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Minutes

Ad Hoc Discussion Group on Medicaid Legislation

November 3, 1986

Participants

Susan Ames-Zierman, National Association of Developmental Disabilities Councils
Allan Bergman, United Cerebral Palsy Associations Marty Ford, Association for Retarded Citizens, U.S. Bob Gettings, National Association of State Mental Retardation Program Directors Patty Green Roth, National Association of Protection and Advocacy Systems Ruth Katz, National Association of State Mental Retardation Program Directors Paul Marchand", Association for Retarded Citizens, U.S. Tom Nerney, The Association for Children and Adults with Severe Handicaps

The second meeting of the Ad Hoc Discussion Group on Medicaid Legislation came to order at 1:10 p.m. on November 3, 1986.

Review of the Minutes

Participants were asked to review the minutes of the October 29 meeting and provide feedback. In general, everyone agreed that the minutes accurately summarized the group's discussion. One minor change was made in the second sentence of paragraph two on page four of the minutes. The revised sentence should read "...Those in favor of mandatory case management services expressed the belief that a statutory mandate is a necessary pre-condition to assuring the provision of quality services" (change underlined).

Regarding the involvement of other groups in the activities at the Ad Hoc Group, it was decided to discuss this issue at a future meeting. Two alternatives were suggested: (a) brief interest groups on the status of the Ad Hoc Group's deliberations at an open meeting of the CCDO Task Force on Medicaid; and/or (b) share copies of the meeting minutes with other interested groups.

Political Strategies

Next, participants turned their attention to possible political strategies for seeking strong bipartisan support for any reform proposal emerging from the group's discussions. ARC/US representatives told the group that, based on instructions from its Governmental Affairs Committee, they would be meeting with

Christy Ferguson on Tuesday, November 4 to discuss Senator Chafee's plans for introducing a revised Medicaid reform bill next year. They also hoped to determine if Senator Chafee planned to work with Senator Weicker in drafting a compromise bill that might incorporate features of both the "Community and Family Living Amendments" (S. 873) and the "Quality Services for Disabled Individuals Act" (S. 1948).

Since Senator Chafee's staff reportedly is in the process of drafting a revised version of CFLA for introduction next year, several participants noted the urgency of completing a set of specifications for reform legislation just as soon as possible, in order to: (a) impact on the Chafee drafting process; and (b) involve other Finance Committee members in the process, so the eventual bill will not be perceived to be exclusively a "Chafee initiative".

The group also decided to await the outcome of Tuesday's election before finalizing the list of senators who should be the target of an inter-organizational lobbying initiative, aimed at enacting long term care reform legislation. Depending on whether the Democrats or the Republicans control the Senate, it was noted, the list of "target" senators might change.

The group then turned its attention to a discussion of "state infrastructure" and related state plan requirements within a piece of Medicaid reform legislation. The discussion generally followed Allan Bergman's outline, entitled "Proposed Items for 'Infrastructure' and 'Capacity Building' in State Plan Development" (Attachment A). The points that were discussed are summarized below.

I. Client Coordination

Everyone concurred that it would be necessary to define "case management" before the concept could be operational - ized in federal law. Furthermore, it was agreed that two distinct but interrelated types of case management, or client coordination, are essential: (a) individual case coordination; and (b) systems level coordination. The former type of coordination is necessary within each major service program or facility; it involves the day-to-day tracking of the delivery of services to the client in accordance with his or her IHP, as well as making necessary adjustments in the client's service plan to accommodate any changes in his/her needs over time. By contrast, systems level coordination is essential to assure that: (a) the client receives all of the appropriate services he or she needs, delivered in the proper sequence, intensities and quality; and (b) the activities of two or more agencies serving the same client are properly dovetailed.

Participants agreed that ACMRDD accreditation standards should be examined in an effort to distinguish between these two types of client coordination, both in terms of nomenclature and differential functional responsibilities. [N.B., ACMRDD standards define only one level of case management -- individual program coordination -- and specify that each service agency must designate a staff member responsible for carrying-out this function on behalf of each of its clients (see Attachment B).]

Everyone present agreed that an employee of an agency responsible for the direct provision of day and residential services to the subject client cannot effectively act as a systems level coordinator, due to the potential for conflict of interest. Because of the vast differences in state service systems and the lack of objective comparisons between different administrative models, most of the participants agreed that it would be impractical to mandate, in federal law, the adoption of a specific type of client coordination system. Instead, it was agreed that the statute should spell out (under the state plan requirements) certain basic principles that a state must follow in designing a case management system, while allowing each participating state to determine the best way of organizing a system that adheres to such statutory principles. The group also agreed to use the term "client service coordination", rather than "case management", due to the negative connotations of the latter term.

