

STATEMENT OF TESTIMONY

on the
**MEDICAID QUALITY SERVICES TO THE MENTALLY RETARDED
AMENDMENTS OF 1988**

H.R. 5233

**and MEDICAID HOME AND
COMMUNITY QUALITY SERVICES ACT OF 1987**

H.R. 3454

Respectfully Submitted
to the Subcommittee on
Health and the Environment
of the

HOUSE ENERGY AND COMMERCE COMMITTEE

by

James Toews

Assistant Administrator for Developmental Disabilities
Oregon Division of Mental Health
and Department of Human Resources

speaking on behalf of the

National Association of State Mental Retardation
Program Directors, Inc.

September 30, 1988

HIGHLIGHTS

Despite the central role Medicaid has played in the ongoing transformation of services to persons with developmental disabilities, several key aspects of current Title XIX policy stand as major impediments to the accomplishment of the states' basic programmatic goals, including:

the inequities associated with existing methods of determining eligibility for Medicaid-funded long term care services, especially the present linkage between eligibility and the individual's presumed need for institutional services;

the rapidly escalating cost of delivering ICF/MR services, which is choking off the capacity of states to provide services to unserved persons;

the lack of a reliable, ongoing mechanism for assuring federal financial participation in the cost of home and community-based services, which avoids the problems associated with the Section 1915(c) waiver program;

the bifurcation of administrative responsibility in many states for carrying out Title XIX policies.

The most critical feature of any legislation designed to reform current Medicaid policies affecting the MR/DD population is the establishment of a firm statutory basis for claiming Title XIX reimbursement on behalf of eligible persons residing at home or in other non-institutional settings. Since this is one of the central aims of both H.R. 5233 (Waxman) and H.R. 3454 (Florio), NASMRPD is pleased to express its general support for these measures. However, both bills also contain features that NASMRPD views as barriers to the enactment and implementation of reform legislation, including the provisions discussed below:

The parameters of eligibility set forth in H.R. 3454 are unrealistic; we prefer the narrower definition contained in H.R. 5233. Conversely, we recommend that eligibility for community-based services under Medicaid be completely decoupled from an institutional needs test, as proposed in H.R. 3454.

Home and community-based services should be available as an optional, rather than a mandatory, Medicaid state plan coverage.

The unilateral establishment of federal standards is an ill-advised means of striking a balance between federal and state interests.

NASMRPD supports the inclusion of reasonable employee protections in the proposed legislation, but has serious concerns about certain aspects of the subject provisions of H.R. 5233.

States should not be prohibited, on the basis of the freedom of choice principle, from covering optional community habilitation services in instances where state law restricts the types of agencies that are eligible to serve as vendors of such services.

NASMRPD recognizes the importance of restricting the utilization and cost of expensive, 24 hour care settings, but is concerned that a cap of Medicaid payments to larger ICF/MR

facilities might have undesirable side effects as long as the operating costs of such facilities are so heavily driven by federal regulatory and enforcement actions. We also see little merit in adding statutory conditions of participation applicable to ICF/MR facilities. There is a pressing need, however, to develop an active treatment performance criteria that can serve as a reasonable basis for determining compliance with federal ICF/MR regulatory standards. To facilitate the development of such performance criteria, NASMRPD recommends that an outside commission be established.

NASMRPD opposes the transfer of survey, certification and enforcement responsibilities to the HHS Secretary in the case of state-operated ICF/MR facilities, as proposed in Title II of H.R. 5233, but supports the addition of specific statutory enforcement options. In addition, we recommend that the existing statutory authority for ICF/MR reduction and correction plans (Section 1922) be amended, rather than replaced by new reduction plan provisions.

Our Association also strongly opposes delegating broad authority to the Secretary to establish national ICF/MR admission and continued stay criteria, as proposed in Title III of H.R. 5233. Such an authority would give the Secretary sweeping powers to tighten ICF/MR eligibility standards and, thereby, modulate the numbers and types of persons receiving such services to fit preconceived federal budgetary goals. Indeed, before considering revisions in ICF/MR eligibility criteria, there is a need to examine the effectiveness of the ICF/MR service delivery model.

Finally, NASMRPD strongly endorses the provisions of Title IV of H.R. 5233 related to rate setting and payment policies governing Medicaid-funded ICF/MRs as well as community habilitation services. We also endorse Section 502 of the Waxman bill, which would grant the states explicit statutory authority to assign Medicaid administrative functions to the state MR/DD agency.

I. INTRODUCTION

My name is James Toews. I am the Administrator of Developmental Disabilities Programs in the State of Oregon. I also serve as a member of the Governmental Affairs Committee of the National Association of State Mental Retardation Program Directors. NASMRPD is a non-profit organization of the designated officials in the fifty states and territories who are directly responsible for the provision of long term care services to a total of over half a million children and adults with developmental disabilities.

In FY 1986, federal Medicaid payments represented 34 percent the aggregate revenues received by state mental retardation/developmental disabilities agencies for institutional and community-based services - up from 19.3 percent in 1977. If state matching funds were taken into account, almost two-thirds of the budgets of these agencies (64 percent), on average, were made up of federal-state Medicaid dollars. It should be obvious from these figures that our Association has a vital stake in the future evolution of Medicaid policy.

