitation services which, in some respects, are unreasonable. As will be pointed out in greater detail in the discussion below, there are ways of accomplishing the same basic purposes without imposing unilateral "federal solutions".

3. Proposed Revisions. Add a new Section 1925(j) to the Act, entitled "Conditions of Covering Optional Community Habilitation and Supportive Services," and include in this new section the following provisions:
- a. Federal Health and Safety Standards. Include subparagraph (1) of Section 1925(j), which shall read as follows:
- (1) In order to cover community habilitation and supportive services, as authorized under Section 1905(a)(21), a state must provide assurances satisfactory to the Secretary that health/safety standards and client protections will be established, maintained and enforced. Such standards and protections, at a minimum, must include:
- (A) fire safety standards applicable to any institution, foster home, group living arrangement or any other supervised residential setting that receives Medicaid payments on behalf of one or more recipients of community habilitation and supportive services. Such standards must be appropriate to the needs of such recipients, given the character of the physical structure involved.
- (B) a requirement that all facilities providing Medicaid-reimbursable community habilitation and supportive services comply with all applicable state and local laws governing safety and sanitation.
- (C) a requirement that all physical facilities in which community habilitation and supportive services are provided, designed, constructed, furnished, equipped and maintained in a manner to protect the health and safety of recipients, personnel and the general public.
- (D) provision for protecting and promoting the rights of each recipient of community habilitation and supportive services, including each of the following rights:
- (i) The right to be free from physical, verbal, sexual, or psychological abuse, corporal or psychological punishment, aversive stimuli (except where such techniques are used in accordance with objectives specified in an individual's service plan and state policies governing the use of such techniques) and involuntary seclusion unless prescribed as part of a prescribed behavior management program.
- (ii) The right to be free from any restraints imposed for purposes of discipline or convenience of the staff, not required to treat the client's diagnosed symptoms.
- (iii) The right to privacy with regard to accommodations, medical treatment, written and telephonic communications, visits, and meetings of family and of client groups.
- (iv) The right to confidentiality of personal and clinical records. The right to receive services with reasonable accommodation of individual needs and preferences (including the right to retain and use personal possessions and clothing), except where the health or safety of the individual or other clients would be endangered, and

(v) The right to receive adequate notice and explanation of the reasons therefore before the room or roommate of the client living in a residential facility is changed, allowing for client approval, whenever possible.

(vi) The right to voice grievances with respect to services that are (or fails to be) furnished, without discrimination or reprisal (or threat of discrimination or reprisal) for voicing the grievances and the right to prompt efforts by the facility or program to resolve grievances the client may have, including those with respect to the behavior of other clients. The rights of the individual to organize and participate in client groups and the right of the client's family to meet with the families of other clients on the premises of the facility or program.

(vii) The right of the client to participate in social, religious, and community activities that do not interfere with the rights of other facility/program clients.

(viii) The right to choose among available qualified professional staff of the facility or program, to be fully informed in advance about planned services, to be fully informed in advance of any changes in service plans that may affect the client's well-being, and to participate in planning services or changes in such services.

(ix) The right not to be compelled to perform services for the facility or program and, if the client chooses to perform such services, to be compensated for such services at prevailing wages commensurate with the client's skills.

(x) Any other right established by the Secretary.

Justification. The above language would provide specific statutory guidance regarding the minimum health and safety standards and client protections a state would have to observe in providing Medicaid-reimbursable community habilitation and supportive services. By including these fundamental safeguards in federal law, rather than delegating broad administrative discretion to either the states or the Secretary, Congress would have greater assurance that all services funded with Medicaid dollars would be required to meet such basic requirements. [N.B., An alternative approach, which might make more sense in the overall context of the legislation, would be to reposition the requirements relative to client rights that presently appear in Section 1925(c) of the bill (line 9, page 17 through line 7 on page 33) and revise them so that they are applicable to Medicaid-reimbursable services provided both in ICF/MR-certified facilities and community-based settings. If this approach were to be used, it would be important to distinguish those rights that are applicable differentially to persons residing in congregate facilities, whether they are certified as ICF/MRs or are providers of community habilitation and supportive services, and other rights that have more general applicability.]

- b. Program Licensure/Certification. Include subparagraph (2) of Section 1915(j), which shall read as follows:

(2) In order to cover optional community habilitation and supportive services under its State plan, a State must provide

assurances satisfactory to the Secretary that, no later than one year following the effective date of coverage of subsequent to covering community habilitation and supportive services under its State plan, it will establish and maintain a program for licensing and certifying all facilities and programs that provide community habilitation and supportive services covered under the State plan. Such program, at a minimum, must include:

(i) standards governing the provision of each element of community habilitation and supportive services covered under the State plan, as well as each class of residential facilities or other out-of-home living arrangements (except for private homes that are not licensed or certified foster homes) in which recipients of such services reside. Such standards shall include standards governing provider participation and be -

(A) based on timely assessments of the individual's service/support needs and organized to assure individual development, independent functioning, productivity and community integration,

(B) furnished in accordance with the individual's service plan, prepared in accordance with subparagraph (4) of this subsection.

(C) provided in a manner that fosters opportunities for the individual to develop relationships with other members of the community (including individuals who are not disabled),

(D) designed to assist the individual in acquiring the functional life skills necessary to enhance the capacity of the individual to achieve independence, to be integrated into the community, to increase productivity and to interact with other individuals (including individuals who are not disabled).

(ii) methods and procedures for conducting on-site reviews at least once every fifteen months of each program and facility providing community habilitation and supportive services and determining whether such programs and facilities are in compliance with applicable state standards promulgated in accordance with subparagraph (i) of this paragraph; and

(iii) methods and procedures for assuring prompt correction of all deficiencies identified during on-site reviews conducted in accordance with subparagraph (ii) of this paragraph, including termination of payments to a non-complying program or facility and such other penalties deemed appropriate and designed to minimize the time between the identification of violations of standards and the final imposition of the needed remedies.

Justification. The above language would create a clear statutory framework within which the states would be required to regulate the delivery of Medicaid-reimbursable community habilitation and supportive services. Yet, at the same time, it would avoid the rigidities that would be associated with

uniform federal standards, by leaving the states sufficient flexibility to adopt regulatory requirements that take cognizance of local needs and circumstances. This approach would provide a more reasonable basis for balancing federal and state interests in assuring that Medicaid-reimbursable community habilitation and supportive services are appropriately monitored and regulated.

Additional Quality Assurance Procedures. Include subparagraph (3) of Section 1925(j), which shall read as follows:

(3) In order to cover optional community habilitation and supportive services under its State plan, a State must provide assurances satisfactory to the Secretary that, within one year of date of covering community habilitation and supportive services under its State plan, it will establish and maintain a quality assurance program which includes, at a minimum —

(i) methods and procedures for assessing the impacts of community habilitation and supportive services on the lives of recipients of such services, with particular emphasis on the extent to which such services assist individuals to —

(A) acquire new and enhanced adaptive skills and positive social behaviors,

(B) function more independently and have enhanced opportunities to make personal choices,

(C) achieve social integration and participate more fully in community life,

(D) achieve greater productivity, taking into account the particular nature and extent of the individual's disabilities,

(E) achieve the written goals and objectives set forth in the individual's service plan.

Each state shall be required to review the outcome-oriented instruments and methods promulgated by the Secretary in accordance with Section 103(b) of this Act and, no later than January 1, 1993, either—

(A) adopt such instruments and methods as part of its methodology for assessing the impacts of community habilitation and supportive services on the lives of recipients of such services, or,

(B) inform the Secretary, in writing, why such instruments and methods are inappropriate for use as part of the state's methodology for assessing the impact of community habilitation and supportive services.

(ii) methods and procedures for conducting periodic assessments of consumer satisfaction with community habitation and supportive services provided under the State plan.

(iii) methods and procedures for conducting periodic assessments of the adequacy of the physical and social environment of out-of-home residential settings in which recipients of community habitation and supportive services live. Such on-site assessments shall be carried out by review bodies composed of parents, guardians, relatives, or neighbors of such individuals. No member of such review body may be affiliated with the residential facility or program being reviewed or be a parent, guardian or relative of any occupant of such facility/program.

(iv) a methodology for assuring that prompt corrective action is taken when any violation of the requirements of paragraph (1) of Section 1925(j) or the standards promulgated in accordance with subparagraph (2)(i) of Section 1925(j) is identified as a result of the quality assurance activities required under subparagraphs (i), (ii) and (iii) of this paragraph, and

(v) methods and procedures for assuring that the results of the reviews and assessments required under subparagraphs (i), (ii) and (iii) of this paragraph are analyzed in developing and making subsequent revisions in the statewide implementation strategy required under subparagraph (5) of this paragraph.

Justification. These provisions are included because of the growing recognition in the field of developmental disabilities that it is not possible to assess the quality and appropriateness of services by adopting a uni-dimensional approach. In other words, while traditional impact and process-oriented approaches to facility/program licensure and certification must be a basic component of any quality assurance system, it is also essential to employ techniques that focus on the impact services are having on the lives of the recipients, such as measures of program outcomes and quality of life. Although the technology for conducting such assessments is still evolving - a persuasive reason for retaining the national research and demonstration authority contained in Section 103 of the bill -- states have been experimenting with various types of quality of life and client outcomes measures for the past several years. Therefore, it would not be premature to include a set of requirements that would obligate states which elected to cover community habitation and supportive services under its Medicaid state plan to build such components into its overall quality assurance program. However, states will require time to design, field test and institute such new quality assurance methods. Therefore, the proposed language would allow a state one year after the effective date of such coverage to put these additional QA components into place.

In recognition of the uncertainties associated with any national research and demonstration initiative, the proposed language would require the states to either integrate new measures of program outcomes into their own methods of assessing the impact of community habitation and supportive services or state, in writing, why they elected not to do so. This approach would assure that the results of new, federally-sponsored research is not ignored, while

avoiding absolute statutory mandates until the results of such work is completed (see further discussion of Section 103 of the bill below).