II. Staff Training and Development

Everyone agreed that a state should be required to describe in its state plan the policies and procedures it will adopt to assure that:

- all personnel delivering services supported in whole or in part with funds appropriated under this legislation have received pre-service education and/or training appropriate to the nature of their duties;
- Every agency providing Medicaid reimbursable services under this legislation will maintain written personnel policies that comply with the provisions of relevant state laws and regulations;
- in-service training and continuing education services are furnished to the staff of agencies providing Medicaid-reimbursable services to developmentally disabled persons.

The group also agreed that the Secretary should be responsible for developing and field testing competency-based

standards for use in hiring service agency staff and assessing staff performance. Given the present state-of-the-art in this area, however, a majority of those present were reluctant to mandate, in federal law, that states adopt and utilize such competency-based standards. It was also agreed that the cost of pre-service orientation, in-service training and continuing education should be considered reimbursable administrative costs under a state Medical Assistance plan.

III. Statewide Capacity Building

There was a consensus among the participants that the states should be required to spell out in their state plans the steps that will be taken to assure that providers (and potential providers) have access to needed technical assistance and expertise in designing and implementing new and expanded community-based programs. In this regard, states would be expected to specify the methods and procedures that will be used to make such capacity building resources available.

IV. Statewide Crisis Intervention and Individualized Support Services

All participants agreed that states should be required to spell out, in their state plans, the methods that will be used to assure that crisis intervention services are available, in order to prevent the need to relocate clients with special behavioral, sensory, physical or medical problems to more restrictive living environments. The expectation is that such services normally would be provided at the client's regular place of residence or program site, not in isolated or segregated settings; furthermore, the aim of such services would be to help the family, surrogate family or the local provider agency acquire the skills necessary to successfully serve the particular client, rather than separating him/her from an environment where he/she otherwise would enjoy greater opportunities for independence and/or community integration.

Using the example of clients with severe behavior problems, one group member noted that several states have set up or are establishing segregated programs to remove such clients from their regular program or living environment. After they have been removed and, ostensibly, retrained, staff in the regular program don't want them back. It was noted that this problem also applies to other low incidence problems (e.g., serving deaf-blind-retarded individuals).

V. Quality Assurance

Everyone concurred that quality assurance is a major topic that will have to be discussed separately at a future meeting.

VI. Protective Services

All participants agreed that states should be required to specify in their state plans the methods and procedures to be used in assuring that all children and adults have access to protective services. The agency or agencies providing protective services should meet the following minimum criteria:

- it should have access to any service program or facility, as well as all relevant records on a client, 24 hours a day;
- it should have standing in court to take legal action against a facility or program;

it should be independent of any agency responsible for delivering or overseeing the delivery of direct services to such clients; and

- it should have the legal capacity to intervene on behalf of both disabled children and adults.

A state may elect to have an existing agency carry out protective service functions (e.g., a P & A agency or a child welfare agency). But, if it does so, it must assure that the agency fully meets the above criteria.

VII. Institutional Depopulation and the Development of Community Alternatives

After considerable discussion, the group agreed that a state should be obligated to include in its state plan a detailed multi-year strategy for developing community-based services (including a full array of day, residential and support services). This key aspect of the state plan should contain, at a minimum:

- a selection policy and criteria that assures all eligible or potentially eligible DD individuals equal access to community-based services, regardless of their current place of residence or the nature/severity of their handicapping conditions;
- a specific component that spells out the steps the state will take to assure that the current aggregate population of larger Medicaid-certified resi-

dential facilities (i.e., with 16 beds or more) will be reduced by no less than 50 percent within a period not to exceed ten (10) years from the date of approval of the state plan. [N.B., The assumption of the group was that ten years would be an outside limit, but many states would elect to move more rapidly in order to free up additional resources for community-based services.]

- a specific component that outlines the steps the state will take, over the ten-year period, to assure the expanded availability of services to qualified recipients who are living with their natural or adoptive families or in other non-Medicaid-certified facilities.
- a multi-year plan for systematically increasing the proportion of total federal, state and local dollars obligated for community-based vs. institutional services, as the state implements the deinstitutionalization and community expansion components of its plan [N.B., Under the proposed arrangement each state, over the ten-year period, would act as its own "control group"; thus a state with a 70:30 institutional-to-community expenditure ratio would not be obligated to achieve the same ratio, at the end of the ten-year period, as a state which started with a 30:70 ratio.]

The participants also agreed that states would be obligated to set new deinstitutionalization goals after the original ten-year period ended. However, rather than attempting to specify those goals in the legislation, the Secretary of Health and Human Services would be required to study the impact of serving developmentally disabled persons in alternative residential and day program settings and report his findings to Congress. It is anticipated that this report, which would be due, in final form, eight years after the enactment of the original legislation, would form the basis for setting new "communitization" goals in subsequent amendments to the statute.

