Consortium for Citizens with Developmental

Task Force on Medicaid Long Term Care
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Mr. Andreas G. Schneider
Assistant Counsel
Subcommittee on Health and the Environment
Committee on Energy and Commerce
U.S. House of Representatives
Rayburn Building, Room 2415
Washington, DC 20515

Dear Andy,

It is our understanding that the Subcommittee will be considering several technical and clarifying amendments to Medicaid law in **the** not too distant future. Therefore, we thought we would call to your attention several minor statutory revisions which would greatly facilitate the provision of Title XIX-reimbursable services to persons with developmental disabilities.

1. Deeming Under Home and Community-Based Waivers. The technical amendments to the home and community based waiver **authority,** which **were** contained in Section 9411(c) **of last year's** reconciliation bill (P.L. 99-509), modified **the** language **of** Section 1915(c)(3) **of the** Act **in** such **a** manner **that the Secretary no longer has authority to waive parental/spousal deeming requirements on behalf of otherwise eligible participants in approved waiver programs. Prior law authorized the Secretary to grant waivers of "Section l902(a)(10)". P.L. 99-509 altered this language to read: "Section 1902(a)(10)(B) (relating to comparability)". This minor change in the statutory reference is crucial since, according to HCFA officials, Che Secretary's authority to waive deeming requirements had rested on Section 1902(a)(10)(£) of the Act.**

   The subject change will create serious problems for many of the 32 states with developmental disability waiver programs, since: (a) it will limit participation of children with severe disabilities Co those whose families meet the Medicaid income/resource test of eligibility (i.e., it will exclude Katie Beckett-type youngsters); and

(b) it will result in a one-third reduction in the SSI allowance of eligible adults living at home with their parents. In North Carolina, for example, an estimated 56 percent of all current participants in the State's existing waiver program would have their families' income deemed, and many of them (particularly the 106 affected children) will no longer be eligible for waiver services. Preliminary data from the LaJolla waiver evaluation project suggest that the impact will be significant in other states as well (although, not as severe as in the case of North Carolina). For example, Lajolla's 1985 data shows that roughly a third of all DD/CMI waiver recipients were living with their parents (32.1%); in addition, 22.6 percent of all DD waiver participants were under 21 years of age, although we do not know the percentage of these children who were living with their parents or another relative.

We understand that a proposal to "fix" the OBRA drafting error is being developed within HCFA; but, knowing that the internal review process of HCFA often takes many weeks, we thought we would call this issue to your attention directly. If, as we hope, you decide to draft a technical amendment on this matter, we would urge you to make it effective retroactive to the original effective date of OBRA, so that there will be no subsequent questions regarding the legality of waiver expenditures during the interim period.

2. Freedom of Choice in the Provision of Targeted Case Management Services. As you know, when Congress authorized the states to cover, under their state Medicaid plans, targeted case management services, a proviso was included which requires a state to offer recipients a choice among available service providers (Section 9508, COBRA). HCFA has not yet issued regulations or manual instructions implementing the provisions of Section 9508; however those states which have submitted Medicaid plan amendments to cover targeted case management services for persons with developmental disabilities and chronic mental illness have been informed by HCFA regional office personnel that a state may not establish qualifying standards which tie certification to the provider's capability of ensuring that an eligible individual receives other needed services. We consider this interpretation to be unne-cessarily restrictive. In fact, it will make it difficult, if not impossible, for many states to furnish persons who are development ally disabled or mentally ill with Medicaid-reimbursable case management services, since, in these jurisdictions, a state, county or private,

non-profit agency is designated, under state law or regulation, to serve as the exclusive provider of case managment services in each geographic catchment area of the state.

Experience in the field of mental health and developmental disabilities demonstrates that services can be developed and used most efficiently, effectively and economically where they are coordinated by a single case management agency that is able to assure access to other services required by individuals with such disabling conditions. The case management agency is generally responsible for assuring that eligible persons with severe disabilities receive the various services they require, by coordinating the preparation and implementation of their individual habilitation/treatment plans. In the absence of an agency that can perform these critical functions, case management becomes little more than an information and referral service, and the individual in need of service has no assurance that he or she can gain access to needed programs.

As an illustration, approximately twenty years ago the Lanterman Act **in** California divided the state into 21 service areas and mandated that a non-profit regional center be designated to serve as the hub of each area. The statutory responsibilities of these regional centers are to provide intake, diagnostic/evaluation and case management services to persons with developmental disabilities and purchase, from qualified vendor agencies, any daytime, residential and support services such individuals may require.