II. CURRENT LIMITATIONS OF MEDICAID POLICY

Fundamental changes have occurred in the way states serve persons with mental retardation and other developmental disabilities over the past ten years. These changes are reflected in both the steady decline in the number of persons served in large, state-operated residential centers (from 151,000 in 1976-77 to 93,000 in 1986-87)³ and in the increasing proportion of public dollars expended on community-based services. Between FY 1977 and FY 1986, aggregate expenditures for community MR/DD services increased from \$761 million to \$4.2 billion, or by 446 percent. By FY 1986, states were spending about half their budgets (48.8%) on community-based services - up from 23 percent in FY 1977.⁴

Access to Medicaid financing has played a crucial role in fostering this major reconfiguration in the delivery of services to persons with developmental disabilities. The availability of Title XIX payments has permitted states to improve the services provided in public institutions, while at the same time rapidly expanding access to

community services. Furthermore, the establishment of the Medicaid waiver program in 1981 has helped many states to accelerate the shift toward home and community-based services. Yet, despite the central role Medicaid has played in this historic transformation of services for persons with developmental disabilities, several key aspects of current statutory policies stand as major impediments to the accomplishment of the states' basic programmatic goals. These impediments are briefly summarized below.

First, the current means of determining an individual's eligibility for Medicaid-reimbursable long term care services creates grave inequities and unfairly denies many persons with developmental disabilities access to appropriate training and support services. The statutory requirement is that an individual must be admissible to an intermediate care facility for the mentally retarded (ICF/MR) in order to qualify for Medicaid long term care benefits, whether furnished in an ICF/MR-certified facility or through a home and community-based waiver program. The problem is that no generally acceptable criteria exist for determining when an individual needs ICF/MR level of care; each state has established its own ICF/MR admission and continued stay criteria, usually based on a variety of considerations. Furthermore, states have demonstrated over the past decade that most, if not all, persons once thought to require institutional services can be served just as effectively or better through an individually tailored array of community-based programs.

The variability in state criteria and the growing body of opinion that it is both impractical and inappropriate to distinguish between the need for institutional versus community services lie at the heart of many of the problems states experience with the HCB waiver program. Utilization of both ICF/MR and waiver services varies enormously from state to state, due to both historical and ideological factors. By testing the allowable limits of HCB waiver services against the use of ICF/MR services, both the current statute and HCFA administrative policies have created three key problems:

- First, the allowable scope of HCB services in any state is measured against a standard that is of questionable validity.
- Second, access to HCB services becomes a function of where a persons lives and not

his/her service needs.

- Third, states that have deemphasized congregate care services in favor of smaller, more integrated living arrangements are being penalized.

These outcomes of present Medicaid policy are, by any measure, perverse.

Second, the ICF/MR program, which constitutes the primary mechanism for financing long term care services for persons with developmental disabilities, has proven to be an increasingly costly and inherently restrictive approach to delivering services. While there is no question that the availability of Medicaid financing through the ICF/MR program has been a critical factor in converting many custodially-oriented facilities into more resident-centered treatment programs, it seems highly unlikely that the states can evolve coherent strategies for meeting the burgeoning demands for developmental disabilities services as long as 95 percent of Medicaid payments for specialized DD long term care services are channelled to the states through the ICF/MR program. In reaching this conclusion, we are influenced by the following realities:

- ICF/MR is a facility-based model of delivering services, in which the residential facility serves as the hub of a comprehensive, 24 hour system of services to its residents. Although many states now have both large, multi-purpose facilities and small, community-based residences certified as ICF/MRs, there are inherent limitations on the methods of delivering ICF/MR services. These limitations, in many ways, are out of step with emerging, state-of-the-art principles governing the provision of community-based services, including the emphasis on family-based services, integration into the mainstream of the community, dispersal of program responsibility, external case management and greater opportunities for independence and self-actualization.
- Pressure to increase spending in ICF/MRs is severely limiting the ability of states to meet new service demand. Outlays are increasing at a rate greatly disproportionate to the growth in service caseloads. As a result, many states are experiencing growing waiting lists for service, despite steadily increasing expenditures. For

example, the average per capita cost of operating state ICF/MR facilities, which still represent nearly two-thirds of all certified beds, more than tripled over the past ten years (from \$44.23 a day in FY 1976-77 to \$148.13 a day in FY 1986-87).⁵ Between FY 1985-86 and FY 1986-87 alone, aggregate state expenditures for public MR/DD facilities increased by almost seven percent, despite an estimated seven percent drop in the number of persons residing in such facilities. The recently revised federal ICF/MR standards are likely to trigger additional increases in the operating costs of certified facilities, thus further complicating the task of extending appropriate residential and daytime services to persons who are currently unserved or underserved.

- Since the advent of the ICF/MR "look behind" program four years ago, HCFA has played an increasingly assertive role in overseeing the provision of services in ICF/MR-certified facilities, nationwide. While no one could deny that the resulting federal surveys have uncovered unacceptable conditions in some facilities, they also have had a fundamentally disruptive effect on state planning and policy development, by establishing a largely subjective standard of performance and then placing broad oversight authority in the hands of state and federal surveyors who are immune to the fiscal, programmatic and administrative consequences of their compliance determinations. A more reasonable balance must be struck between a state's ability to design and implement a holistic approach to improving services, regardless of the source of funding, and HHS/HCFA's legitimate role in assuring that federal dollars are used effectively and in accordance with statutory law.

The above observations are not intended to downplay the important role that the ICF/MR program has played in improving the quality of residential facilities for persons with developmental disabilities, nationwide. However, a way must be found to bridge the growing gap between the states' overarching service goals for persons with developmental disabilities and their specific obligations under federal law to residents of ICF/MR facilities. Otherwise, as a nation, we run the risk of maintaining a two-tiered service system - one which drains off the lion's share of federal-state resources to serve a small fraction of the population in need of long term care services.