Some of the participants felt that statutory treatment of deinstitutionalization after the first ten years deserves further discussion. Therefore, it was agreed that the group would return to this topic at a future meeting.

VIII. Incentives and Fiscal Impact

The group agreed that it would be desirable to give states incentives to develop certain types of community-based services, especially in-home support and training services for

families caring for severely disabled persons at home and non-facility-based residential services. However, no generally acceptable suggestions for accomplishing this end were offered. The idea of a higher, differential matching ratio was mentioned again, but it was pointed out that: (a) if states were permitted to claim reimbursement for services not previously eligible for Medicaid cost sharing, the increased cost of the program to the federal government would be prohibitive (probably killing chances for enactment of the legislation); (b) but, if states were only allowed to claim reimbursement for services initiated after the enactment date of the legislation, those jurisdictions with a substantial investment of state general revenue dollars in such programs would be treated unfairly.

One member of the group pointed out that this dilemma, not only applied to the use of differential matching ratios, but strikes at the very core of the problem of designing basic reform legislation. As long as benefits remain an open-ended entitlement (a basic assumption accepted at the group's initial meeting), when service eligibility and coverage are expanded (as also agreed to at the first meeting) you face a choice between a rapid escalation in the federal cost of the program or locking in the interstate inequities associated with the existing maldistribution of federal Medicaid receipts.

The group agreed that this issue requires further discussion and would be raised again at a future meeting.

* * * * *

There was a consensus that the agenda for the next meeting would proceed as follows :

- quality assurance [N.B., Bob Gettings distributed copies of a paper on this subject he had prepared for discussions with Representative Waxman's staff on nursing home reform legislation; Allan Bergman indicated that he had sent copies of two relevant papers to all members of the group, by mail.]
- state and federal administration
- living arrangements
- other planning considerations
- interstate equity
- employee protection

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The next meeting is scheduled for Monday, November 10 at 1:00 p.m. in the ARC/US's conference room.

ATTACHMENT A

Proposed Items for "Infrastructure"
and "Capacity Building" in State
Plan Development

ATTACHMENT A

PROPOSED ITEMS FOR "INFRASTRUCTURE" AND
"CAPACITY BUILDING" IN STATE PLAN DEVELOPMENT

1. Statewide Independent Service Coordination (case management)
2. Statewide Staff Training and Development
 - A. Competency Based Staff Certification
 - B. Minimal Requirements for Employment
3. Statewide Technical Assistance
 - A. For New Service Development
 - B. For Program Conversion
4. Statewide Crisis Intervention Team(s):

To be Deployed to Place Where Inappropriate Behavior Exhibited
5. Quality Control Mechanisms:
 - A. Independent
 - B. Accessible by Public
6. Statewide Adult Protective Services
7. An Institutional Depopulation Plan Which Emphasizes Individuals with the Most Complex Needs Relocating to Community Services First.
8. IHP/IPP
 - A. To Focus on Practical Life Skills to Reduce Dependency on Paid Staff
 - B. Dollars Follow Person Based on Need
9. Due Process/Procedural Safeguards

ATTACHMENT B

ACMRDD Standards

Section 1.5, Individual Program Coordination

1.5 Individual Program Coordination

Definition

Individual program coordination is the process by which responsibility for implementation of the individual's program plan is established. The process includes providing support, obtaining direct services, coordinating services, collecting and disseminating data and information, and monitoring the progress of the individual.

Principles

Each agency providing services to an individual should assign a person to coordinate the agency's activities in implementing the individual's program plan. This person should be responsible for implementing the agency's role in the individual program plan and for assuring that all relevant staff, as well as the individual and, when appropriate, the individual's family, focus their efforts on attaining the objectives specified in the plan. The individual program coordination process should be terminated only when services to the individual have been terminated.

When two or more agencies provide services to an individual, an agency should be designated to be responsible for coordinating the individual's overall program plan.

Standards pertaining to all agencies

- ___ 1.5.1* Each individual served by the agency is assigned a person who is responsible for coordinating the agency's activities in implementing the individual's program plan.
 - ___ 1.5.1.1* The person responsible for coordinating the individual's program is identified to the individual, the individual's family, and the appropriate staff members.
 - ___ 1.5.1.2 The agency's written procedures provide for opportunities for the individual or the individual's family to request a change of the person responsible for coordinating the individual's program.
 - ___ 1.5.1.2.1 Procedures for requesting change of the person responsible for coordinating the individual's program are made known to all parties concerned.
- 1.5.2 The person responsible for coordinating the individual's program:
 - ___ 1.5.2.1* attends to the total spectrum of the individual's needs, including but not necessarily limited to, housing, family relationships, social activities, education, finance, employment, health (including special health needs), recreation, mobility, protective services, and records;
 - ___ 1.5.2.2* locates, obtains, and coordinates services outside and inside the agency, as needed by the individual;