Individual Service Plans. Include subparagraph (4) of Section 1925(j), which shall read as follows:

(4) In order to cover optional community habilitation and supportive services under its State plan, a State must provide assurances satisfactory to the Secretary that all such services will be developed and provided in accordance with the provisions of an annual written, individual service plan that —

(i) is prepared in collaboration with -

(A) such individual, persons requested to participate by the individual, and, where appropriate, the spouse, parent, guardian, other family member, or advocate of such individual, and,

(B) individuals who have been involved in providing services to the individual or who are likely to be involved in providing services to the individual (including individuals responsible for providing case management services to the individual);

(ii) is based upon an assessment of the strengths of the individual and the services and supports necessary to -

(A) enable such individual to attain or retain, to the extent possible, capabilities for independence and self care,

(B) promote increased interaction between the individual and other disabled and non-disabled individuals within the community, and

(C) promote enhanced opportunities to engage in paid employment in integrated work settings;

(iii) specifies -

(A) the individuals responsible for providing services and supports in accordance with the plan and the frequency and duration with respect to which such services and supports are to be provided,

(B) the particular objectives to be achieved with respect to an individual,

(C) the services, supports and program strategies for achieving each objective, and,

(E) the priority which is to be assigned to the achievement of each objective; and

(iv) is re-evaluated at least once each year.

Justification. The purpose of the suggested language is to make it clear that all Medicaid-reimbursable community habilitation and supportive services must be furnished in accordance with the provisions of an individualized service plan - a commonly accepted practice in the field of developmental disabilities today. The proposed provisions also would specify the components of an acceptable service plan, as well as the process for developing and periodically re-evaluating such a plan.

- e. Implementation Strategy. Include subparagraph (5) of Section 1925(j), which shall read as follows:

(5) In order to cover optional community habilitation and supportive services under its State plan, a State must provide assurances satisfactory to the Secretary that, within one year of the effective date of coverage of such services under the State plan, it will promulgate and periodically revise a long range strategy for effectively utilizing Medicaid payments on behalf of persons with mental retardation and related conditions. This written strategy shall include detailed provisions for achieving an integrated, statewide approach to the utilization of Medicaid dollars on behalf of such persons and, at a minimum, shall contain the following information and data -

(i) the estimated number and functional characteristics of persons to be served in intermediate care facilities for persons with mental retardation, by year and type of facility,

(ii) details regarding any plans for altering the number and composition of persons to be served in intermediate care facilities for persons with mental retardation in future years, including the schedule to be followed in implementing such actions and the steps to be taken to assure that appropriate programming and living arrangements are developed for all persons who would be displaced by such changes;

(in) steps that will be taken to assure continued compliance with federal standards governing the operation of intermediate care facilities for persons with mental retardation, including any planned modifications in staffing levels, staff training and/or physical plant additions/renovations;

(iv) details regarding the services to be made available to inappropriately placed nursing facility residents with mental retardation and related conditions in order to comply with the preadmission screening and resident review requirements of OBRA-87 (P.L. 100-203), including the number of such persons scheduled to

receive alternative services, by year and type of residential and daytime service,

(v) the specific types of community habilitation and supportive services to be made available under the State plan, as well as the estimated number and functional characteristics of the persons who will receive such services, by year and type of residential and daytime setting in which such services will be provided,

(vi) the specific types of services for persons with mental retardation and related conditions to be covered under Secretarial waivers approved in accordance with Section 1915(c) and/or Section 1915(e) of the Act, including the estimated number and functional characteristics of persons to be served and the types of services to be offered under each such waiver program, and,

(vii) the specific types of ongoing services and supports to be made available to persons with mental retardation and related conditions under optional State plan coverages other than community habilitation and supportive services, including the estimated number and functional characteristics of persons to be served, by year and type of service.

In developing its long range strategy, a State must assure the Secretary that a draft copy of the written strategy will be made available for public comments, and that public hearings will be held to obtain feedback from interested individuals and organizations before the plan is finalized and implemented.

Justification. The primary rationale for including a requirement that each state spell out its long range strategy for utilizing Medicaid dollars on behalf of persons with mental retardation and related conditions is: (a) to ensure that an appropriate statutory framework exists in each state for making decisions regarding the use of Medicaid financing on behalf of this particular target population that encompasses all relevant aspects of Medicaid policy, and (b) to ensure that various, actors who have a stake in the provision of services to persons with developmental disabilities (i.e., provider agencies; parent/advocacy organizations; professional groups; etc.) have an opportunity to participate in the development of the state's future plans and policies, as they relate to the utilization of Medicaid dollars. The proposed language implicitly recognizes that each state faces its own unique set of circumstances and, consequently, may choose to deploy Medicaid dollars in different ways; yet, at the same time, each state should be obligated to prepare a detailed plan for utilizing Medicaid dollars in an integrated fashion, after seeking input from the interested public.

Employee Protections. Redesignate Section 1925(j) as Section 1925(j)(6) and revise the language of the existing bill as follows:

- (1) Delete the phrase "subsection (i)" from Section 1925(j)(6)(i) of the bill (line 21, page 75) and replace it with the phrase "section 1922".
- (2) Add the words "and supportive" after the word "habilitation" and before the word "services" in Section 1925(j)(6)(i) of the bill (line 22, page 75).
- (3) Add the following phrase after the word "section 1905(a)(21)" and before the word "unless" in Section 1925(j)(6)(i) of the bill (line 23, page 75): "which would jeopardize the employment status of employees of publicly operated facilities or programs for persons with mental retardation and related conditions",
- (4) Delete the phrase "under existing collective bargaining agreements" from Section 1925(j)(6)(i)(A) of the bill (lines 6-7, page 76).
- (5) Delete the phrase "through the current certified representative" from Section 1925(j)(6)(i)(B) of the bill (lines 9-10, page 76).
- (6) Strike subparagraph (C) and (D) (lines 11-16, page 76) and redesignate subsequent sections accordingly.
- (7) Add the following phrase immediately after subparagraph (C) of Section 1925(j)(6)(ii) (after line 7, page 78): "except where the Secretary finds (after consultation with the Secretary of Labor) that a State has an equivalent grievance procedure in operation."

Justification. The legislation should afford public employees adequate safeguards against the loss of employment or reductions in their job status pay, or benefits that may result from the phase down or closure of a publicly - operated residential facility. However, the existing bill: (a) does not specify the circumstances that would pose an actual threat to the job security of facility employees; (b) does not explicitly limit such job protections to public employees; (c) would make it considerably more difficult for states to make reasonable accommodations for public employees whose jobs are threatened by a facility closure or phase-down, by requiring that an employee's rights be protected under 'existing collective bargaining agreements' and "through the current certified representative"; and (d) impose an entirely new set of grievance procedures, even though some states already have in place grievance procedures that would serve the same purpose.

In the view of NASMRPD, the present subsections (C) and (D) represent extraordinary protections that would be widely at variance with protections normally extended to state employees under applicable state laws and would create enormous equity problems for the states.

The proposed language is designed to rectify the preceived defects outlined above, without disturbing the underlying thrust of the requirements spelled out in the existing bill. It also would consolidate the employee protection requirements with other similar obligations that would be placed on a state, under a new Section 1925(j) entitled "Conditions of Covering Optional Community Habilitation and Supportive Services."

- g. **Public Participation.** Include a subparagraph (7) of section 1925G), shall read as follows:

(7) In order to cover optional community habitation and supportive services under its State plan, a state must provide assurances satisfactory to the Secretary that it will offer interested individuals and organizations an opportunity to comment on draft plans and policies with respect to the requirements contained in subparagraph (2) through (6) of this paragraph before promulgating or publishing such policies or plans in final form. Such opportunities for public participation shall include, at a minimum,

(i) publication of adequate written notice of the availability of such draft plans and policies in newspapers circulated throughout the state. Such notice shall include information on where and when copies of such plans and policies can be reviewed and/or obtained at reasonable cost, the deadline for filing comments on such draft plans and policies and where such written comments can be filed.

(ii) hold public hearings on such draft plans and policies prior to final publication in locations that are reasonably accessible by all citizens of the State;

(iii) take into account the written and oral comments received from interested individuals and organizations in revising such draft policies and plans.

Justification. The principal purpose of including in the legislation requirements dealing with public participation is to assure that all affected parties have a reasonable opportunity to express their views regarding future service delivery decisions affecting the utilization of federal-state Medicaid dollars. The proposed language accepts the fact that the allocation of scarce resources always involves tough public policy choices, which are unlikely to be equally acceptable to all of the competing forces that have a stake in the evolution of policy. Under such circumstances, the only equitable means of resolving disputes is to assure that all actors have an adequate chance to express their views before state policies and plans are established.

4. Programmatic Implication. By grouping together in one subsection of the bill all of the conditions a state must satisfy in order to cover community habilitation and supportive services under its state Medicaid plan, Congress would be creating a clear framework within which states could develop and carry out its future plans for delivering Medicaid-financed services to persons with developmental disabilities. Such a framework implicitly recognizes that the disputes which inevitably will arise can only be resolved at the state level; and yet, to the extent that a significant amount of federal funds are involved, the federal government has a substantial interest in seeing that such disputes are resolved in an equitable manner. The proposed language is intended to strike balance between statutory specificity regarding **what states must** do, while leaving decisions regarding **how** to do it to the states.

Cost Implications. Although the proposed additional requirements are extensive, they should involve relatively modest increases in federal-state Medicaid costs. Any added expenditures presumably would involve higher administrative costs. Even here, it seems doubtful that the increase would be substantial.