Third, while Medicaid home and community-based waivers have helped the large majority of states to partially extricate themselves from over-reliance on ICF/MR funding, in practice the waiver program has proven to be an imperfect long range vehicle for restructuring Title XIX financing of DD services. The crucial limitation of the waiver program is that broad administrative authority to determine the circumstances under which waivers may be approved has been delegated to an Administration that is fundamentally opposed to any growth in federal Medicaid outlays. Consequently, by federal regulations, states are required not only to prove that average per capita expenditures will not increase as a result of the proposed waiver (as specified in Section 1915(c) of the Act) but also that the total number of recipients of Medicaid-funded DD services (i.e., ICF/MR residents plus waiver participants) will not increase. As a result, states are faced with powerful fiscal incentives to limit waiver services to persons who are relatively expensive to serve in community settings, rather than emphasizing low cost services that are delivered to a wider segment of the potentially eligible service population (e.g., family support services). Even more critical, however, is that present administrative policies pose an enormous (dilemma for the states: in order to shift persons to more appropriate services and settings and have Medicaid dollars follow, a state must accept a cap on the number of individuals who receive Title XIX long term care benefits. Present policies force a state to employ high cost, often more restrictive, ICF/MR services if it wishes to secure Medicaid-funding for more individuals. These policies are neither sensible nor appropriate.

Another drawback of the waiver authority is the high degree of uncertainty surrounding the continuation of federal funding, especially when a state must negotiate a renewal of its waiver authority with HCFA. Even during the intervening years, however, experience indicates that a state must be prepared to cope with a significant degree of federal intrusion that often borders micro-management of the program. This operating framework is counterproductive and ultimately poisons federal-state relations.

It is important to emphasize that, despite the drawbacks of the current HCB waiver program, most states have elected to participate. Currently, 38 states have specialized MR/DD waiver programs in operation. The fact that these states are required to limit further growth in ICF/MR bed

capacity in order to qualify for a waiver provides a useful measure of the states' desire to disengage themselves from the ICF/MR program as the principal source of future Medicaid funding for long term care services on behalf of persons with developmental disabilities. In other words, the states clearly are searching for more flexible and cost effective methods of supporting home and community-based services to this population. The basic problem is to identify a more permanent and reliable means of assuring federal financial participation in the cost of delivering such services, which grants states reasonable administrative flexibility while at the same time assuring adequate Congressional and Executive Branch oversight, as well as an acceptable, predictable rate of growth in federal Medicaid outlays.

Finally, in many states, the barriers to developing and carrying out a coherent strategy for serving persons with developmental disabilities are not limited to problems emanating directly from federal statutory and regulatory requirements. Instead, the bifurcation of responsibility for developing and executing policies governing the utilization of Medicaid dollars on behalf of this population frequently represents a major impediment to progress.

By federal law, each state that elects to participate in the Medicaid program must designate a single state administrating agency to serve as the organizational component of state government that is accountable for seeing that federal Medicaid policies are carried out. At the same time, each state has an organizational unit that is responsible under state law for organizing and delivering services to persons with mental retardation and other developmental disabilities. Difficulties in reconciling the distinctive aims of these two agencies often results in the lack of a holistic approach to managing Medicaid resources on behalf of this particular target population of recipients. The result frequently is disjointed administration of the program, characterized by poor interagency communications plus an absence of clear programmatic goals. Unfortunately, where such situations exist, potential beneficiaries of Medicaid-funded services usually are forced to bear the consequences.

III. PROPOSED LEGISLATION TO RESTRUCTURE MEDICAID

The purpose of today's hearing is to consider legislation to restructure Medicaid eligibility, coverage and long term care benefits applicable to persons with developmental disabilities. More

specifically, the Subcommittee is seeking input on two pending bills: H.R. 5233, the "Medicaid Quality-Services to the Mentally Retarded Amendments of 1988", as introduced on August 11, 1988 by Chairman Waxman, and H.R. 3453, the "Medicaid Home and Community Quality Services Act", as introduced on October 8, 1987 by Representative James Florio.

Although the two bills take much different approaches to restructuring Medicaid policies, both would address, in substantial ways, some of the current shortcomings in the program as outlined above. In particular, both H.R. 3454 and H.R. 5233 would go a long way toward:

- *equalizing financial incentives to placing eligible persons with developmental disabilities in community-based programs vs. institutional facilities, thus increasing the prospects that services would be furnished in the most appropriate programmatic and physical setting;*
- *allowing the states greater flexibility in using federal dollars to achieve long range systemic reforms by recognizing key elements of home and community-based care as full fledged, Medicaid-reimbursable state plan services;*
- *shifting the emphasis of Medicaid funding toward habilitation services that assist individuals with severe disabilities to achieve greater independence and assume productive roles in American society, by allowing states to claim Title XIX reimbursement for certain prevocational and supported employment services that are furnished to eligible recipients in community settings;*
- *permitting states increased latitude in designing and financing out-of-home care services through their Medicaid programs, including various types of supported living arrangements which, unlike an ICF/MR-certified facility, do not require the residential operator to oversee the provision of a 24 hour array of services and establish no minimum number of residents per residential site; and*
- *granting the Governor of each state explicit authority to delegate to the state MR/DD agency specific management functions related to the administration of Medicaid-reimbursable services for persons with developmental disabilities.*

Our Association believes that the most critical feature of any legislation designed to reform current Medicaid policies that impact on the MR/DD population is the establishment of a reliable basis for claiming Title XIX reimbursement for long term care services on behalf of such persons while they reside at home or in other non-institutional settings. Since our analysis suggests that either H.R. 3454 or H.R. 5233 could achieve this fundamental aim, NASMRPD is pleased to express its general support for both bills.