The relevant **language of the** Social Security **Act** (Section **1915(g)(l)) reads as** follows: "The provision of case **management services under this** subsection shall not **restrict the choice of the** individual **to** receive medical **assistance in violation of Section** 1902(**a**)(23) . " **We** think **the statute should make it clear that -- at least in the case of services to persons with developmental disabilities or chronic mental illness — (a) the state may not lock a recipient into a particular case manager, but can limit the number and types of agencies that are eligible to provide case management services (e.g., a state or county agency); and (b) the case manager must permit the individual recipient a choice among available medical assistance services that meet his or her needs. We have no specific language to propose, but would be quite willing to work with you on drafting a narrowly worded exception that would deal with our concerns, while, at the**

same time, placing minimal restrictions on the recipient's choice among qualified service providers.

Effective Date of the COBRA Definition of Habilitation Services. In 1985, Representative Waxman, with your able assistance, sponsored an amendment to permit states to claim Medicaid-reimbursement for prevocational, educational and supported employment services on behalf of persons who are developmentally disabled and participants in an approved home and community care waiver program, providing such habilitation services were not otherwise available through state/local educational or vocational rehabilitation agencies. Title XIX-payments for these new elements of habilitation services could be claimed only on behalf of waiver recipients who previously resided in **a** Medicaid-certified hospital, skilled nursing or inter-mediate care facility (including an ICF/MR). As you know, this amendment eventually became Section 9502(a) of COBRA.

Although regulations implementing this provision of COBRA have not yet been issued, HCFA officials have informed states which have requested authority to cover prevoca-tional, educational and/or supported employment services under their waiver programs that the new definition of habilitation services applies only to those recipients deinstitutionalized after the effective date of the legislation (April 7, 1986). This interpretation would deny states the authority to claim reimbursement for such services on behalf of approximately 80 to 90 percent of all formerly institutionalized clients who are currently participating in HCB waiver programs, since they were enrolled in the program **prior to April** 7 **of last** year. According to LaJolla data, approximately one-third of **all waiver** participants (31.9%), **as** of September 30, 1985, **resided in an** ICF/MR **or another institutional setting immediately prior to entering the waiver program. Since approximately** 22,000 **persons with mental retardation or other developmental disabilities were participating in waiver programs as of that date, we estimate that roughly 7200 persons who otherwise would be eligible to receive either pre-vocational, educational or supported employment services would be denied them under HCFA's interpretation.**

There is nothing in the legislative history of Section 9502(a) that we are aware of which supports HCFA's reading of the law. Clearly Congress did not wish to allow the states to claim retroactive reimbursement and, therefore, set the date of enactment as the effective date of this provision. However, there is no indication that Congress intended the broader definition of habilitation services

to apply only to persons exiting Medicaid-certified institutions after April 7, 1986.

Under the circumstances, we would urge the Subcommittee to consider a technical amendment to Section 9502(j)(l) **of** COBRA which makes it clear that a state may claim reimbursement for pre-vocational, educational and supported employment services rendered to eligible waiver participants who were deinstitutionalized into the waiver program prior to the effective date of Section 1902(a); however, they may not claim reimbursement for any such services furnished prior to April 7, 1986.

We wish to stress that this change will not increase the federal cost of the waiver program, since the affected recipients will receive other forms of day habilitation services (usually of a non-vocational nature) that will cost as much or more. Indeed, the estimates supplied to HCFA by several states which thus far have requested authority to use the broader definition of habilitation services indicate that there are likely to be some savings associated with moving clients from non-vocational to vocationally-oriented services over a period of several years .

4. ICF/MR Reduction/Correction Plans Under COBRA. Section 9516 of COBRA grants any states the option of reducing the population of an intermediate care facility for the mentally retarded over **a** period of up to 36 months when it has been found out of compliance with federal standards as **a** result of **a** HCFA look behind survey. In order to qualify for this provision, the facility must have deficiencies which **do** not pose an immediate threat to the health and safety **of** its residents. Although Congress **included** language **in Section** 9516 requiring **the Administration to issue proposed** regulations implementing **Section 9516 within 60 days, the law contains no requirement governing the publication of final regulations.**

To date HCFA has not issued final implementing regulations. The lack of regulations is compounded by the fact that HCFA interprets the language of Section 9516 to means that the reduction plan option will only be available to facilities which receive their list of deficiencies on or after the effective date of final rules. In defense of Che agency's position, HCFA officials point out that Congress directed HHS/HCFA to promulgate regulations and, therefore, must have intended that the implementation of Section 9516 be delayed until such regulations are issued. Furthermore, they note that Section 1919(f) of the Act

only permits the Secretary to approve reduction plans for a period of three years following the effective date of final regulations.