Special Waiver Authority for Community-Based Services for Persons with Mental Retardation and Related Conditions

1. Provisions of the Existing Bill. No related provision.
2. Problems with the Existing Language. Not applicable.
3. Proposed Revision. Add a new Section 104 to the revised bill, which shall read as follows:

Section 104: Special Waiver Authority for Community -Based Services for Persons with Mental Retardation and Related Conditions

(a) In General --

(1) Section 1915 of the Social Security Act (42 U.S.C. 1396n) is amended -

(A) in subsection (h), as transferred and redesignated by section 4102(a)(1) of the Omnibus Budget Reconciliation Act of 1987, by inserting "(1)" after "(h)",

(B) in subsection (e), by striking paragraph (2) and by redesignating paragraph (1) as paragraph (2) and by transferring and inserting such paragraph at the end of subsection (h),

(C) by inserting after subsection (d) the following new subsection;

"(e)(1) Subject to paragraph (2) and section 1925(j)(6), the Secretary shall grant a waiver to provide that a State plan approved under this title shall include as medical assistance under such plan payment for part or all of the cost of community-based services (other than room and board) which are provided pursuant to an individual program plan to individuals with mental retardation and related conditions with respect to whom there has been a determination that but for the provision of such services the individuals would be likely to require the level of care provided in an intermediate care facility for persons with mental retardation, the cost of which could be reimbursed under the State plan.

"(2) A waiver shall not be granted under this subsection unless the State provides assurances satisfactory to the Secretary that -

"(A) necessary safeguards (including adequate standards for provider participation) have been instituted to protect the health and welfare of individuals provided services under the waiver and to assure financial accountability for funds expended with respect to such services;

"(B) with respect to individuals with mental retardation and related conditions who -

"(i) are entitled to medical assistance for intermediate care facility services for persons with mental retardation under the State plan,

"(ii) may require such services, and

"(iii) may be eligible for such community-based services under such waiver, the State will provide for an evaluation of the need for such intermediate care facility services for persons with mental retardation;

"(C) such individuals who are determined to be likely to require the level of care provided in an intermediate care facility for persons with mental retardation are informed of the feasible alternatives to the provision of intermediate care facility services for persons with mental retardation, which such individuals may choose if available under the waiver;

"(D) the State will provide for a hearing to be held at least 35 days prior to submission of the proposed waiver, with reasonable notice thereof to the staff and clients of habilitation facilities in the State, members of clients' families, and the general public; and

"(E) the State has effectively made community-based services of adequate quality, similar to the services proposed to be provided under the waiver, accessible to similar individuals eligible for medical assistance.

Each State with a waiver under this subsection shall provide to the Secretary annually, consistent with a reasonable data collection plan designed by the Secretary, information on the impact of the waiver granted under this subsection on the type and amount of medical assistance provided under the State plan and on the health and welfare of recipients."

"(3) A waiver granted under this subsection may include a waiver of the requirements of section 1902(a)(1) (relating to statewideness), section 1902(a)(10)(B) (relating to comparability), and section 1902(a)(10)(C)(i)(III) (relating to income and resource rules applicable in the community). Subject to a termination by the State (with notice to the Secretary) at any time, a waiver under this subsection shall be for an initial term of 3 years and, upon the request of a State, shall be extended for additional 5-year periods unless the Secretary determines that for the previous waiver period the assurances provided under paragraph (2) and under section 1925(j)(6) have not been met. A waiver may provide, with respect to post-eligibility treatment of income of all individuals receiving services under the waiver, that the maximum amount of the individual's income which may be disregarded for any month is equal to the amount that may be allowed for that purpose under a waiver under subsection (c).

"(4) A waiver under this subsection may, consistent with paragraph (2) and section 1925(j)(6), provide medical assistance to individuals for case management services, community habilitation and support services, respite care, non-facility-based residential services, supportive services, and other medical and social services that can contribute to the health and well-being of individuals and then-ability to reside in a community-based setting.

"(5)(A) In the case of a State having a waiver approved under this subsection, notwithstanding any other provision of section 1903 to the contrary, the total amount expended by the State for medical assistance with respect to intermediate care facility services for persons with mental retardation and community-based services under the State plan for individuals with mental retardation and related conditions during a waiver year under this subsection may not exceed the projected amount determined under subparagraph (B).

"(B) For purpose of subparagraph (A), the projected amount under this subparagraph is the sum of the following:

"(i) The aggregate amount of the State's medical assistance under this title for intermediate care facility services for persons with mental retardation during the base year increased by a percentage which is equal to the lesser of 11.5 percent times the number of years (rounded to the nearest quarter of a year) beginning after the base year and ending at the end of the waiver year involved or the sum of -

"(I) the percentage increase (based on an appropriate market-basket index representing the costs of elements of such services) between the beginning of the base year and the beginning of the waiver year involved, plus

"(II) the percentage increase between the beginning of the base year and the beginning of the waiver year involved in the number of persons with mental retardation and related conditions in the State, plus

"(HI) 2 percent for each year (rounded to the nearest quarter of a year) beginning after the base year and ending before the waiver year.

"(ii) The aggregate amount of the State's medical assistance under this title for community-based services for persons with mental retardation and related conditions during the base year increased by a percentage which is equal to the lesser of 11.5 percent times the number of years (rounded to the nearest quarter of a year) beginning after the base year and ending at the end of the waiver year involved or the sum of -

"(I) the percentage increase (based on an appropriate market-basket index representing the costs of elements of such services) between the beginning of the base year and the beginning of the waiver year involved, plus

"(II) the percentage increase between the beginning of the base year and the beginning of the waiver year involved in the number of persons with mental retardation and related conditions in the State, plus

"(III) 2 percent for each year (rounded to the nearest quarter of a year) beginning after the base year and ending at the end of the waiver year.

"(iii) The Secretary shall develop and promulgate by regulation (by not later than October 1, 1990) -

"(I) a method, based on an index of appropriately weighted indicators of changes in the wages and prices of the mix of goods and services which comprise intermediate care facility services for persons with mental retardation (regardless of the source of payment for such services), for projecting the percentage increase for purposes of clause **(i)(I)**;

"(II) a method, based on an index of appropriately weighted indicators of changes in the wages and prices of the mix of goods and services which comprise community-based services (regardless of the source of payment for such services), for projecting the percentage increase for purposes of clause (ii)(I); and

"(III) a method for projecting, on a State specific basis, the percentage increase in the number of persons with mental retardation and related conditions in each State.

Effective on and after the date the Secretary promulgates the regulation under clause (iii), any reference in this subparagraph to the 'lesser of 11.5 percent shall be deemed to be a reference to the 'greater of 11.5 percent'.

(iv) The Secretary, in determining the aggregate amount of medical assistance under this title for intermediate care facility services for persons with mental retardation and community-based services on behalf of such persons in future years, shall take into account, after consultation with the affected State, the effects on the State of compliance with section 1919(e)(7) of the Act;

(v) If there is enacted, after December 22, 1987, an Act which amends this title and which results in an increase in the aggregate amount of medical assistance under this title for intermediate care facilities for persons with mental retardation and home and community-based services for individuals with mental retardation and related conditions, the Secretary, at the request of a State with a waiver under this subsection for a waiver year or years, and in close consultation with the State, shall adjust the projected amount computed under this paragraph for the waiver year or years to take into account such increase".

"(C) In this paragraph:

"(i) The term 'community-based services' includes services described in subsection (c)(4)(B), services described in paragraph (5), and services furnished pursuant to a waiver under subsection (c).

"(ii)(I) Subject to subclause (II), the term 'base year' means the most recent year (ending before the date of the enactment of this subsection) for which actual final expenditures under this title have been reported to, and accepted by, the Secretary, adjusted to take into account subsequent, documented increases or decreases in expenditures through the quarter proceeding the quarter in which the waiver request is submitted to the Secretary.

"(II) For purposes of subparagraph (C), in the case of a State that does not report expenditures on the basis of the disability described in such subparagraph for a year ending before the date of the enactment of this subsection, the term 'base year' means fiscal year 1990.

"(6)(A) A determination by the Secretary to deny a request for a waiver (or extension of waiver) under this subsection shall be subject to review to the extent provided under section 1116(b).

"(B) Notwithstanding any other provision of this Act, if the Secretary denies a request of the State for an extension of a waiver under this subsection, any waiver under this subsection in effect on the date such request is made shall remain in effect for a period of not less than 90 days after the date on which the Secretary denies such request (or, if the State seeks review of such determination in accordance with subparagraph (A), the date on which a final determination is made with respect to such review)."

(2) The amendments made by paragraph (1) shall become effective on the date of the enactment of this Act.

"(C) Conforming Amendments —

(1) Section 1902(a)(10)(A)(ii)(VI) of such Act (42 U.S.C. 1396a(a)(10)(A)(ii)(VI)) is amended by striking "subsection (c) or (d)" each place it appears and inserting "subsection (c) or (d)" each place it appears (c),(d),or(e)".

(2) Section 1915(h) of such Act is amended by striking "(c) or (d)" and inserting in lieu thereof "(c), (d), or (e)".

4. Programmatic Implications. The proposed language would add to Medicaid law a separate, new home and community-based waiver authority for persons with mental retardation and related conditions. This new authority would parallel, in most respects, the existing special waiver authority established for elderly persons (in accordance with Section 1915(d) of the Act) under the provisions of OBRA-87 (P.L. 100-203). The intent of this new authority is not to replace the proposed optional state plan coverage discussed above, but rather to allow the states another, alternative method of covering home and community-based services for persons with mental retardation and related conditions under their Medicaid state plans. The

underlying assumption is that, since states are at different stages in the evolution of community-based developmental disabilities services, federal law should offer a variety of options that may be suited to the circumstances facing various states.

The principal advantage of using the proposed new waiver authority (compared to the existing Section 1915(c) waiver authority) is that a state would be able to avoid the imposition of federal controls on the number of recipients of waiver services. As in the case of the existing waiver authority, a state would be forced to operate under a self-imposed cap on aggregate community-based plus ICF/MR expenditures; however, HCFA's present "cold bed" methodology for calculating the maximum waiver caseload would not apply under the proposed, new waiver authority.

The suggested language is taken largely from an early draft version of H.R. 5233, which in turn was closely patterned after Section 1915(d) of the Act. However, the following modifications have been made in the original Waxman proposal:

the language of a technical amendment to Section 1915(d), which was included in the recently enacted "Tax Corrections" bill (H.R. 4333), has been incorporated. Basically, this amendment provides a method of adjusting the base year amount to take into account new legislative mandates included in any subsequent legislation that may be enacted by Congress.