At the same time, we wish to make clear that there are features of both H.R. 3454 and H.R. 5233 which our members feel would create unnecessary barriers to the enactment and/or implementation of reform legislation. On behalf of NASMRPD members, I respectfully request that the Subcommittee take the following views into account in redrafting legislation for introduction early next year:

- A. Eligibility. H.R. 3454, as introduced, would link eligibility for a wide range of Medicaid reimbursable "community and family support services" to the statutory test of disability used in determining eligibility for Supplemental Security Income (SSI) benefits. Initially, only individuals with a severe disability originating prior to age 22 would be considered eligible for such specialized Medicaid benefits; however, the age of onset threshold would increase by one year for each additional fiscal year the legislation was in effect, until it reached a maximum of age 50.

By contrast, H.R. 5233 would define the term "mentally retarded" and a "person with a related condition" in exactly the same way as those terms are currently defined in HCFA regulations. In particular, a person with a "related condition" would mean any individual with a severe, chronic disability that: (a) is likely to continue indefinitely; (b) is attributable to cerebral palsy, epilepsy or any other condition -- besides mental illness -- that is closely related to mental retardation and requires similar services; and (c) results in substantial functional limitations in at least three out of six specified areas of major life activity.

While NASMRPD recognizes the importance of identifying appropriate loci of public responsibility for financing services to individuals who are severely disabled during

adulthood, we do not believe that the present legislation is the proper vehicle for resolving this complex question. Therefore, our Association recommends that the Subcommittee adopt the more restrictive definition of the eligible target population contained in the Waxman bill. The basic aim of the legislation must be to restructure Medicaid policy as it impacts on persons with developmental disabilities. Fundamental conceptual and structural changes would be necessary to accommodate the needs of other disability target populations; in the process, the original legislative aims might be lost or diffused. At present, little is known about the number of non-elderly persons requiring long term care services due to a severe disability originating in adulthood, the types of services they require, the estimated federal-state costs associated with furnishing such services and Medicaid's current and potential role in meeting the needs of such individuals. Similarly, in the case of persons with mental illness originating in childhood, we believe it is preferable to consider the merits of expanding coverage to this group in the context of general mental health Medicaid reform legislation, rather than as part of legislation that is designed to address the needs of persons with other developmental disabilities.

Unlike the Florio bill, 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 for institutional services to establish eligibility. 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.

As pointed out earlier in this testimony, making eligibility for community habilitation services conditional on an individual's presumed need for institutional (ICF/MR) services poses numerous problems for the states. Certainly, there would be significant disincentives for a state to elect to cover an optional categorically eligible group if an institutional needs test were to be applied to this group and not to categorically eligible residents.

NASMRPD recommends that eligibility for community habilitation services be completely decoupled from the test of need for institutional services.

Given the strict test of disability that would be applied, the primary effect of such action would be to permit states that so elect to cover children with severe disabilities who are living at home and similarly disabled adults with income or resources (often as a result of OASDI eligibility) that exceed the SSI means test. The most equitable public policy would be to permit a state to apply the same income and resource test of eligibility for community services as it applies in determining eligibility for institutional services, without having to link an individual's need for services to his or her presumed need for institutional services.

- B. Scope of Reimbursable Services. H.R. 3454 and H.R. 5233 adopt quite different approaches to defining the scope of community-based services that would be coverable under Medicaid. Perhaps the most significant difference is that, under the Florio bill, the states, as a condition of continued participation in the Medicaid program, would be required to furnish at least a minimal array of community and family support services (i.e., case management, protective intervention, specialized vocational, and individual and family support services) no later than the beginning of the second fiscal year after enactment of the legislation. In contrast, the states would be under no obligation to offer "community habilitation services" under the terms of the Waxman bill, since it would be treated as an optional service coverage.

One of the basic, organizing principles of the Medicaid program since its inception has been that each state exercises considerable latitude in defining the scope of its own program, within certain parameters set forth in federal law. As a

result, Congress generally has elected to expand the scope of reimbursable services by adding new optional coverages, rather than mandating the provision of particular services (other than those acute health care services (hospital care, physician services, etc.) that must be available to all eligible recipients). Given this history, NASMRPD recognizes that there is likely to be substantial opposition to adding new mandatory service coverages, especially given the additional budgetary pressure new service mandates could entail. **Rather than further delaying action on legislation to provide a reliable basis for supporting non-institutional long term care services for persons with developmental disabilities, we would prefer to see the states given the option of covering such services now.** The fact that 38 states have chosen to participate in the Medicaid home and community-based waiver program suggests that many, if not all, states will elect to cover community habilitation services if it is offered as an optional service under Medicaid.

The Florio bill would offer the states a very wide range of alternatives for claiming Medicaid reimbursement on behalf of eligible persons residing at home or in other community-based settings. Besides the four elements of community and family support services that it would be obligated to offer, a state could elect to cover any of 20 other elements of such services that are enumerated in the bill; plus, a state would be free to cover any other type of service found by the Secretary to conform to the purposes of the legislation.

By comparison, the types of community-based services that would be coverable under the Waxman bill are considerably narrower. However, experience with the Medicaid HCB waiver program suggests that the distinction between the types of costs that would be treated as Title XIX reimbursable under the two measures may not be as striking as would first appear to be the case. To date, HCFA generally has given states rather broad latitude in defining the elements of habilitation services that may be treated as Title XIX-reimbursable costs under an HCB waiver program. Thus, for example, most of the training and support service costs (other than room and board payments) typically incurred in operating residential and daytime programs designed to assist waiver participants with developmental

disabilities to acquire and retain adaptive skills usually are considered to be reimbursable habilitation expenditures under a HCB waiver program. Assuming this same interpretation were carried over to the state plan option proposed in the Waxman bill, it should be possible for a state to recover approximately the same portion of the cost of typical MR/DD day and residential services as it could under the Florio bill.