- 1.5.2.3 secures relevant data from other agencies providing service, to keep the individual program plan up to date;
 - 1.5.2.4 provides documentation concerning coordination of the individual program plan;
 - .1.5.2.5* monitors the operation of the services that are provided the individual in accordance with the individual program plan;
 - .1.5.2.6* intervenes when necessary to assure implementation of the plan;
 - |__1.5.2.7 requests, when necessary, review of the individual program plan by the individual's interdisciplinary team; and
 - |_ 1.5.2.8 facilitates the transfer of the individual to another service or agency,
 - 1 | when such transfer is appropriate to meet the individual's needs.
- .5.3" When two or more agencies provide services to an individual, an agency is designated to be responsible for coordinating the individual's overall individual program plan.

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Elizabeth Boggs, Association for Retarded Citizens, U.S.
Bob Gettings, National Association of State Mental Retardation
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McWhorter, The Association for Children and Adults with
Severe Handicaps Tom Nerney, The Association for Children and
Adults with Severe
Handicaps

The third meeting of the Ad Hoc Discussion Group on Medicaid Reform Legislation came to order to 1:15 p.m. on November 10, 1986.

Review of the Minutes

Participants were asked to offer comments, additions or deletions to the minutes of the November 3 meeting of the Ad Hoc Discussion Group. One representative of TASH requested that the minutes reflect the fact that TASH does not support lowering the age cutoff for the onset of a disability from 35 to 22 years. Another participant asked that the term "individual service coordination" be used instead of "client coordination". She also asked that the discussion of case management be reopened.

Group members agreed that, in addition to preparing minutes of the meeting, it would be useful to begin to develop a consolidated list of legislative specifications thus far agreed to by the group. Such a list, it was pointed out, should help to keep the group on task, by allowing members to identify gaps and inconsistencies in the emerging proposal.

Summary of ARC/US Meeting with Christy Ferguson

ARC/US officials met with Christy Ferguson on November 5, 1986 to discuss Senator Chafee's plans for introducing a revised Medicaid reform bill next year. Ms. Ferguson said that Senator Lloyd Bentsen (D-TX) would probably be the next chairman of the Senate Finance Committee. She added that his key staff member on health legislation has indicated that the Senator potentially could support Medicaid reform legislation if it were "cost neutral" and if states (e.g., Texas) were given the option to move slowly.

There was substantial discussion regarding the impact Ms. Ferguson had received from Don Muse, a CBO budget analyst, with respect to the fiscal impact of assumptions related to DD Medicaid reform legislation. Muse assumes that if the goal of community-based services is to transition eligible recipients to employment, the legislation would be cost neutral. Non-vocationally-related services, however, would increase federal costs and, therefore, presumably would make it more difficult (if not impossible) to get such a bill through Congress.

Ms. Ferguson also told the ARC/US representatives that no mandatory phase down provision would be included in Chafee's new bill. Several issues that are still under discussion, she noted, are:

- the inclusion or exclusion of the otherwise eligible individuals with mental illness;
- the inclusion or exclusion of individuals disabled after the age of 22;
- whether services should be treated as optional, mandatory or some mix thereof;
- whether there should be a cap on the number of eligible recipients or bed capacity;
- how quality of care should be monitored/enforced under the revised program;
- whether the bill should include any service guarantees; and whether differential matching should be authorized for certain preferred services;

Ms. Ferguson told the ARC/US representatives that the revised bill would be based on the following assumptions:

- states would not be required to reduce current institutional expenditures;
- the states that opt to develop community services would probably do so without a legislative mandate to down-size large facilities;
- federal law should not be biased against serving people who already reside in the community.

She indicated that the assumptions and issues under discussion were based on her meetings with Don Muse of CBO and Chris Button of the Senate Subcommittee on the Handicapped. She said she

planned to assemble a "working group" of Senate staffers to discuss these issues and develop a bill; the group would consist of representatives from the offices of Senators Dole, Bentsen, Baucus, Bradley and possibly, Heinz. Finally, Ms. Ferguson stated her expectation that a draft bill would be completed by the end of November. She said she hoped to meet with Ad Hoc Group members individually and collectively over the next month or so to obtain their input.

Everyone agreed that Ms. Ferguson should be briefed on the agreements reached by the Ad Hoc Group sometime after the November 19 meeting, but that it would also be appropriate for the group to contact staffers from the offices of other key senators.

Interorganizational Lobbying Initiative.