All references to developmentally disabled individuals have been changed to "persons with mental retardation and related conditions" to conform to the remainder of the bill.

All references to "habilitation facility services" have been changed to "intermediate care facility services for persons with mental retardation".

A provision has been added to make it clear that the Secretary must take into account the impact of the nursing home screening/assessment provisions of OBRA-87 as they affect inappropriately placed nursing facility residents with mental retardation and related conditions, in establishing base year costs of ICF/MR and HCB waiver services in future years.

The language defining the "base year" period has been amended to assure that a state's aggregate Medicaid expenditures are based on current, rather than historical, expenditure levels for long term care services on behalf of persons with mental retardation and related conditions.

D. Optional Categorical Eligibility.

Provisions of the Existing Bill. As introduced on August 11, 1988, H.R. 5233 would establish a two-tiered system of eligibility for Medicaid-reimbursable "community habilitation services". Categorically eligible recipients of Medicaid (generally those who are eligible for SSI or AFDC cash payments) would be entitled to receive optional community habilitation services if a state elected to cover this service under its Medicaid plan. There would be no requirement that such individuals meet a special test of eligibility related to their need for institutional services. Indeed, the language of Section 101(b) of the bill specifies that such services may be furnished "...without regard to whether or not individuals who receive such services have been discharged from a nursing facility or habilitation (ICF/MR) facility."

States, however, also could elect to cover an optional categorically eligible group of recipients, consisting of non-Medicaid eligible individuals who would be entitled to receive Title XIX services if they were residing in a Medicaid-certified institution and who, in the absence of the community habilitation services they need, would require the level of care provided by a habilitation (ICF/MR) facility.

2. Problems with the Existing Language. Linking eligibility for community habilitation services to an individual's presumed need for institutional (ICF/MR) services would create grave inequities and unfairly deny many persons with developmental disabilities access to appropriate community training and support services. The most effective method of avoiding this problem would be to eliminate entirely the statutory tie between eligibility for community habilitation and supportive services and the institutional needs test. However, if such action proves to be infeasible at this time due to budgetary constraints, there are interim steps that might be taken that would tend to minimize, albeit not eliminate, the problems associated with this institutional needs test. These interim steps are outlined below.

3. Proposed Revisions. Amend Section 1902(a)(10)(A)(ii) of the Act by adding before the comma at the end of subclause (V) the following phrase:

, provided that if the State establishes such a separate income standard for individuals with mental retardation and related conditions who are in any medical institution, the State must establish the same separate income standards for all other individuals with mental retardation and related conditions.

Amend subclause XII of Section 1902(a)(10)(A)(ii) of the Act, as added by Section 101(d) of the bill (lines 3-13, page 6), by: (a) inserting the words "and supportive" after "habilitation" and before "services" on line 8, page 6; and (b) adding the following phrase before the semi-colon at the end of the subclause that reads:

, provided that any individual entitled to receive benefits in accordance with section 202(d)(1)(B)(ii) of the Act shall be eligible to receive community habilitation and supportive services on the same basis as a recipient of disability benefits under section 1611 of the Act.

4. Programmatic Implications. The first amendment would require states that choose to establish a higher income eligibility standard for persons with mental retardation and related conditions who need institutional care to apply the same income eligibility standards to persons in need of community habilitation and supportive services. This change would represent a small but nonetheless important step toward eliminating the institutional bias of current Medicaid policy.

second amendment would assure that the institutional needs test would not be applied to persons with mental retardation and related conditions who are entitled to receive adult-childhood Social Security benefits. By definition such adults are unable to engage in any substantial gainful activity" and, consequently, often have no other source of income besides their survivor's/dependent's benefit under Social Security. Though the average monthly benefit for this group is currently only \$23730, it is often just enough to disqualify them for SSI benefits and, in turn, Medicaid coverage. In many instances, the higher income standard that would result from the first amendment would allow such persons to qualify for Medicaid benefits. Recognizing that this group of individuals must meet the same strict federal disability test as SSI recipients and face essentially the same problems of gaining access to appropriate services, the second amendment would permit such adult-childhood recipients of Social Security disability benefits to be treated the same as SSI recipients for purposes

of determining their need for community habilitation and supportive services (i.e., the institutional needs test would not apply).

5. Cost Implications. Requiring states to apply the same income eligibility standards to recipients of community habilitation and supportive services as they apply to ICF/MR recipients would expand eligibility for such services slightly. Experience with Medicaid home and community-based waiver programs (where states have the option of using a higher institutional income eligibility standards) suggests that the number of additional persons who would qualify for services would not exceed five (5) percent of the total number who otherwise would be eligible.

Exempting beneficiaries of adult-childhood Social Security benefits from the institutional needs test potentially could involve a somewhat greater increase in costs. According to figures included in a recent HHS/ASPE report (Report to the Secretary from the Working Group on Policies Affecting Mentally Retarded and Other Developmentally Disabled Persons, March, 1988), an estimated 319300 persons with mental retardation and related conditions receive Social Security survivors/dependents benefits as a result of mental retardation and other congenital abnormalities (disregarding those who are also eligible for SSI benefits), or roughly 40 percent of the number of SSI recipients with the same disabling conditions. Thus, under a worst case scenario, the total number of potentially eligible persons would not increase by more than 30 percent. This outside estimate, however, is almost certain to be high, since many members of the affected target population would probably qualify whether or not an institutional needs test were applied.

E. Disregard of Parental Deeming.

1. Provisions of the Existing Bill. None.
2. Problems with the Current Language. Not applicable.
3. Proposed Revisions. Modify Section 1902(e)(3) of the Act by adding to the end of that subclause the following:

A State may limit eligibility under this subclause to particular categories of potentially eligible recipients, without regard to the requirement of section 1902(a)(10)(B), as long as the Secretary finds that such categories as shall be proposed by the State include all individuals with similar services need who meet the criteria outlined above.

4. Programmatic Implications. In 1982, Congress amended Section 1902 of the Social Security Act to permit states, on an optional basis, to extend Medicaid coverage to certain disabled children living at home who otherwise would not be eligible for benefits because the income and resources of their families would be deemed to be available to them. In order to qualify under this so-called "Katie Beckett" provision, the following conditions must be met:

the individual would have to be eligible for Medicaid benefits if he/she were to be institutionalized;

the individual must require the level of care provided in a Medicaid-certified hospital, skilled nursing or intermediate care facility,

the state must find that it is appropriate to provide such care outside of an institutional facility; and

the estimated cost of care at home must be no more than the estimated cost of institutional care.

According to a telephone survey conducted by HCFA officials in March 1988, 21 states and the District of Columbia had elected this "Katie Beckett" coverage option (Medicaid Source Book: Background Data and Analysis, November 1988, p. 70). However, informal discussions with officials in a number of states suggests that, even where the Section 1902(e)(3) coverage option has been adopted, it: (a) generally is applied to a very narrow segment of the potential population - typically ventilator-dependent children who otherwise would require care in an acute care hospital; and (b) rarely used to extend Medicaid services to children with severe and profound mental retardation and other developmental disabilities who are living at home with their parents. The reason most frequently cited by state officials for not electing the Katie Beckett option, or not applying it more broadly to the potentially eligible population, is the uncertain fiscal consequences of extending eligibility to a group of potential eligible whose numbers are largely unknown.

The suggested language would attempt to make the Section 1902(e)(3) coverage option more attractive to the states by allowing them to extend coverage to discrete, defined target populations of potentially eligible children. The assumption underlying this proposed amendment is that more states would be willing to elect the option and apply it more broadly if they were permitted to focus on categories of children with specific types of disabling conditions and home-based service needs.

In the context of present legislation, the basic aim is to encourage states to emphasis family-based intervention strategies for children with severe developmental disabilities, especially in view of the mounting evidence that such services often have a positive impact on the demand for more costly out-of-home placements. However, in the interest of equity, the proposed language would not restrict a state's choice of the particular disability groups to which it elected to extend Section 1902(e)(3) coverage.

5. Cost Implications. The cost of this proposed amendment should be negligible. Although it could be argued that any change which may result in an expansion in the number of Medicaid eligible recipients inevitably could lead to higher Title XIX outlays, one must recall that, under the existing "all or nothing" choice, states already have the option of extending coverage to a broad range of potentially eligible children with severe disabilities. The proposed amendment would not alter in any way the basic parameters of eligibility set forth in current law; it would simply give states the choice of focusing on discrete portions of the potentially eligible population.

F. Abrogation of Freedom of Choice.

1. Provisions of the Existing Bill Section 101(g) of H.R. 5233 (lines 6-10, page 8) specifies explicitly that, in furnishing optional community habilitation services, states may not "abrogate the right of Medicaid clients to freedom of choice". The intent of this provision of the Act (Section 1902(a)(23) of the Social Security Act) is to prohibit a state from locking a recipient into a particular physician or other approved provider of Medicaid-reimbursable services.
2. Problem with Current Language. While the underlying aim of Section 101(g) is generally consistent with the philosophy espoused by state MR/DD agencies in organizing and delivering community services, it could prevent some states, on technical grounds, from covering community habilitation and supportive services under their Medicaid plans. For example, in any state in which, by state law, a county or regional board/center serves as the sole, authorized provider of community day and/or residential services (or the state itself functions in this capacity), HCFA is likely to rule, as it has in other similar instances, that potential recipients' freedom to choose would be violated and, thus, deny the state authority to cover community

habilitation services under its state Title XIX plan- Before Congress modified the freedom of choice provision as part of the 1987 reconciliation act, this is exactly the position HCFA took when several states attempted to add optional targeted case management services to their state plans.

3. Proposed Revisions. Change the period to a comma at the end of Section 101(g) of the bill and add the following phrase:

, except that states shall not be prohibited from contracting or otherwise entering into financial arrangements with other public or quasi-public entities, designated in accordance with state law, under which such entities are responsible for purchasing services from other eligible providers of services within a defined geographic catchment area of the state.