The history of the waiver program, however, strongly suggests that the potential exists for any future Administration to narrowly construe the elements of services that would be claimable under the proposed, new Medicaid service rubric; if such administrative action were taken, Title XIX federal financial participation in the cost of habilitation programs would be severely restricted. NASMRPD representatives would be glad to work with Subcommittee members and staff to assure that the language of the bill and the accompanying report preclude federal administrative interpretations that would inappropriately narrow the scope of reimbursable services.

The differences between the two bills lie primarily in the area of non-habilitative support services (e.g. respite care and other forms of family support services) that would be treated as reimbursable costs under H.R. 3454 but not under H.R. 5233. **NASMRPD considers such services an absolutely vital part of any state's MR/DD community service array, and is desirous of working closely with the Subcommittee and its staff in identifying specific elements of family support services that may be treated as Medicaid-reimbursable community habilitation services.**

Federal Standard Setting Authority. In order to qualify for Medicaid reimbursement under the terms of H.R. 5233, a provider of community habilitation services in a supervised residential setting would have to meet standards promulgated by the Secretary of Health and Human Services. These federal standards, which the Secretary would have to issue no later than October 1, 1989, would be required to include provisions governing client rights and protections, case management, the completion of comprehensive functional assessments, the process of developing, monitoring and up-dating individual program plans, the use of a uniform client performance accounting system and

the application of minimum health, safety and sanitation rules.

The introduction of uniform federal standards governing the operation of Medicaid-supported community residences 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 substantially the cost of operating Medicaid-funded residential programs, without necessarily achieving any measurable improvements in the quality and appropriateness of services provided to residents. **Although NASMRPD recognizes the federal government's legitimate interests in assuring that recipients of Medicaid-funded community services receive high-quality services, we believe that the unilateral establishment of federal standards is an ill-advised approach to accomplishing this objective.** In this regard, it should be noted that more than two-thirds of the states have offered Medicaid-financed HCB waiver services in community residential settings over the past eight years without any major indications that federal standards are necessary. Indeed, the flexibility to tailor minimum operating standards to the needs of particular types of residents and the nature of the residential environment has been one of the principal advantages of the HCB waiver authority. A number of states have taken advantage of this flexibility to design new, more effective and normalizing living arrangements for waiver participants in recent years – a step that simply would not have been possible had rigid, clinically-oriented federal standards been imposed.

NASMRPD finds the general approach to quality assurance used in the Florio bill to be a more appropriate way of striking a balance between federal and state interests in assuring that all recipients of Medicaid-funded community DD services maintain compliance with minimum program standards. The legislation spells out in considerable detail the minimum components of a comprehensive system for monitoring the quality of

Title XIX-reimbursable community and family support services. In addition to establishing and monitoring compliance with state licensure and/or certification standards, a state would be required to arrange for independent, third party reviews of each Medicaid-funded program and also conduct periodic surveys of client and family satisfaction with the services provided. The Secretary of Health and Human Services would be responsible for reviewing a state's quality assurance plans and performance on a periodic basis, but would be prohibited from promulgating federal standards governing the provision of community and family support services.

Whether the Subcommittee decides to use an approach similar to the Florio bill or some other method of assigning HHS/HCFA an appropriate oversight role, NASMRPD representatives would be happy to work with the Subcommittee's members and staff in hammering out a workable alternative that recognizes the need for accountability while at the same time permitting states to forge effective approaches to service delivery.

- D. Employee Protections. As a condition of covering optional community services under their state Medicaid plans, states would be obligated, under Section 501(a) of the Waxman bill, to provide assurances that certain explicit job protections are afforded to current employees whose jobs may be affected by such coverage. The Florio bill also would require each state to spell out, as part of its detailed implementation strategy, the steps that would be taken to afford public employees protection against the loss of their jobs when residents were transferred out of public institutions. In general, the types of protections specified in the Florio bill are less explicit than in the Waxman bill.

NASMRPD recognizes that states have an obligation to see that state employees whose jobs are threatened by the closure or phase-down of a public residential facility receive assistance in locating new jobs, either in the public or private sector. Given the shortage of trained manpower to staff community programs, we also are acutely aware of the importance of finding positions for persons who have had prior experience in serving persons with developmental disabilities. **Consequently, our Association supports the inclusion of**

reasonable employee protections in the proposed legislation. Nonetheless, we have serious concerns about certain aspects of Section 501 of H.R. 5233.

First, the legislation should specify the circumstances under which the applicable employee protections would be triggered. There is no direct, cause-and-effect relationship between the provision of Medicaid-reimbursable community services and threats to the job security of present employees. More than two-thirds of the states, for example, have established and operated Medicaid home and community-based waiver programs over the past eight years without any demonstrable evidence of broad-scaled lay-offs or job termination actions involving employees of public mental retardation institutions that are attributable to the provision of waiver services. **Any employment safeguards that are added to the Act should be directly related to the events which actually threaten the job security of facility employees - i.e. the phase-down or closure of large, publicly-operated residential facilities.**

Second, as currently drafted, H.R. 5233 would not limit the applicable job safeguards to public employees (as H.R. 3454 would). When a state is the employer, it can take steps to locate alternative positions for public servants who are displaced by the closure or phase-down of a publicly-operated facility. On the other hand, a state often is not in the same position with respect to the employees of private facilities. **Therefore, the legislation should limit the applicability of job protections to state employees only.**

Third, under the proposed Section 1925 (j)(1)(A) and (B) of the Act, which would be added by Section 501 of the Waxman bill, a state would be obligated to give the Secretary assurance that employee rights would be preserved under **existing collective bargaining agreements** and through **current certified representatives**. This language raises serious questions about whose interests are being protected: the employees or the unions that represent them. Past experience with the closure of public mental retardation facilities underscores the importance of a multi-faceted plan if the interests of existing employees are to receive maximum protection (e.g., early retirement options, transfer to comparable positions in other state agencies, etc.), especially in view of the

fact that many older public residential facilities are located in rural areas where there are relatively few alternative job opportunities in either the public or the private sector. For example, in a number of instances, former state MR facilities have been converted into prisons, with some members of staff of the former facility transferred to the prison staff. It is important to note that such lateral interagency transfers would be much more difficult to arrange if the employees of the two agencies were represented by different collective bargaining agents.