This interpretation of statutory intent, however, ignores the explicit language of Section 1919(b)(l) of the Act, which specifies that the applicable provisions "shall become effective on the date of ...enactment" (i.e., April 7, 1986). It seems obvious that had Congress intended to set a prospective effective date, it would have so specified in Section 1919(b)(l). In addition, if the law required the Department to make administrative judgments that were crucial to the effective implementation of this statutory provision, HCFA's position might be more defensible. But as the agency's proposed regulations illustrate, the provisions of Section 9516 are highly prescriptive and do not leave much room for administrative interpretation.

We urge the Subcommittee to include among its technical amendments language which makes it clear that HCFA must accept reduction plans from facilities that meet the criteria of the Act and were officially notified of their deficiencies by HCFA on or after April 7, 1986.

In addition to the technical amendments outlined above, we believe there are two further, short term steps Congress could take to ensure greater equity in the delivery of Medicaid-reimbursement services to persons with developmental disabilities. These changes would involve substantive revisions in federal law that would have little, if any, budgetary impact.

1. Reconsideration of the Scope of the COBRA Habilitation Definition. In the long run, we believe the only equitable **means of resolving the question of reimbursable habilitation services versus non-reimbursable vocational training is for Congress to enact a consistent definition of habilitation services that is applicable to all Medicaid-funded services to persons who are developmentally disabled (whether they receive services through HCB waiver programs, ICF/MRs, or other available service options). Of course, we feel very strongly that such a definition should permit states to furnish pre-vocational and vocational training services to those severely disabled persons who need ongoing social supports, despite the fact that they are capable of some level of gainful employment. With rare exceptions, these clients generally do not qualify for vocational rehabilitation services and, thus, all too often, are relegated to a life of continued dependence. Again, we would emphasize that, for clients**

who otherwise qualify for Title XIX-reimburseable services, the provision of prevocational or vocational training would not result in higher costs to the Medicaid program. We are prepared to provide you with data to support this statement.

2. The Differentiation Between Habilitation and Educationally-Related Services. HCFA's existing policies distinguishing between reimbursable habilitation services and non-reimbursable educational services have the effect of denying school-aged handicapped children access to Medicaid-reimbursable services that they otherwise would be entitled to receive. Under HCFA's guidelines, "all services described in the [child's] IEP [individualized education program] are excluded from FFP [under Medicaid], whether provided by state employees, by staff of the ICF/MR or by others". Furthermore, the guidelines go on to state that any education and related services which are required to be provided under federal and state laws but are not specified in the child's IEP, nonetheless, do not qualify for Medicaid reimbursement (Section 4396, State Medicaid Manual).

HCFA's administrative policy on this matter contradicts the intent of Congress in enacting the 1986 amendments to the Education of the Handicapped Act (P.L. 99-457). One provision of P.L. 99-457 specifies that nothing in the Act should be "...construed to permit a state to reduce medical or other assistance available or to alter eligibility under Title V and Title XIX of the Social Security Act **with respect to the** provision of **a** free appropriate public education for handicapped children within **a** state..." **(Section** 613(e) **of the** Education **of** the Handicapped Act, **as amended).**

One method of solving the current problem would be to add language to Title XIX authorizing states to claim reimbursement for "educationally-related services" (but not educational services) that are: (a) required by a severely disabled child of school-age who meets the eligibility criteria for receipt of Medicaid services; (b) covered under the state's medical assistance plan; and (c) required by the subject child in order to receive a free appropriate public education as specified under the Education of the Handicapped Act. Such a provision would make it clear that the states could not claim reimbursement for educational services, but could treat as a reimbursable cost any service available under the state's Medicaid plan to a child who, except for the fact that he or she is enrolled in a special education program, would

be eligible to receive such services. Thus, for example, a state would be entitled to claim physical therapy services on behalf of a Medicaid-eligible handicapped child who is enrolled in a public school program if such services were reimbursable under the state's Medicaid plan and were consistent with service needs specified in the child's individualized plan. This approach would prevent HCFA from denying services to otherwise eligible Medicaid recipients.

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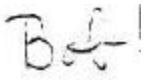
Should you have any questions concerning the suggestions outlined above, or should you require further supportive information or documentation, please call Bob Gettings at 683-4202. Thank you in advance for your consideration of these suggestions.

Sincerely,



Robert M. Gettings

On behalf of

American Association of Mental Deficiency American Speech/Language/Hearing Association Association for the Education of Rehabilitation Facility Personnel
Association for Retarded Children/U.S. Mental Health Law Project
National Association of Private Residential Facilities for the Mentally Retarded
National Association of Protection and Advocacy Systems
National Association of Rehabilitation Professionals **in the Private Sector National Association of State Mental Retardation Program Directors**
National Council on Rehabilitation Education
National Easter Seal Society National Head Injury Foundation National Mental Health Association National Rehabilitation Association United Cerebral Palsy Association