4. Programmatic Implications. As the scope and complexity of community-based developmental disabilities services increases, more and more states are finding that it is impossible to effectively manage the delivery of such services through a centralized bureaucracy. Therefore, they are moving to decentralized arrangements under which day-to-day managerial functions are carried out by sub-state agencies (usually county agencies or regional centers), within regulations and policies established by the state. The proposed amendment is an attempt to reflect this reality in statutory Medicaid policy.

The above language would make it clear that a state would be authorized to enter into a "master" contractual agreement with a county or regional center (whether it was a public or non-profit, private agency) to oversee the development and operation of community habilitation and supportive services with a defined geographic catchment area of the state. However, a state could only enter into such agreements with entities that were designated, in accordance with state law, to carry out sub-state managerial functions on a catchment area basis; in addition, the designated entity (i.e., the county agency; regional center; etc) would be required to purchase services from vendors who met state provider participation requirements. The latter point is particularly important because it upholds the basic freedom of choice principle of the Medicaid program.

5. Cost Implications. This modification in the language probably would have no direct fiscal impact, since states that were desirous of covering such services under their state Medicaid plan would eventually find a way of doing so. It would, however, permit states to build on existing administrative arrangements of proven effectiveness.

G. Outcome-Oriented Evaluation Projects.

1. Provisions of the Existing Bill. The Secretary, under Section 103 of H.R. 5233 (line 21, page 8 through line 15, page 9), would be required to develop, through demonstration projects and contracts, outcome-oriented instruments/methods of evaluating the quality of Medicaid-supported community habilitation services. The deadline for completing work on these instruments/methods would be January 1, 1991. In order to qualify for continued Medicaid support of community habilitation services, a state would be required to use the instruments and methods developed by the Secretary in evaluating such services and to discontinue payments to any provider found to be furnishing substandard services. This requirement would apply to community habilitation services reimbursed under a Medicaid home and community based waiver program as well as under the new optional state plan coverage.
2. Problems with the Current Language. While the basic intent of this provision of the bill (i.e., to develop better service outcome measures) is strongly supported, there are two major flaws in the language as presently drafted. First, it obligates the states to

implement new program evaluation techniques before they are even developed. The ultimate product of any research and development initiative, by definition, is uncertain at the outset. In the field of developmental disabilities work on client outcome measures has been underway for at least fifteen years and yet, even though most experts would agree that more sophisticated techniques for evaluating the impact of services on recipients are needed, there still is no consensus in the field regarding the particular outcome measures that should be applied. Nor should one underestimate the difficulty of obtaining such a consensus, given the enormous complexities associating with measuring human responses to service interventions. As a result, it is not wise to assume that the required demonstration projects/studies necessarily will yield a product that can be immediately implemented in all states.

Second, the bill is unclear how a state's responsibility for applying these Secretari-ally-developed client-outcome instruments/methods to assess the performance of providers of community habilitation services would intersect with its parallel responsibility to enforce Secretarial standards in supervised residential settings where recipients of such services live. Are the clients outcome instruments/methods to be considered part of the Secretary's standards and, if so, who is responsible for establishing "pass-fail" criteria? And, what is the relationship between such client outcome methods/instruments and the "uniform client performance accounting system" the Secretary is suppose to create as part of the standards he promulgates on or before October 1, 1989?

3. Proposed Revisions. Change the deadline for developing the new methodology (line 25, page 8 through line 1, page 9) from "January 1, 1991" to "January 1, 1992". Also, delete subsection (b) of Section 103 (lines 4-15, page 9) in its entirety and add the following new subsection (b):

(b) Report to Congress. Not later than April 1, 1992, the Secretary shall submit a report to the House Energy and Commerce Committee and the Senate Finance Committee -

(1) summarizing the findings and implications of the demonstration projects and contractual studies conducted in accordance with subsection (a), and

(2) recommending actions that should be taken with respect to implementation of method and instruments developed as a result of such projects and studies.

[N.B., See Section B-3-c above for the steps states would be required to take with respect to the Secretary's recommendations.]

H. Monitoring of Compliance and Denial of Payments.

1. Provisions of the Existing Bill. No provision.
2. Problems with the Current Language. Not applicable.
3. Proposed Revisions. Add a new Section 105 to the bill, which reads as follows:

Section 105: Monitoring of Compliance and Denial of Payments

(a) The Secretary shall be responsible for monitoring compliance with the assurances contained in section 1925(j) in each State that elects to cover under its State plan the services authorized under section 1905(a)(21).

(b) The Secretary shall withhold payments for community habilitation and supportive services under this title if he finds that a state is substantially failing to carry out the assurance provided to the Secretary in accordance with section 1925(j).

(c) A determination by the Secretary denying a state plan amendment submitted in accordance with Section 1905(a)(21) or to withhold payments in accordance with subsection (b) shall be subject to review to the extent provided in section 1116(b).

4. Programmatic Implications. The principal aim of the above provisions is to clarify the oversight and enforcement authority of the Secretary, as well as the recourses available to a state if it is dissatisfied with a Secretarial determination affecting the coverage of, or payments for, community habilitation and supportive services under its state Medicaid plan. The proposed language would delegate to the Secretary explicit authority to: (a) monitor each state's adherence to the assurances it provides in accordance with the conditions of covering community habilitation and supportive services, as spelled out in Section B above. The Secretary also would be authorized to withhold payments if at any time he determined that a state was failing to fulfill such assurances. A finding of non-compliance would be subject to the general appeals procedures established under Section 1116(b) of the Act.
5. Cost Implications. None.

Title II - Quality Assurance for Habilitation Facility Services

A. Statutory Terminology

1. Provisions of the Existing Bill. Under H.R. 5233 all statutory references to "intermediate care facilities for the mentally retarded" would be changed to "habilitation facility".
2. Problems with the Present Language. The proposed change in terminology would create unnecessary confusion in the field of developmental disabilities, especially given the fact that the bill would simultaneously establish a new, optional state plan coverage called "community habilitation services." In addition, the proposed change would appear to serve no useful purpose. For better or worse, the DD field has become familiar with the ICF/MR terminology. In the interest of emphasizing the person-centered goals of the program, however, it would be advisable to modify all statutory references to read "intermediate care facilities for persons with mental retardation".
3. Proposed Revision. Change all statutory references, as they would be added or modified by the bill, from "intermediate care facility for the mentally retarded" or "habilitation facility" to "intermediate care facility for persons with mental retardation".
4. Programmatic Implications. The suggested language, would retain the acronym ICF/MR, thus preserving continuity of terminology. At the same time, it would adopt the "people first" approach to referring to individuals with disabilities that has become accepted practice in the field of developmental disabilities over the past few years.
5. Cost Implications. None

B. Requirements for ICF/MRs

1. Provisions of the Existing Bill. Section 201 of the draft bill would incorporate in federal statute detailed operating standards applicable to "habilitation facilities"

(currently referred to as ICF/MRs). The general format and some of the specific contents of these standards would closely parallel the provisions of Section 1919(a) through (d) of the Act (applicable to nursing facilities), as added by the Omnibus Budget Reconciliation Act of 1987 (OBRA-87; P.L. 100-203). These nursing facility "conditions of participation" have been modified to include key provisions of the revised ICF/MR regulatory standards, published by HHS/HCFA on June 3, 1988.

A habilitation facility would be required, under the terms of the bill, to provide each client, in accordance with his or her individual program plan, with "continuous active treatment services" Such services would have to be coordinated by a qualified mental retardation professional.

The definitions of the terms "habilitation facility" and "active treatment" contained in the bill are lifted, practically verbatim, from the revised federal ICF/MR standards. In addition, by no later than October 1, 1989, the Secretary would be instructed to develop and promulgate "an operational definition of continuous active treatment that promotes a consistent assessment of whether a habilitation [ICF/MR] facility is in compliance with..." the new statutory "conditions of participation".

Finally, the Secretary of HHS would be responsible for: (a) establishing guidelines for a state's appeal procedures involving transfers and discharges from a habilitation facility, and (b) criteria for assessing habilitation facilities' compliance with a number of administrative and clinical requirements. These responsibilities would parallel the responsibilities assigned to the Secretary with respect to nursing facilities under Section 1919 of the Act.

2. Problems with the Present Language. The revised ICF/MR standards published by HHS/HCFA in June, 1988 are designed for the specific purpose of regulating the provision of ICF/MR services (rather than the anaigram of nursing facility and ICF/MR requirements proposed in the bill). While critical aspects of those standards, as well as the programmatic assumptions that underlie them, need to be carefully evaluated (see discussion under Title V, Section C below), it is difficult to envision how the addition of detailed statutory standards, at this point in time, would contribute to a resolution of such problems or, indeed, afford the residents of such facilities any greater assurance that they would receive appropriate, high quality services. In fact, the addition of extensive statutory conditions of participation, in all likelihood, would lead to further confusion and delays in standard development and enforcement, since, once the bill was passed, the Secretary would have to go "back to the drawing board" and develop a new set of regulatory standards.
3. Proposed Revisions. Delete Section 201(b) of the bill (line 21, page 10 through line 8, page 17). [N.B., Section 1925(f)(4) of the bill would be revised to clarify the Secretary's rulemaking authority; see discussion under Section C-3 before.]

Delete all of subclause (ii) of Section 1925(c)(1)(A) after the word "symptoms." (line 25, page 17 through line 19, page 18) and substitute the following sentence:

The Secretary shall specify in regulations issued in accordance with subsection (f)(4), the circumstances under which physical restraints may be used.

Delete the words "any facility" on line 1, page 23 and substitute the following phrase: **the** facility in which the individual resides and".

Delete the remainder of subclause (D) of Section 1925(c)(1) of the bill after the word "annually" (lines 10-14, page 23) and substitute the following: "the appropriateness of the drug plan of each client receiving psychopharmacologic drugs is reviewed by the facility, using personnel who are competent to conduct such reviews."

