MEMORANDUM

DEPARTMENT OF HEALTH, EDUCATION, AND WELFAI
OFFICE OF THE SECRETARY
OFFICE OF THE GENERAL COUNSEL
Health Care Financing & Human
Development Services Division

TO : Marjorie H. Kirkland
Senior Program Specialist

DATE: DEC 21 1978

#1

FROM : Robert A. Dublin
Attorney

SUBJECT: Identification of the New Developmental Disabilities Act

In your November 29, 1978 memorandum you raised four specific questions concerning the impact of the Rehabilitation Amendments of 1978 upon the Developmental Disabilities Act. We shall answer them in order.

1. Your first question is whether or not it is correct to say that the Developmental Disabilities Act is now a part of the Rehabilitation Act. The answer is that such a view is incorrect. The fact that title V of the amendments to the Vocational Rehabilitation Services Act of 1978 amended the statutes governing the Developmental Disabilities program does not make the Developmental Disabilities Act a part of the Vocational Rehabilitation Services Act, any more than amendment to the Internal Revenue Code in the Social Security Act makes the Internal Revenue Code a part of the Social Security Act.

2. Your second inquiry concerns how the Act should be cited. Section 502 of the 1978 amendments amends section 100 of the Developmental Disabilities Act and states that it may be cited as "the Developmental Disabilities Assistance and Bill of Rights Act." This is essentially the same popular name as appeared in P.L. 94-103. With respect to citations to the United States Code those remain the same. The Developmental Disabilities legislation begins at 42 U.S.C. section 6001 and continues on for numerous other sections. These amendments will result in changes to some of the sections found in the United States Code and some deletions. However, there is essentially no change in the codification of the Developmental Disabilities legislation. As to when the corrections will appear in the Code that is something which we have no way of knowing.

Other 2 answers not included.

FY 12-7

#2

Position Paper

Subject : Section 515 - Payments under Title I of the Mental Retardation Facilities and Community Mental Health Centers Construction Act must begin on and after October 1, 1978.

Issue : The way the above statement reads, it would appear that RSA must implement the DD Amendments as stated in the Act regardless of the continuing resolution authorization level.

Discussion: If the above issue is the case, the following situations prevail:

I. Protection and Advocacy (P&A)

Under the P&A authorization (Sec. 500 of the amendments), no State (other than Guam, the Northern Mariana Islands, American Samoa, the Virgin Islands, and the Trust Territory of the Pacific Islands) shall be alloted an amount which is less than the greater of $50,000 or the amount of the allotment to the State for the previous year. Please note Sec. 508(b)(3)(B). If this takes care of an appropriation which is less than the amount needed to provide the specified minima and the hold harmless clause, do the territories named receive the same proportion of the $20,000 minimum allotment they received in "78.

If this is not the case, the above stated territories would receive (in lieu of any supplemental appropriation) allotments so small that they would, in all liklihood, choose not to participate in the P&A program and would, by this action, have to drop from the basic dd formula grant program as well.

II. Basic State Formula Grant Program

Under the basic State grant authorization, Sec. 510 of the amendments, allotments to American Samoa, Guam, the Virgin Islands, the Northern Mariana Islands, and the Trust Territory of the Pacific Islands may not be less than $100,000 and any other State may not be less than the greater of $250,000, or the amount of the allotment received by the State for the fiscal year ending September 30, 1978.

If State reallotments are made to the States based on the above requirements and from an appropriation of $30,085,000, some States will probably sue: either the

large States because their allotment was reduced (against the law), or the small States because they did not receive the higher minimum allotments required by the law.

III, University Affiliated Facilities

Authorization levels for the UAF activity under P.L. 95-602 are:

1. $12,000,000 for FY 1979 of which $9,000,000 supports both university affiliated facilities and satellite center grants and the difference supports grants for feasibility studies; needs assessments; training; and research projects.

2. For FY 1980, $14,000,000 is authorized with $10,000,000 for facility support and the difference for grants as indicated in 1. above.

Along with the authorized funding levels are mandated that a grant to a university affiliated facility shall not be less than $150,000 and a grant to a satellite center shall not be less than $75,000. (Section 509 of the Amendments)

FY 1979 fund availability as of December 1, 1978, under a continuing resolution, is $6.5 million; the same level of support as FY 1968.

The Conference Report No. 95-1780, page 111, states: "Additionally, it is not the intention of the conferees that grants to UAF which currently exceed $150,000 be reduced to provide funds to meet the minimum grant for other institutions; sufficient funds have not been authorized so that this should not occur." To fulfull this intent, $7,573,990 would need to be appropriated for FY 1978. $6.5 million is contained in the continuing resolution. An additional $1,073,990 is needed.