Finally, the proposed Section 1925(j)(2) of the Act, which would be added under Section 501 of the Waxman bill, would require a state to establish specific grievance procedures for affected employees. **While the inclusion of a grievance procedure seems reasonable, states with comparable grievance procedures under existing collective bargaining agreements should not be obligated to establish distinct procedures that are applicable only to employees covered by the provisions of the proposed Section 1925(j). A provision, therefore, should be added that allows a state to request and the Secretary to approve the use of existing, comparable grievance procedures.**

- E. Freedom of Choice. Section 101(g) of H.R. 5233 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 services.

While the underlying aim of Section 101(g) is generally consistent with the philosophy espoused by most state MR/DD agencies in organizing and delivering community services, it could prevent some states, on technical grounds, from covering community habilitation 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.

NASMRPD recommends that language be added to the bill to make it clear that, in instances where state law restricts the types of agencies that are eligible to serve as vendors of Title-reimbursable "community habilitation services", a state will not be precluded from covering such services under its Medicaid plan.

Limitation on Medicaid Payments to Large ICF/MR Facilities. Section 4 of H.R. 3454 would impose a cap on federal financial participation in the cost of large SNF, ICF and ICF/MR facilities (with 16 or more beds). Aggregate federal payments on behalf of the residents of such facilities would be limited to the amount the state received on behalf of non-elderly individuals with severe disabilities in the fiscal year immediately preceding enactment of the legislation. The bill would provide exceptions to a state's otherwise applicable freeze level when: (a) the rate of inflation, as measured by the Consumer Price Index, exceeds six percent; and (b) additional outlays are necessary to implement a plan of correction, resulting from a federal ICF/MR look behind review, that involves a net reduction in the facility's population.

Although this particular provision of H.R. 3454 has generated more controversy, by far, than any other feature of the bill, NASMRPD has never viewed it as central to the aims of the legislation. The population of large, public institutions has been dropping at a steady rate for over twenty years (e.g., between 1977 and 1986, state institutional populations declined by 32.7%, or at an average annual rate of 4.3% per year); the population of large privately operated ICF/MR facilities also is declining, albeit at a slower pace. Given the states long-standing commitment to reducing their reliance on large congregate care settings in general and state-operated residential centers in particular, we feel confident that the trend toward maintaining fewer beds in large ICF/MR facilities will continue, regardless of whether legislation similar to Section 4 of the Florio bill is enacted

into law. As indicated earlier in this testimony, in our opinion the establishment of a firm, ongoing basis for supporting home and community-based services on behalf of to this population is the most critical issue that must be resolved.

When the Florio bill was being developed, most of our member states informed us that they would be able to accommodate an aggregate freeze on FFP for large ICF/MR facilities, provided the legislation, as proposed, also included broad authority to seek reimbursement for home and community-based services. In reaching this conclusion, these states, in effect, were telling us that they felt reasonably confident that they could continue to reduce their institutional populations at a rate that would permit them to remain within the payment freeze level, if they were assured of Medicaid participation in the cost of financing community-based service alternatives.

Since that time, however, a number of events have occurred that make such predictions much less certain – most notably the growing uncertainty surrounding the impact that federal look behind reviews, combined with the recently issued, revised ICF/MR standards. The available evidence suggests that states may be trapped in an upward price spiral that they have little control over. The open-ended requirements of HCFA's new regulatory standards, as interpreted and enforced through federal look-behind surveys, could easily lead to a rapid escalation in the cost of operating ICF/MRs, which the states are simply unable to offset through further reductions in facility populations. A freeze on federal financial participation in the cost of large ICF/MRs, under these circumstances, would mean that states would be forced to divert state general revenue dollars that otherwise would be used to expand community-based programs to rectify deficiencies in ICF/MR facilities. NASMRPD members are keenly aware of the importance of controlling the utilization and cost of the most expensive service options (i.e., intensive, 24 hour treatment centers) if the states are to fulfill the ambitious service agenda that lies ahead. We simply wish to point out that our ability to exercise real control over ICF/MR operating costs will be severely limited as long as HCFA's regulatory and enforcement policies result in ever-increasing spending levels in such facilities.

G. Modifications in Statutory Requirements

Governing ICF/MR Facilities. 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 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 a few key provisions of revised ICF/MR regulatory standards, published by HHS's Health Care Financing Administration (HCFA) on June 3, 1988.