Add a comma after the word "Secretary" on line 10, page 36 of the bill and insert the following phrase: "based on the findings and recommendations of the National Advisory Committee on Services to Persons with Mental Retardation and Related Conditions, as established in accordance with Section 501(b) of this Act". Also, on line 11, page 36, change "October 1, 1989", to October 1, 1990" and on line 15, page 36, change "(b)(2)(A)" to (f)(4)(A)". Also, add the following at the end of that subparagraph:

Prior to issuing a final operational definition, the Secretary shall publish in the Federal Register the finding and recommendations of the National Advisory Committee on Services to Persons with Mental Retardation and Related Conditions, prepared in accordance with subsection (k)(3)(i), and allow at least sixty (60) days for the receipt of public comments.

Change the heading of subparagraph (4) of subsection (f) by adding before the word "Criteria" "Regulations and" (line 24, page 36) and inset the following phrase after the word "establish" and before the word "criteria" on line 25, page 36: "regulations governing the provision of services in intermediate care facilities for persons with mental retardation and". Also, delete the word "the" and substitute "such", modify "requirement" to read "requirements" and add after that word "and the requirements" on line 1, page 37.

4. Programmatic Implications. The aim of the proposed amendments is to distinguish between two sets of federal requirements governing the operation of ICF/MRs. The first category of requirements would deal with policies that can be expected to be relatively immutable (e.g., client rights; health, safety and sanitation requirements). These requirements would be set forth in federal law. The second category of requirements would deal with those aspects of policy that are subject to continuing change as the technology of delivering services evolves. In this case, the Secretary would be delegated broad regulatory discretion in establishing detailed operating standards. This approach would help Congress and the states to avoid the pitfall of tying ICF/MR services to a set of detailed statutory standards which, in all likelihood, would become outmoded in a relatively short period of time.

The proposed language also would modify the bill's existing requirement that the Secretary issue an operational definition of "continuous active treatment", by: (a) requiring the Secretary to consider the recommendations of the National Advisory Committee on Services to Persons with Mental Retardation and Related Conditions in developing this definition; and (b) publish the Committee's findings and recommendations on this subject in the "Federal Register", for public comment, prior to issuing a final operational definition.

5. Cost Implications. No direct cost impacts; although, to the extent that it would be possible to maintain greater flexibility in adopting federal standards to changing needs, one could argue that senseless expenditures that were tied to outmoded requirements could be avoided.

Survey and Certification Process.

1. Provisions of the Existing Bill. Section 202 of the bill would add new statutory requirements governing surveys and certification of habilitation facilities. In addition, it would transfer responsibility for surveying and certifying state-operated habilitation (ICF/MR) facilities from the state survey agency to the Secretary. These requirements are identical, in most respects, to the provisions of Section 1919(g) of the Act (applicable to nursing facilities), as added by OBRA-87.

2. Problems with the Present Language. Transferring survey and certification authority over state-operated habilitation (ICF/MR) facilities to the federal government would tend to further accentuate the existing conceptual gap between ICF/MRs and various other modalities through which states deliver services to persons with developmental disabilities, thus making it even more difficult to maintain a smoothly articulated system of service options for this population. At a time when the field of developmental disabilities is undergoing dynamic changes — changes that are redefining the very basis for organizing and delivering services — Congress should not impose new roadblocks, however well-intended, to the establishment of a holistic framework for reformulating DD service policies at the state level.

3. Proposed Revisions. Delete from subclause (C) of Section 1925(g)(1) the phrase beginning with the word "through" on line 17, page 39 through the word "subsection" on line 19, page 39. [N.B., The effect of this change would be to designate "the state" as the responsible party for conducting investigations of client abuse and neglect (including misappropriation of client property), rather than specifically designating the state Medicaid survey agency to carry out such duties.]

Insert the following phrase after the word "provided" and before the comma in subclause (B) of Section 1925(g)(2) of the bill (line 2, page 41): "in accordance with the operational definition of active treatment promulgated by the Secretary under subsection (f)(2)". Also, in subclause (i) of subsection (g)(2)(D) of the bill (line 16, page 41) change "July 1, 1989" to October 1, 1990" and add immediately thereafter ", which reflects the operational definition of active treatment promulgated by the Secretary in accordance with subsection (f)(2)",

Delete the parenthetical phrase "(other than facilities of the State)" from subsection (g)(1)(A) of the bill (line 2, page 39), and delete the last sentence of that same clause of the bill (lines 4-7, page 39). [N.B., The effect of this proposed amendments would

be to leave primary responsibility for surveying and certifying state-operated ICF/MRs with the designated state survey agency (i.e., rather than transferring such authority to the Secretary).]

4. Programmatic Implications. The Secretary already has broad statutory authority to "look-behind" the survey results of state survey agencies, as well as the certification decisions of single state Medicaid agencies. And, furthermore, the Secretary has aggressively exercised this authority in the case of state-operated ICF/MRs over the past few years. There is no reason to believe that the existing system of "checks and balances" would be materially improved by shifting primary survey and certification authority to the Secretary in the case of state-operated ICF/MRs.

With respect to the designation of the state Medicaid survey agencies to investigate alleged cases of client abuse and neglect, this function has been assigned to different agencies in different states. For example, the state police are in charge of conducting such investigations in a number of states. There is no reason to believe that this function will be carried out more effectively if it is assigned to the state survey agency in all states; therefore, state policymakers should be permitted to assign this function to the agency or agencies with the best capabilities to carry it out.

5. Cost Implications. None

D. Enforcement Process

1. Provisions of the Existing Bill. Section 203 of H.R. 5233 would spell out, in statute, the actions a state would be required to take when it found a habilitation facility out of compliance with the statutory certification standards outlined above, as well as the steps a state would be expected to take to remedy the situation. Again, these

provisions closely parallel the requirements of Section 1919(h) of the Act (applicable to Medicaid-certified nursing facilities).

The bill also would transfer to the Secretary responsibility for enforcing standards and imposing penalties in state-operated habilitation facilities. In addition, the Secretary would be authorized to terminate any privately operated habilitation facility (and take other steps to remedy the situation), if he found that the health and welfare of the residents of such facility were in immediate jeopardy or the facility had other persistent deficiencies.

The Secretary would be empowered to take the following steps to remedy deficiencies in habilitation facilities that were identified as part of a validation survey: (a) deny Medicaid payments; (b) impose civil monetary penalties; and (c) appoint a temporary manager of the facility. In addition, the Secretary could authorize continued Medicaid payments for up to six months during the period of correction if: (a) the state survey agency found that such actions were preferable to termination; (b) the state submitted an acceptable correction plan; and (c) the state agreed to repay the federal government if corrective actions were not taken in accordance with the approved plan of correction.

2. Problems with the Present Language. Here again, the most critical issue is the proposed transfer of direct authority to impose sanctions in state-operated habilitation (ICF/MR) facilities to the Secretary. The same arguments outlined above in the case of survey/certification authority also apply in the case of enforcement.
3. Proposed Revisions. Delete Section 1925(h)(3)(A) of the bill (lines 6-11, page 54) and redesignate subclauses (B) and (C) of subsection (h)(3) as (A) and (B), respectively. Also, delete the word "Other" from the heading of subclause (B) (line 12, page 54) and delete the word "other" on line 13, page 54. [N.B. These proposed changes would grant the Secretary the same enforcement authority in the case of state-operated facilities as he would have in the case of privately-operated ICF/MRs.]

Delete Section 1925(h)(3)(C)(ii) of the bill (lines 3-10, page 56). Also, eliminate the phrase "the amounts of any fines" from subclause (ii) of (h)(3)(C) of the bill (line 8, page 57) and substitute the word "penalties" for "fines" on line 14, page 57. [N.B. These revisions would remove the Secretary's proposed authority to impose civil monetary penalties.]

Add the following sentence at the end of subclause (ii) of (h)(3)(D) of the bill (line 14, page 58): "Such guidelines shall explicitly permit the approval of corrective actions which may include all categories of deficiencies (including deficiencies in the provision of active treatment, facility staffing, health services and dietary services) that do not immediately jeopardize the health or safety of the subject facility's clients."- 4. Programmatic Implications. The reasons for leaving primary enforcement authority for state-operated ICF/MRs with the states are the same as those discussed under C-4 above. The suggested amendments also would delete the proposed Secretarial authority to impose monetary fines on non-compliant ICF/MRs. The major reason for opposition to this additional Secretarial authority is that it would tend to exacerbate federal-state relations should the Secretary ever levy such fines against a state-operated ICF/MR. Furthermore, the Secretary has sufficient powers under Section 1910(c) of the existing Act to enforce federal operating requirements without resorting to monetary fines.
- 5. Cost Implications. None.

E. Reduction Plans

1. Provisions of the Existing Bill. Section 203 of H.R. 5233 would authorize the states to submit a reduction plan when a habilitation (ICF/MR) facility was found out of compliance with federal certification standards due to physical plant deficiencies. The conditions under which such plans could be submitted generally parallel existing statutory requirements applicable to ICF/MR phase down plans under Section 1922 of the Act. [N.B. The existing authority, added by Section 9516 of COBRA, would be simultaneously repealed.] The difference between Section 1922 and the proposed provisions are as follows: (a) reduction plans would only be authorized when the cause of the deficiency was related to the physical plant (i.e., not both the physical plant and staffing, as specified under current law); (b) states would be required to meet a more rigorous set of employee protections (see discussion of I-B-3-f above); and (c) reduction plans would be authorized based on findings by the state survey agency, as well as by a federal survey team.
2. Problems with the Present Language. A state would be authorized to apply for a Secretariaily-approved reduction plan only when its deficiencies were related to the facility's physical plant. Consequently, a facility which had deficiencies in the area of active treatment, health services, dietary services, etc., would not be eligible.
3. Proposed Revisions. Delete from Section 1925(i)(1) all words beginning with the word "relating" and ending with the word "plant" and substitute the following: "(including deficiencies related to the provision of active treatment, facility staffing, client behavior and facility practices, the provision of health care and dietetic services, the protection of client rights, the nature and operation of the physical plant and governance of facility)".