Allan Bergman -distributed copies of the revised memo to the states regarding the joint lobbying initiative on Medicaid long term care reform. It was decided that Senators Bentsen, Baucus (D-MT) and Dole (R-KS) should be added the list to be contacted bringing the total number of target states to nine. Each national group (ARC/US, UCPA, NADDC, NASMRPD, NAPAS and TASH) will receive nine copies of the memo. A cover memo may be added, then each organization will send a copy of the memo to its member or representative in each of the nine states.

Next, the participants turned their attention to the substance of the meeting -- Medicaid reform legislation.

Case Management.

One participant, who had not been present for the November 3 meeting, noted that: (a) one staff member (i.e., a case manager) should not be responsible for changing a client's IHP; instead, this should be a team function; and, (b) it needs to be clear that the interprogram case coordinator is working on behalf of the assigned disabled individual and not on behalf of the "service system". She offered to draft language which clearly delineates intra-agency coordination and interagency case coordination.

Next, there was a brief discussion of whether the duties of the individual service coordinator should be specified in legislation. There were two schools of thought. Some participants felt that such duties should be specifically delineated in legislation or the Secretary should be charged with issuing regulations specifying the coordinator's duties, minimum client-to-coordinator V_ ratios, etc. Others suggested that there should be a state plan requirement which obligates the state to specify the structure and operation of its individual service coordination system, including mandated ratios, duties, etc.

Quality Assurance.

The participants agreed, after considerable discussion, that responsibility for establishing and enforcing program standards should be shared by the federal and state governments. The federal government should continue to play a major role in setting and overseeing the enforcement of standards applicable to Medicaid-certified long term care facilities serving developmentally disabled recipients, while the states should have primary responsibility for establishing and monitoring compliance with community service standards. More specifically:

- HHS should retain its existing statutory authority to promulgate and monitor compliance with ICF/MR standards, including conducting federal validation, or "look behind" surveys. [N.B., However, the states would be authorized to reclassify community ICF/MR facilities as vendors of other types of Medicaid-reimbursable services and, thus, subject to state community services regulations.]
- A state agency (or agencies) designated by the Governor (as part of a special supplement to the state Medicaid plan) should be responsible for establishing and enforcing standards governing various categories of community day, residential and support services. Such standards, as well as procedures for monitoring compliance and assuring enforcement, should be subject to review and approval by HHS as part of the state plan review process.
- The legislation should specify the essential elements that must be included in state standards governing various types of community services funded under this authority. [N.B., The states would be free to develop their own regulatory standards, but, at a minimum, they would have to cover certain essential areas specified in the legislation.]
- The legislation should require the Secretary of Health and Human Services to complete periodic assessments of the adequacy of licensing, monitoring, enforcement and other quality assurance functions in each participating state;

There was only limited discussion of the statutory parameters of acceptable community service standards and no conclusions were reached. In addition, it was pointed out that a decision would have to be made with regard to the criteria HHS would use in assessing the adequacy of state quality assurance practices. If the Secretary were to apply the state's own standards in judging

the adequacy of programs, federal survey teams would face the unwieldy task of judging compliance with 50 separate sets of standards. If, on the other hand, separate federal criteria were to be mandated, they might conflict with existing state requirements and become, de facto, separate federal standards. Either way substantial problems could occur.

State and Federal Administration

The conversation began with a statement from one member that there should be a logical "home" within the Department of Health and Human Services for Medicaid LTC services furnished to developmentally disabled recipients. Another individual added that it ought to be a discrete administrative unit within the Health Care Financing Administration. Everyone agreed.

Regarding state administration, there was agreement that each participating state should have the flexibility to delegate specific functions to the most appropriate state agency, without violating the principle of a single state agency. It was noted that states have considerable flexibility under existing law to manage their Medicaid programs in the way they see fit. The purpose of the new legislation would simply be to make these alternatives more explicit and, thus, encourage states to seek streamlined, interagency methods of managing Medicaid services on behalf of developmentally disabled recipients.

Living Arrangements.

Three subareas under the topic "living arrangements" were discussed: size, distance between facilities and grandfathering of certain existing facilities that exceed the specified size standard.

Any facility with sixteen or more clients, it was agreed, would be considered "large" for purposes of the mandatory phase down provision (see discussion in the 11/3 meeting minutes).

Most of the participants agreed that the existing definition of a "community living facility", which appears in CFLA (S. 873), -- including the limitation on size (i.e., three times the average household size in the area) -- should be included in the new legislation. The arguments in favor of this approach were that (a) an upper limit is necessary to prevent the establishment of larger, non-normalizing community residences; and (b) this provision of S. 873 had not attracted much criticism in the past. The counter argument was that: (a) a source of opposition to legislation could be side-stepped by not defining the term in legislation since the states would be required to slice the population in most larger facilities (i.e., those with 16 or more beds) anyway; and (b) there was little support for establishing

large (9-15 bed) group homes at the present time, even without federal definition specifying size limitation.