NASMRPD sees little merit in adding statutory conditions of participation applicable to intermediate care facilities for the mentally retarded, since there is no evidence that including such provisions in law would offer a sounder basis for defining the requirements governing participation in the program or afford residents of such facilities greater assurance of high quality services. Although, as pointed out below, our members have serious concerns about certain aspects of the revised ICF/MR standards recently published by HHS/HCFA, those standards are designed for the specific purpose of regulating the provision of ICF/MR services (rather than being an amalgam of nursing facility and selected ICF/MR requirements); in addition, they are the products of several years of analysis and interaction between HCFA officials and various segments of the MR/DD community and, like any regulation, have the same binding effect as statutory law. Furthermore, the circumstances which led Congress to add conditions of participation applicable to Medicaid and Medicare-certified nursing facilities - i.e., a recalcitrant Administration that seemed set on a course of de-regulating the program - simply do not apply in the case of the ICF/MR program. **NASMRPD, therefore, opposes the inclusion of such provisions in the final version of any legislation the Subcommittee may report out.**

It is important to point out that the key issues in this entire area do not involve regulatory mechanics; nor are states advocating for a return to custodial care in ICF/MRs. The fundamental

issue is the contents and effectiveness of services furnished to persons residing in ICF/MRs. The present regulatory framework is based on a model of service delivery that is expensive to maintain, nearly impossible to assess objectively, and not underpinned by objective evidence concerning its effectiveness. These issues need to be addressed rather than memorialized in statute.

There is one critical aspect of current ICF/MR policy that we believe deserves the Subcommittee's prompt attention - i.e., the development of an active treatment performance criteria that can serve as a reasonable basis for determining a facility's compliance with this keystone requirement of HHS/HCFA's regulatory standards. Determinations of compliance with the active treatment condition of participation are, by their very nature, highly judgmental, which has lead some observers (including some HCFA officials) to express concern about the uneven application of this requirement nationwide - not only in large, multi-purpose ICF/MR facilities, but also in small community-based residences. Furthermore, in order to qualify an individual for active treatment services, a facility must make an affirmative determination that the individual is dependent. Continued eligibility for services, therefore, is tied to continued dependency, which works at cross purposes with one of the central organizing goals of MR/DD services - i.e., to help recipients of services achieve greater independence.

We wish to emphasize that it is not a question of whether the provision of an individually tailored array of habilitation services should be the central concept around which ICF/MR services are organized; clearly, it should. Nor are we arguing for a watered-down standard of performance that would permit certified facilities to function, once again, as custodially-oriented care centers. Instead, the critical question is: can the goal of resident-oriented treatment services, as conceptualized in HCFA's regulatory definition of active treatment, be stated in operational terms that lend themselves to a consistent assessment of whether any given facility is or is not in compliance with this aspect of federal regulatory requirements.

Section 1925(f)(2) of the Act, which would be added by Section 201(d) of H.R. 5233, would

require the Secretary to issue an operational definition of continuous active treatment by October 1, 1989. The intent of this provision is to "... promote a consistent assessment of whether a habilitation [ICF/MR] facility is in compliance with the requirements ..." of the Act. This constitutes a step in the right direction, but it does not go far enough. HHS/HCFA personnel would be left with absolute discretion in solving a problem which, by and large, they would argue either does not exist or cannot be solved.

NASMRPD, therefore, recommends that the Secretary be required to establish an outside commission, consisting of a representative group of experts in delivering ICF/MR services to persons with developmental disabilities, to: (a) review HCFA's current regulatory definition of active treatment (including associated interpretive guidelines), as well as HCFA's methodology for assessing compliance with this regulatory condition of participation; and (b) to formulate recommendations to the Secretary and Congress on steps that might be taken to assure a more consistent application of the subject regulatory standards from facility to facility and state to state. The Secretary, in turn, should be required to publish the findings and recommendations of the commission as a Federal Register notice and solicit public comments. Once these public comments are received and analyzed, the Secretary should be obligated to publish, by a date specified in law, any necessary modifications in applicable regulations and guidelines to implement a revised procedure for assessing compliance with the active treatment condition of participation. Pending the issuance of such regulations, in final form, a statutory moratorium should be imposed on enforcing the active treatment requirements of the June 3, 1988 revised rules, with the former regulatory requirements used as a basis for assessing the compliance of facilities during the interim period.

Section 202 of the Waxman bill would add new statutory requirements governing the conduct of surveys and the certification of habilitation (ICF/MR) 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.

NASMRPD members have expressed conflicting views regarding the merits of transferring authority to survey and certify state-operated ICF/MR facilities to the Secretary. Some state directors feel that it would be preferable to "answer to a single master", and, given the fact that HHS/HCFA has become the final arbiter of compliance since initiating its expanded look behind program in 1984, it would be less confusing if state survey agencies were eliminated from the decision-making loop. Other state directors, however, feel that transferring survey and certification authority over state-operated 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. After weighing the pros and cons on this subject, **NASMRPD is convinced that there is merit in leaving primary survey responsibility with the states in the case of all ICF/MR facilities (including publicly-operated facilities), if for no other reason than to maintain a system of checks and balances.**

Section 203 of the Waxman bill would spell out, in statute, the actions a state would be required to take when it found a habilitation facility out of compliance with statutory certification standards, 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 facilities were in immediate jeopardy or the facility had other persistent deficiencies.

NASMRPD supports the addition of statutory language specifying the penalties that a state (or the Secretary) may exercise when it identifies deficiencies in the operation of an ICF/MR facility. In the past, the lack of clarity

in this area has led to the uneven application of penalties in similar regulatory deficiencies. There also has been a tendency (especially on the part of HCFA) to view termination of certification as the only viable enforcement option, when, arguably, lesser penalties may have been more appropriate and effective.

Our views regarding the transfer of enforcement authority to the Secretary in the case of state-operated ICF/MRs are similar to our views concerning the proposed shift of the survey and certification functions. The states should retain primary enforcement authority over all ICF/MR-operated facilities, including publicly-operated facilities. The results of the federal look behind surveys demonstrate that the Secretary has sufficient authority to intervene where a state has failed to exercise its enforcement powers effectively.