Also, change the reference from "subsection (h)(1)(B)" to "subsection (h)(1)(A)" (line 6, page 60) and delete all words beginning with the parenthesis on line 6, page 60 through "(h)(3)(b)(ii)" on line 7, page 60.
4. Programmatic Implications. The proposed changes would restore Congress' original intent in enacting Section 1922 of the Social Security Act in 1986 - i.e., ICF/MR facilities with non-life-threatening deficiencies should have the choice of either: (a) correcting those deficiencies over a period of six months, while maintaining the same population; or (b) correcting such deficiencies as part of a longer range plan (up to 36 months) to close or reduce the population of the facility. The limitation on the circumstances under which Section 1922 correction/reduction plans may be approved is the product of HCFA's misinterpretation of the intent of Congress. Thus, it is important that the language of revised reduction plan provision be clear on this point.
5. Cost Implications. No significant cost impacts would be associated with the proposed change.

Title III - Appropriate Placement for Persons with Mental Retardation

- A. Provisions of the Existing Bill. Title HI (Section 301) of H.R. 5233 would require a state, as a condition of approval of its Medicaid plan on or after October 1, 1989, to have in effect a preadmission screening program for mentally retarded individuals (and individuals with related conditions) who are admitted to habilitation (ICF/MR) facilities. In addition, states would be required to review each resident of a habilitation (ICF/MR) facility and determine whether he/she needs ICF/MR level of care and whether he/she needs community habilitation services. These reviews would have to be based on an "independent evaluation" of the person's service needs. All such initial reviews would have to be completed by October 1, 1990 and repeated annually thereafter. States would be obligated, by October 1, 1989, to take the following steps with respect to persons found to be inappropriately placed in habilitation (ICF/MR) facilities:

For persons needing active treatment - consult with the family, arrange for discharge; and provide active treatment in an alternative setting;

For persons not requiring active treatment — discharge such individuals after orientation.

After July 1, 1989, states would be denied reimbursement on behalf of any resident of a habilitation (ICF/MR) facility who had not been prescreened prior to admission. In addition, a state would be required to establish an appeals process for use by any individual who felt he or she was adversely affected by screening/resident review determinations. States also would be required, as a condition of approval of a state Medicaid plan, to establish an appeal process for transfer/discharge from habilitation (ICF/MR) facilities. This process would have to conform to Secretarial guidelines.

Finally, under Section 301 of the bill, the Secretary of HHS would be directed to develop criteria governing the appropriateness of serving MR/DD persons in habilitation (ICF/MR) facilities, as well as criteria governing individual appeals of preadmission screening and resident review determinations. The Secretary also would be charged with monitoring the state's compliance with the requirement that active treatment be furnished to persons found to be inappropriately placed in habilitation (ICF/MR) facilities and transferred to other settings.

- B. Problems with the Current Language. The subject provisions of H.R. 5233 are patterned after the nursing facility preadmission screening and resident review requirements that were incorporated in last year's reconciliation legislation (OBRA -87; P.L. 100-203). Basically, these requirements make little sense in the context of the present legislation since they direct the states to determine (and re-determine annually thereafter) whether existing residents of ICF/MR facilities need active treatment and if they do to transfer them to a facility in which they can receive such services. But, the legislation constitutes something of a non-sequester since, by definition, the only setting in which active treatment can be provided is an ICF/MR.

Viewed more broadly, however, Section 301 poses another and more troubling question: should there be national standards of eligibility governing admission to, and continued stays in, ICF/MR facilities. Currently, each state, by and large, establishes its own, individual criteria of eligibility for ICF/MR services. What Title HI of H.R. 5233 portends is the exercise of closer federal scrutiny over who is admitted to and stays in ICF/MR facilities. The potentially disturbing aspect of such a delegation of authority is that it would give the Secretary sweeping powers to tighten ICF/MR eligibility criteria and, thereby, limit the number and types of persons eligible to receive such services at a time when HCFA places high priority on containing the growth of federal Medicaid costs. Not only would the Secretary have authority to restrict participation in the ICF/MR program, but he would also be able to limit participation in HCB waiver programs and, at least to some degree, in programs financed through the proposed optional habilitation state plan service.

- C. Proposed Revisions. Strike Section 301 (pages 65-73) from the bill. Redesignate affected sections accordingly and strike all other references to Title III.
- D. Programmatic Implications. The proposed change simply continues current policy. No systematic evidence exists that present policies have resulted in wide-spread inappropriate placements to ICF/MR facilities. Lacking evidence that there is a significant problem to be addressed in this area of federal policy, NASMRPD believes that the dangers posed by giving HHS/HCFA authority to unilaterally and arbitrarily impose admission and continued stay criteria has great potential harm and disruption in the lines of persons with developmental disabilities. The bill's failure to require that the Secretary engage in a systemic, open investigation of whether problems might exist and the alternatives for addressing such problems prior to proposing nationwide criteria is particularly troubling.
- E. Cost Implications. None.

Title IV - Payment for Services

- A. Provisions of the Existing Bill. Section 401(a)(1) would add a new subclause (F) to Section 1902(a)(13) of the Social Security Act. The purpose of this new subclause would be to specify payment practices that states would have to observe in reimbursing providers of community habilitation services and ICF/MR services. In particular, Section 401(a)(1) provides that payments for community habilitation services would have to be based on rates that are:

"reasonable and adequate to meet the costs of providing services in conformity with applicable State and Federal laws, regulations, and quality and safety standards...."

With respect to ICF/MR services, payments would have to be based on rates that are:

"reasonable and adequate to meet the costs which must be incurred by efficiently and economically operated facilities in order to provide care and services in conformity with applicable State and Federal laws, regulations, and quality and safety standards...."

The provisions governing payments to ICF/MRs parallel the existing requirements of the so-called "Boren Amendment" (Section 1902(a)(13)(A) of the Social Security Act).

Section 402(a)(2) of the legislation would amend Section 1902(h) of the Social Security Act by prohibiting the Secretary of HHS from "limit[ing] the amount of payment that may be made under a [state Medicaid] plan...for community habilitation services or [ICF/MR] services."

- B. Problems with the Present Language. Generally, the language of Title IV is far superior to the provisions of existing law, especially the proposed prohibition against the imposition of the so-called "Medicare upper-limits" test in the case of payments for ICF/MR and community habilitation services. However, the provisions governing payments for community habilitation services pose two potential problems. First, the proposed language would establish a "reasonable and adequate" standard for assessing payments for such services, without also including the Boren Amendment's "efficient and economical" test of the costs of furnishing services. The Boren Amendment test was inserted into the statute in 1980 to provide the states with a means of controlling excessive increases in payments to hospitals and nursing facilities, which had occurred under the former "reasonable and adequate" payment test. The Boren Amendment test, for example, permits a state to employ payment caps and regulate changes in rates by reference to such economic variables as general inflation rates. Lacking language similar to the Boren Amendment's "efficient and economical" test, states could experience difficulty in managing the growth in payments for community habilitation services.

In addition, the proposed language would lock states into Medicaid's facility-based, cost-related reimbursement model in paying for community habilitation services. This model channels payments to provider agencies which furnish discrete categories of services to recipients, rather than permitting a state to design and implement broader-based, client-centered payment models aimed at permitting greater individualization of payments and, consequently, program services. In particular, a facility-based payment model creates significant obstacles to managing services within a "supportive services" framework.

The following modifications in the provisions of Title IV are proposed to deal with these two related problems.

- C. Proposed Revisions. Include the following specific changes in Section 401(a)(1) of the bill:
1. Boren Amendment Test. In Section 1902(a)(13)(F)(i) insert "and supportive" after "habilitation" on line 20, page 69 and "economically and efficiently" before "providing" on line 23, page 69 of the bill.

Justification. The first change simply aligns the subject section with the proposed change in Title I of the bill, as it deals with the new optional state plan service. The second change would allow a state to impose payment tests based on Boren Amendment principles and, consequently, limit payments to providers with costs exceeding normal ranges. This change would avoid the destabilizing implications of basing payments solely on the "reasonable and adequate" cost test that bedeviled state Medicaid programs prior to the adoption of the Boren Amendment. It also would bring payment policy for community services into line with payments policies governing ICF/MR services.

State Plan Standards. In Section 1902(a)(13)(F)(i) insert "provided that:" after "standards", strike the last "and" on line 25, page 69 and add the following new subparagraphs:

(A) in order to cover optional community habilitation and supportive services under its State plan, a State must publish its proposed methods of payment for such services concurrent the publication of draft plans and policies specified under the provisions of Section 1925(j)(7);

(B) the State shall provide reasonable notice to interested individuals and organizations of any proposed changes in the methods of payment in accordance with the provisions of Sections 1925(j)(7)(i)-(iii);

(C) the methods adopted by a State shall take into account the costs of economically and efficiently complying with applicable State and federal laws, regulations, and quality and safety standards, including personnel costs and required staffing levels, geographic factors, changes in the costs of services from period to period, and, as appropriate, allowances for meeting the extraordinary costs of furnishing services to specified categories of recipients;

(D) nothing in this section shall prohibit a state from establishing a system of standardized, capitated payments applicable to providers which are contractually obligated to furnish or arrange to furnish community habilitation and supportive services specified in an individual's program plan. Such payments may be organized to reflect expected variations in service requirements among specified categories of recipients;

(E) the state shall establish a system of periodic audits to verify payments made for community habilitation and supportive services, including audit of expenditures incurred by primary providers as well as subcontractual agencies; and,

(F) the state shall assure that payments take into account only the costs related to the provision of community habilitation and supportive services, provided that a state may establish a system of incentive payments aimed at encouraging the efficient and economical provision of such services.

Justification. As with other proposed changes to H.R. 5233, these suggested modifications are aimed at clearly specifying the parameters within which a state would be permitted to make payments for community habilitation and supportive services. Subparagraphs (A) and (B) above would require a state to publish its proposed methods of paying for such services in conjunction with the "implementation strategy" described in the proposed Section 1925(j)(5) and under the timetables and procedures laid out in the proposed Section 1925(j)(7). Subparagraph (C) outlines the contents of the materials a state would be required to furnish when describing its proposed methods of payment.