It was agreed by all the participants that existing community residences with 15 or fewer beds should be grandfathered into the program as community living facilities (and, thus, not subject to the mandatory phase down provision). In addition, a majority of the participants agreed that cluster facilities with a total of 24 or fewer beds (i.e., the Florida model) should be grandfathered into the definition of a community living facility.

Fiscal Incentives .

One person expressed a preference for some type of statutory formula which would equalize the ratio of community to institutional expenditures across the states. Such a formula, it was suggested, might address relative state fiscal effort and relative numbers of individuals residing in large facilities, relative per capital income and population. A table ranking the states according to ratios of institutional-to-community spending (Attachment A) was distributed. It was suggested that it would be necessary to penalize states with high per capita ratios of institutionalized persons by gradually reducing their federal matching rates for institutional services. Some agreed with this strategy, others disagreed. Elizabeth Boggs said she would attempt to develop some formulas to address these problems.

* * * * *

The Ad Hoc Group will meet again on Wednesday, November 19, 1986 at 9:00 a.m. at the ARC/U.S. The group will begin by reviewing and modifying, as necessary, the summary of its previous decisions. Then the participants will develop a list of other issues that need to be discussed and proceed from there.

Table 3

FY 1936 Ratios		Institutional Spending	t Total Community	
Spending--Ranked		By State		
Rank	State		I/C"	
1	Michigan		C	.4
2*	Maine	0		.4
3*	Nebraska		C	.4
4*	Florida		C	.4
5*	Minnesota		C	.5
6*	Alaska		C	.5
7*	Ohio		C	.5
8*	New Hampshire	0		.5
9*	Rhode Island		C	.6
10*	California		C	.6
11*	District of Columbia		C	.6
12	Vermont	0		.7
13*	Colorado	0		.7
14*	Pennsylvania	(1.75
15*	Montana	0		1.78
16*	Wisconsin	0		1.85
17*	Kentucky		C	1.85
18*	Indiana	0		1.87
19*	Arizona	0		1.89
20*	Illinois			.0
21*	Idaho			.04
22*	Missouri			.0
23*	Louisiana			.0
24	Utah			.0
25*	Maryland			.0
26*	New York			.1
27*	Iowa			.1
28*	South Dakota			.2
29*	North Dakota			.2
30	Washington			.3
31*	Georgia			.3
32*	Nevada			.4
33	Oregon			.4
34	New Mexico			.4
35	Oklahoma			.5
36	Massachusetts			.5
37	Delaware			.5
38	New Jersey			.6
39*	Wyoming			.7
40*	Connecticut			.7
41	West Virginia			.7
42	Kansas			.8
43*	Texas			.9
44	Hawaii	2		2.08
45*	North Carolina			2.36
46*	Virginia			2.73
47*	Tennessee			2.76
48	South Carolina			2.98
49	Mississippi			3.07
50*	Alabama			1.19
51	Arkansas	<		1.29

*Respondents in this study.

"Represents the total institutional spending of a state divided by that state's total community spending. For example, if a state has 20 institutional dollars and 10 community dollars, its ratio would be 20/10 or 2.00. Community includes SSI State Supplement.

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Celane McWhorter, The Association for the Severely Handicapped Paul Marchand, Association for Retarded Citizens/U.S. Tom Nerney, The Association for Children and Adults with Severe Handicaps Fran Smith, United Cerebral Palsy Associations

The fourth meeting of the Ad Hoc Discussion Group on Medicaid Legislation came to order at 9:30 on Wednesday, November 19, 1986.

Review of the Minutes

Participants were asked to review the minutes of the November 10 meeting and provide feedback. One individual referred to page three of the November 10 minutes, under the heading of "case management"; she clarified her earlier comments, noting that the minutes should reflect the fact that the service coordinator should not be an employee of a provider of direct services.,

Another group member suggested that since Senator Chafee's staff member had met with at least two staff members of the Senate Subcommittee on the Handicapped, it would be better to so indicate, rather than naming one particular member of the Subcommittee's staff.

The group agreed that the minutes would not be disseminated publicly, but, at the discretion of the participants, could be used to keep key leaders of the respective organizations informed about the group's deliberations.

Finally, an individual who was not present on November 10 requested that page six of the November 3 minutes be amended to

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indicate that some group members felt that a fifty percent phase-down of institutional beds should be mandated over a ten -year period; others disagreed with this goal because they believed: (a) that a more rapid phase-down should be mandated; and (b) that the legislation should spell out a process for totally eliminating institutional beds.