Section 203 of H.R. 5233 also would authorize a state 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 requirements governing ICF/MR phase-down plans under Section 1922 of the Act, with several notable exceptions.

NASMRPD sees no reason to repeal the existing ICF/MR correction/phase down plan authority, although we recognize the need to clarify several provisions of existing law. In particular, the present reduction/correction plan authority needs to be expanded to cover all types of deficiencies that do not pose an immediate threat to the health and welfare of facility residents, including deficiencies in the areas of active treatment, health services, dietary services, etc. Because of HCFA's interpretation of the current statutory provision, no state has yet been permitted to submit a reduction or correction plan under Section 1922 of the Act, although several have expressed a desire to do so. Language to accomplish this end is contained in the pending Senate version of the tax corrections bill (S. 2238), and **we would urge the Subcommittee to favorably consider this amendment should it be raised in a conference on such legislation.**

In addition, it is vital that the final legislation spell out clearly the conditions under

which plans of correction may be submitted and approved in the case of facilities with non-life threatening deficiencies. The existing authority in Section 1922 of the Act was eliminated in drafting the provisions of Section 203 of H.R. 5233, thus leaving this issue in statutory limbo.

- H. Preadmission Screening and Resident Reviews. Section 301 of the Waxman bill 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, based on criteria promulgated by the Secretary. 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, using the same Secretarial criteria.

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-sequitur 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 III of H.R. 5233 portends is the exercise of closer federal scrutiny over who gets 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.

NASMRPD see no pressing need to develop uniform national criteria of eligibility for admission to, and continued stays in, ICF/MR-certified facilities. However, should the Subcommittee decide to pursue such a legislative requirement, we would strongly recommend that the process of developing such criteria involve a representative group of experts who are not affiliated with the Department of Health and Human Services and that the findings/recommendations of this group be subject to public review and comment before Congress takes further action. As indicated earlier in our testimony, the concept of who can and should be programmed for in an ICF/MR-certified facility has changed significantly in recent years, and yet sharply differing views on this subject remain within the field of developmental disabilities. **Consequently, it is important that the practical consequences of any proposed national criteria be carefully weighed and openly debated prior to adoption. Certainly our Association would be unalterably opposed to the carte blanche delegation of authority to the Secretary to establish such criteria.** As a result of such action any future Administration would be in a position to curtail ICF/MR and related spending on behalf of persons with developmental disabilities simply by modifying the national test of ICF/MR admissibility.

In addition, it is important to point out that the determination of who may be appropriately served in an ICF/MR is inextricably tied to the very nature of ICF/MR services themselves. As we have testified, a fundamental reexamination of the basis of providing ICF/MR services is needed; such a reexamination ought to precede any action to revise eligibility criteria.

- I. Payment for Services. Title IV of H.R. 5233 would

amend Section 1902(a)(13) of the Act to add specific provisions governing Medicaid payments for community habilitation services and habilitation (ICF/MR) facility services. These parallel provisions would obligate a state to establish payment rates which are "... reasonable and adequate to meet the cost of providing services in conformity with applicable State and Federal laws, regulations and quality and safety standards...". Title IV also would prohibit the Secretary from limiting the amount of federal financial participation received by a provider of habilitation (ICF/MR) facility services or community habilitation services, by linking payments for such services to the so-called "Medicare upper limit". Current HHS/HCFA regulations require a state to limit payments to all providers of Medicaid-reimbursable long term care services (including ICF/MRs) to the amount the facility otherwise would be qualified to receive under the Medicare program.

NASMRPD strongly endorses the provisions of Title IV of the Waxman bill. They would provide a clearer statutory basis for establishing and maintaining a separate rate setting methodology for habilitation (ICF/MR) facilities as well as for the proposed optional community habilitation services. They also would eliminate the potential threat posed by HCFA regulations that tie ICF/MR payments to the Medicare upper payment limit, a limit, we might add, that conflicts with concurrent HCFA actions which are likely to drastically escalate the cost of providing such services.

Medicaid Administrative Responsibilities. Both H.R. 3454 and H.R. 5233 would 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. In addition, H.R. 5233 would explicitly authorize federal Medicaid reimbursement (at the 50% matching level) for administrative costs incurred by a state MR/DD agency in carrying out functions under the state's Title XIX plan. Both provisions would be effective as of the date of enactment.

These provisions are based on the past experiences of states in administering Medicaid-financed services to persons with developmental disabilities, which tend to indicate that more effective management occurs where day-to-day

financial control over Medicaid dollars is vested in the same state agency that is prograitimatically responsible under state law. They would help to promote the consolidation of authority and responsibility and, therefore, more effective and responsive administration of program benefits on behalf of persons with developmental disabilities, **As such, they have NASMRPD's enthusiastic endorsement.**

* * * * *

On behalf of the Association, I want to express to the Subcommittee my appreciation for this opportunity to offer our organization's views concerning the important legislation you are now considering. If we can be of further assistance to the Subcommittee when this legislation is marked up, I hope you will call on us.

REFERENCES

1. Braddock, David, Richard Hemp and Glenn Fuiura, Public Expenditures for Mental Retardation and Developmental Disabilities in the United States; State Profiles (Second Edition), Monograph No. 29, Public Policy Monograph Series, Institute for the Study of Developmental Disabilities, University of Illinois at Chicago, September, 1986.
2. Ibid.
3. Scheerenberger, R.C., Public Residential Services for the Mentally Retarded; FY 1986-87, National Association of Superintendents of Public Residential Facilities for the Mentally Retarded, 1988.
4. Braddock, Ibid.
5. Ibid.
6. Scheerenberger, Ibid.
7. Ibid.
8. Braddock, Ibid.