Subparagraph (D) specifically provides that a state may adopt a capitated payment approach to purchasing community habilitation and supportive services. The flexibility to adopt such a payment strategy would allow states to construct reimbursement systems that avoid the pitfalls of Medicaid's facility-based payment models. A capitated approach would include features similar to those employed by "health maintenance organizations" to furnish health-care and related services.

Subparagraphs (E) simply provides that a state must establish a system for auditing provider agencies as well as their subcontractors. Subparagraph (F) specifies that payments must be based on costs related to furnishing the subject services; however, it also would permit a state to establish "incentive" payments aimed at encouraging the efficient provision of services.

- D. Programmatic Implications. The capacity of a state to maintain and expand community-based services is inextricably tied to its capacity to manage program spending along predictable lines. In the absence of statutory authority similar to the current Boren Amendment provisions, states would lack the capacity to assure executive and legislative branch policymakers that payment levels would remain stable over time. In addition, it also is important that a state be able to limit payments in a reasonable fashion to avoid rewarding inefficient provider agencies. Again, lacking such a capacity, states will be reluctant to expand and improve community-based services.

In addition, it seems clear that alternative methods to Medicaid's facility-based payment model are needed if the states are to encourage highly individualized responses to the needs of persons with developmental disabilities in community-based settings. An HMO-like, capitated payment model would provide states with the means of avoiding many of the pitfalls associated with facility-based payment systems, which are often criticized for subordinating the needs of the individual recipient by locking payments into specific service models. Antecedents for such capitated payment approaches exist today in some state HCB waiver programs.

- E. Cost Implications. In general, permitting payments for community habilitation and supportive services to be subject to a Boren-like test should result in more stable state and federal Medicaid costs over time; in addition, the proposed language should assist the states in avoiding excessive payments that could stem from the "reasonable and adequate" criteria presently set forth in H.R. 5233. To the degree that states are granted the option of using capitated payment systems, there also is a greater likelihood that scarce state and federal dollars would be employed more efficiently and effectively in meeting the needs of persons with developmental disabilities.

Title V - Miscellaneous

- A. Employee Protections.

[N.B. The substance of the provisions of Section 501 of the bill would be transferred to Section 1925 (j)(6) of the bill (see Section I-B-3-f above; pages 26-27) and replaced by new provisions establishing a National Advisory Committee on Services to Persons with Mental Retardation and Related Conditions (see V-C below).]

- B. Administrative Functions.

1. Provisions of the Existing Bill. Section 502 of H.R. 5233 would explicitly permit a state, under its Medicaid plan, to assign to the state MR/DD agency Title XIX administrative functions related to the provisions of services on behalf of persons with developmental disabilities. This section also would explicitly authorize federal Medicaid reimbursement for administrative costs incurred by a state MR/DD agency in carrying out functions under the state Title XIX plan. Both provisions would be effective as of the date of enactment.

2. **Problems with the Current Language.** The subject provisions of the existing bill would take cognizance of the need to have a single focal point of accountability for establishing state MR/DD policies and managing related Medicaid funds, by permitting a Governor or state legislature to assign specific responsibilities for establishing and monitoring Medicaid policies to the state MR/DD agency. Although such language would be a significant improvement compared to existing law (which is silent on this subject), it would not necessarily assist those states where the state MR/DD agency is in a relatively poor position to influence the effectuation of the delegations of legislative/administrative authority necessary to consolidate these management responsibilities. Yet these are likely to be the very states in which poor interagency communication and coordination often serves as a major impediment to the effective management of Medicaid-supported MR/DD services.
3. **Proposed Revisions.** Delete everything after "(B)" in the proposed new subclause (line 8 through line 13, page 79) and substitute the following:

(B) except that, on or after July 1, 1991, such management functions under the plan that relate to the provision of services to persons with mental retardation and related conditions shall be performed by a State agency responsible for services to persons with mental retardation and other developmental disabilities, unless the Governor informs the Secretary prior to July 1, 1991 of the adoption, by law or executive order, of a different assignment of such management functions. The Secretary shall be responsible for specifying the Medicaid-related functions to be performed by a state agency responsible for services to persons with mental retardation and related conditions no later than October 1, 1990.
4. **Programmatic Implications.** The revised language would significantly increase the odds that programmatic responsibility and day-to-day control of Medicaid dollars would be consolidated in the same agency. Yet, at the same time, the Governor and legislature of each state would retain the ultimate authority to decide the most effective/efficient methods of organizing state government.
5. **Cost Implications.** None.

National Advisory Committee on Services to Persons with Mental Retardation and Related Conditions.

1. **Provisions of the Existing Bill.** None.
2. **Problems with the Current Language.** Not applicable.
3. **Proposed Revisions.** Add a new Section 501 to the bill (replacing "Employee Protections..."), entitled "Establishment of a National Advisory Committee on Services to Persons with Mental Retardation and Related Conditions", which shall read as follows:

(a) **In General.** -- Section 1925 of the Social Security Act is further amended by adding at the end thereof the following new subsection:

(k) Establishment of a National Advisory Committee on Services to Persons with Mental Retardation and Related Conditions. --

(1) In General. - The Secretary shall appoint, no later than 90 days after the date of enactment of this Act, a 15 member advisory committee, which shall be called the National Advisory Committee on Services to Persons with Mental Retardation and Related Conditions (hereafter

referred to as the Committee). Before selecting members to serve on such Committee, the Secretary shall consult with leaders of national organizations interested in the welfare of persons with mental retardation and related conditions.

(2) Composition. - The Committee shall be composed of at least --

(i) two persons who represent state mental retardation or developmental disabilities agencies,

(ii) one person who administers a publicly operated intermediate care facility for persons with mental retardation,

(iii) one person who administers a privately operated intermediate care facility for persons with mental retardation,

(iv) one person who is affiliated with a certified representative of employees of a publicly or privately operated intermediate care facility for persons with mental retardation,

(v) one person who administers a community-based residential facility that is financed through a Medicaid home and community-based waiver program,

(vi) one person who administers a community-based daytime or support service program that is financed through a Medicaid home and community-based waiver program,

(vii) one person who resides in an intermediate care facility for persons with mental retardation or who is a parent, guardian or relative of such a person,

(viii) one person who resides in a Medicaid -financed community residence or who is a parent, guardian or relative of such a person,

(ix) one person who represents a university -affiliated program for persons with developmental disabilities,

(x) one person who is a member or staff of a state developmental disabilities planning council, and

(a) one person who represents a national accreditation program that accredits facilities and programs for persons with mental retardation and other developmental disabilities.

(3) Duties and Responsibility. - The Committee shall -

(i) analyze and make recommendations to the Secretary on an operational definition of the term "active treatment" as it applies to intermediate care facilities for persons with mental retardation,

(ii) study the impact of intermediate care facilities for persons with mental retardation on clients living in such facilities and recommend any legislative or administrative steps that should be taken to better integrate the services provided in such facilities with services to persons with mental retardation and related conditions financed through other Medicaid and non-Medicaid funding sources. Such study shall include --

(A) an analysis of current federal and state policies governing the operation of intermediate care facilities for persons with mental retardation, with particular reference to policies that impede the expansion and improvement of state and local developmental disabilities services which are consistent with the most advanced and efficacious practices in serving such persons, and

(B) near term and long range proposals for eliminating such impediments;

(4) Reporting. - The Committee shall submit reports to the Secretary, the Chairman of the House Energy and Commerce Committee and the Chairman of the Senate Finance Committee in accordance with the following schedule:

(i) a report summarizing the Committee's findings, conclusions and recommendations with respect to the subjects specified in subparagraph (3)(i) by no later than July 1, 1991;

(ii) a report summarizing the Committee's findings, conclusions and recommendations with regard to the subjects specified in subparagraph (3)(iv) by no later than October 1, 1992, and

(5) Compensation - Members of the Committee, who are not full-time officers or employees of the United States, shall be —

(i) entitled to receive compensation at a rate equal to the rate of basic pay payable for grade GS-18 of the General Schedule under section 5332 of title 5, United States Code, including travel time, for each day they are engaged in the performance of their duties as members of the Committee; and

(ii) allowed travel expenses while away from their homes in the performance of services for the Committee, including per diem in lieu of subsistence, in the same manner as persons employed intermittently in the Government service are allowed expenses under section 5703 of title 5, United States Code.

(6) Authorization of Appropriations - There are authorized to be appropriated such sums as may be necessary to carry out this subsection.

4. Programmatic Implications. A number of key policy issues exist today which are unlikely to be resolved in the context of the present legislation. Rather than allowing these decisive issues to continue to fester, a national advisory body, representative of all key actors in the field of developmental disabilities, would be created to analyze the related problems and make legislative and administrative recommendations to the Secretary and Congress. Among the critical areas of policies that this national advisory committee would be asked to examine are:

an operational definition of the term "continuous active treatment." The existing bill would direct the Secretary to issue such an operational definition (Section 1925(f)(2); lines 10-15, page 36). The proposed amendments, however, would obligate the Secretary to base his definition on the recommendations of the national advisory committee, after taking into account public comments on the committee recommendations.

legislative or administrative steps that would facilitate better integration of ICF/MR services and MR/DD services financed through other Medicaid and non-Medicaid funding sources. The principal aim of the Committee's work in this area would be to identify ways of bridging the widening gap between the operating philosophies and practices that underlie ICF/MR services versus the operating philosophies and practices that increasingly characterize community-based service to persons with developmental disabilities.

Each of the major aspects of the Committee's work outlined above would be sequenced in a manner which assured that the most pressing issues would be dealt with early in the Committee's work. An estimated two years would be required to complete all of the tasks assigned to the Committee.

5. Cost Implications. The additional federal costs of maintaining the proposed National Advisory Committee (an estimated \$1 million per year for two fiscal years) would be quite modest, especially considering the critical issues that the Committee would be asked to examine.

December 2, 1988