Next, the group agreed to review the -table accompanying the November 11 minutes, which summarized the group's agreements to date: ("Tentative Specifications for Developmental Disabilities Medicaid Reform Legislation"). Members were reminded that the goal was to develop specifications for reform legislation, not actual bill language. Some felt there should be a further discussion of general strategy, including the information that should be communicated to delegations from particular states that had been asked to meet with their senators. The group agreed to reserve time for such a discussion during the afternoon session.

Eligibility.

he group's earlier decisions were briefly summarized and it was noted that a general consensus had been achieved concerning eligibility issues. It was agreed that the second organizing principle should be restated to make it clear that eligibility should be based on individual needs rather than on the recipient's presumed level of care or current place of residence, as currently required under the HCB waiver program.

In addition, the fourth organizing principle also should be revised to place the emphasis on removing financial hardships to families caring for severely disabled children at home as compared to placing them in out-of-home care facilities.

Services

First it was noted that the services section of the table had some errors in arrangement that would have to be corrected in a subsequent draft. The earlier discussions of the group were briefly summarized as follows: (a) the group agreed that the statutory definition of reimbursable services should be broad and explicit, but no consensus was reached on particular services that should be included/excluded; (b) participants agreed that it would not be advisable to give the Secretary broad discretion to deny states the right to cover specific services; and, therefore, the statutory definition should be explicit; (c) protective intervention should be a mandatory service, but no final agreement was reached on whether individual service coordination (case management) services should be mandated; and (d) DD recipients should retain their eligibility to health care and related coverage under Medicaid, but there was no agreement as to the specifics.

It was agreed that the "key provisions" language should make it clear that long term care services should be "available to the extent specified in the state plan". In addition, the term "individual and family support services" should be changed to "individual support services" and "family support services (including respite care)"; "Assistive devices" also was added as a defined service. The modifier "ongoing" was placed before "supported employment", and the phrase "and other services approved by the Secretary" was placed at the end of the list of covered services in the "key provision" column.

Everyone present agreed that individual services coordination should be mandated and defined. In addition, under the state plan of the legislation, each client should be required to have an IHP, developed by an interdisciplinary team and monitored by an individual service coordinator.

The fact that room and board were not considered reimbursable services in earlier proposals was confusing to several group members. Therefore, the third "organizing principle" was amended to read:

(" Because room and board is paid for by other sources, it should not be considered a Medicaid reimbursable LTC service; instead, otherwise eligible SSI recipients should be entitled to receive full monthly benefit payments to cover their monthly room and board expenses, rather than only a reduced personal needs allowance."

In addition, the related "key provision" was amended to make it clear that short term respite care could be treated as a reimbursable service, even though room and board costs generally would not be reimbursable.

Parallel to the fourth "organizing principle", a "key provision" was added, stating: "the legislation should specify that all services should be delivered in accordance with an IHP that is developed by an interdisciplinary team and monitored by an individual service coordinator". Next, the group discussed whether the specifications should be more explicit with regard to the components of an IHP. It was agreed that this issue should be dealt with later in the process of drafting the legislation.

Turning to the question of the components of generic Medicaid service that should be available to developmentally disabled recipients of Title XIX reimbursable LTC services, it was agreed that the legislation should specify that such recipients will be

eligible for any other service available under the particular state Medicaid plan. It was pointed out that this approach had two significant advantages: (a) it would assure maximum opportunity to integrate disabled persons into generic service systems; and (b) it would avoid the necessity of having such generic costs reported as DD-specific expenditures, thus inflating the Medicaid costs of serving this population.

State Plan

The previous work of the group was summarized; it was noted that there had been substantive agreement that the state plan would have to include policies and procedures to assure that: (a) personnel delivering services are qualified by education and/or training to carry out their duties; (b) every service agency maintains written personnel policies; and (c) inservice training and education services are available to all service personnel. Other "infrastructure" decisions dealt with the statewide provision of technical assistance and crisis intervention services.

To address the question of what other components should be included in the state plan, one individual suggested that the group address the following topics:

- the process of developing and submitting the state plan;
- the inclusion of a provision dealing with the concept of the "least restrictive environment" (using a different nomenclature);
- the issue of fixing responsibility for evaluating the adequacy of services and filling identified gaps in services;
- designing and implementing management information systems; and
- implementing protective intervention and individual service coordination services.

The process of developing and submitting the DD-specific components of the state Medicaid plan was discussed. One person argued against a special set of submission requirements, noting that it would place too much authority in the hands of a hostile Administration in Washington. On the other hand, several other individuals pointed out that the legislation should mandate open public participation in the development of the DD components of the plan. There was general agreement that the Secretary should not be granted extraordinary powers to dictate the contents of a state's use of Medicaid funds to support LTC services for developmentally disabled persons; however, the legislation should require state agencies to seek public input before submitting their plans to HCFA. The issue of waiving comparability and

statewideness also was raised. There was a consensus in the group that states should be allowed to waive comparability and statewideness for a time-limited period. The states would need to demonstrate in their state plans how the services affected by such waivers would be expanded and made equally available to all groups of eligible recipients, statewide, during the phase-in period. No agreement was reached on how long the waiver period should be, but a two to five year period was mentioned as a possibility.

The group agreed to add state plan requirements dealing with quality assurance/monitoring and management information systems, but the particulars of such requirements were not discussed. The question of applicability of the existing HCB waiver authority also was raised, and it was agreed to discuss this topic later, when the group focused on strategy.

Definitions.

As noted in previous minutes, all references to "case management" will be changed to "individual services coordination." There was a good deal of discussion regarding the appropriate separation between the service coordination agency and direct service providers. Everyone agreed, in principle, that it was inappropriate for a direct service provider (e.g., a private service vendor) to offer service coordination to clients within its service system. On the other hand, it was pointed out that there are states in which a public or quasi-public agency (e.g., the state MR/DD agency or a regional or county MR/DD agency) is responsible for service coordination and also operates direct service programs. After further discussion it was agreed that language should be added to the state plan provisions of the bill that would require states to show how the services coordination system would be administratively separated from the provision of direct day and residential services to recipients.

Next, the group discussed the definition of a "community living facility." One person said he had a problem with the use of the word "facility", since it connotes a group home to many people, while, in fact, a variety of other living alternatives may be more appropriate for the vast majority of recipients. No consensus was reached, however, on alternative phraseology.

Institutional Phase Down

The discussion generally revolved around the question of whether the legislation should contain mandatory phase down/closure goals and timelines applicable to large congregate care facilities (i.e., those with 16 beds or more). There were two school of thought on this subject. One group felt that:

- it would be inequitable to require all states to meet the same phase down timelines and percentage reduction goals since states with a positive track record in deinstitutionalization would be unfairly penalized;
- the inclusion of mandatory deinstitutionalization goals/timelines would fatally undermine efforts to get a Medicaid reform bill through Congress.
- the most critical need is a stable source of federal funding for community-based services; if this need is met, the vast majority of states will phase down the number of institutional recipients anyway.

The other group of individuals felt that:

- the closure of large institutions must be an essential goal of any Medicaid reform legislation and, therefore, mandatory goals and timelines are the only means of assuring that all states comply;
- a decline in institutional expenditures is the only way of justifying the cost effectiveness of the legislation, especially in view of the anticipated growth in outlays for community services; again, mandatory phase down goals/timelines are essential in order to assure a delineation in institutional costs.

For the same reasons cited above, the latter group generally favored a gradual declination in the federal matching ratio for institutional services over a period of years. The former group, however, was skeptical, pointing out that a lower institutional matching ratio would mean a net reduction in federal Medicaid payments which could easily lead to slower development of community-based services -- especially in states with high rates of institutionalization.

One group member suggested that states receive a highly matching ratio for services to newly deinstitutionalized individuals, with a declination in the ratio over a three to five year period. Someone else asked: "why would Congress and the Administration accept this plan, when it would mean much higher total Medicaid outlays?"

One participant suggested that there may be an alternative to mandatory deinstitutionalization goals/timelines. He used, as an analogy, the 1980 Child Welfare Amendments, which required states to develop a plan for reintegrating every child in a foster care facility into his/her own family home or an adoptive home. Under this approach:

- the legislation would make it clear that every resident in a large institution could and should be served in a community setting and, therefore, the facility would be required to justify, in each resident's IHP, the reasons why continued institutionalization is essential, the resources necessary to effectuate community placement for the subject resident, etc. ' |
- states then would be required to use aggregated data from these post-institutionalization plans to develop future expansions/improvements in community-based services; and
- states also would be required to spell in their state plans the steps to be taken to institute a rigorous, independent utilization review process to assure that institutional clients were being referred to and placed in community programs in accordance with the provisions of the state plan and that no resident got "lost in the shuffle".

Several participants were opposed to this approach because they felt it would imply that institutionalization is appropriate for some people. Also, they felt it would be impractical to complete post-institutional plans on all institutional residents when many of such residents would not be scheduled for placement in the foreseeable future.

There was more discussion about whether there should be differential matching ratios, but no consensus was reached. In addition, no resolution was reached on whether the legislation should include a phase-down provision. Some participants felt it would undermine the success of any proposed bill; others felt it would be an absolute necessity.

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The Ad Hoc Discussion Group will reconvene at 9:30 on Wednesday, October 26 in the conference room of the ARC/US. The "Tentative Specifications" table will be amended to reflect the discussion at the group's November 19 meeting.