Solutions :

1. Leave present allotments in effect.
Notices were sent out prior to enactment of the new law, on the basis of the continuing resolution and the requirements of the old law, P.L. 94-103. (P.L. 95-602, Title V, is however, retroactive to October 1, 1978.).

2. Request a supplemental appropriation be granted in order to implement the new amendments.

3. Request that the Administration approve all or part of the $14 million of reprogrammed money be authorized for expenditure. This will accommodate the new minima and the hold harmless clauses for all three programs.

Recommendation: Alternative 3

#3

Revised Issue Paper

Subject: Allotment to States

Issue: How to determine the extent of need for services and facilities- one of the three factors in the formula.

Discussion: The first attachment results from very new material. It supercedes the options included in the second attachment. The references and discussion in the latter paper still pertains, however.

Recommendation: Use of the SIE Study data.

No decision

Option for Allotment Factor

Until just recently, the situation was still pretty much the same as in previous years. The revised definitions of a developmental disability wi . emphasis being placed on "substantial functional limitations" places even greater difficulty in arriving at the number of individuals eligible for services. In the spring of 1976, the Bureau of the Census, acting as a collection agent for DHEW, conducted a study of income and education. Its unpublished report "Report of the Survey for Income and Education" is based on data collected from personal interviews and conducted on a scientifically selected representative sample of households in the United States. It includes impairments and other information directly from the persons affected or members of the immediate household. This study was not conducted for the singular purpose of identifying the developmentally disabled population as defined in P.L. 95-602.

It is believed because of the survey methods and procedures, that the information available in the study with careful analysis and good judgment, can be used, together with the State Plan, to measure the extent and scope of services to be provided to the developmentally disabled. This information represents the most reliable data now available for estimating the developmentally disabled population.

Subject : Allotments to States (Sec. 132(A)).

Issue : How to determine the extent of need for services and facilities for persons with developmental disabilities in determining the allotment formula under the basic State grant program.

Reference : Sec. 132 (A) of the Act states:

"In each fiscal year, the Secretary shall, in accordance with regulations and this paragraph, allot the sums appropriated for such year under section 131 among the States on the basis of--

(i) the population,

(ii) the extent of need for services and facilities for persons with developmental disabilities, and

(iii) the financial need,

of the respective States. Sums allotted to the States under this section shall be used in accordance with approved State plans under section 133 for the provision under such plans of services for persons with developmental disabilities.

"(3) In determining, for purposes of paragraph (1)(B), the extent of need in any State for services for persons with developmental disabilities, the Secretary shall take into account the scope and extent of the services described, pursuant to section 133(b)(2)(B), in the State plan of the State.".

Sec. 133 (b)(2)(B) of the Act states:

(2) The plan must-

(B) describe (and provide for the review annually and revision of the description not less often than once every three years) (i) the extent and scope of services being provided, or to be provided, to persons with developmental disabilities under such other State plans for Federally assisted State programs as the State conducts relating to education for the handicapped, vocational rehabilitation, public assistance, medical assistance, social services, maternal and child health, crippled children's services, and comprehensive health and mental health, and (ii) how funds alloted to the State will be used to complement and augment rather than duplicate or replace services for persons with developmental disabilities which are eligible for Federal assistance under such other State programs.

Discussion: The extent of need for services and facilities has been a problem ever since the law was initiated. The problem is in identifying the most equitable and practicable available measure of need and incorporating that measure into a formula to determine State allotments. The present system for determining the formula is in Sec. 1386.10 of the regulations:

§ 1386.10 Allotments to States

The allotment to the several States shall be computed by the following formula:

(a) Two-thirds on the basis of total population weighted by financial need determined by the relative per capita income as shown by data supplied by the U.S. Department of Commerce for the three most recent consecutive years for which satisfactory data are available.
(b) One-third on the basis of a need factor based on the ratio of beneficiaries in the State receiving benefits under the Adult Disabled Child Program (section 202(d)(1)(B)(ii) of the Social Security Act) related to population of the State age 18-65 as bearing on the national total of such population weighted by the total population of the State.

Included in the preamble to the NPRM was the following comment which describes the problem and alternative. However, particular attention is directed to proposed § 1386.10(b) which defines the need factor referred to in section 132(a) of the Act. The Act itself refers to allotments being made to States on the basis of the population, the extent of need for services and facilities for persons with developmental disabilities, and the financial needs of the respective States. The statute, however, does not define what is meant by "need" and the purpose of this regulation is to do so. It is based upon the advice of the National Advisory Council and represents what the Department believes to be the best approach available at this time based upon information and comments currently before the Agency.

For the first year of the program, the measure of need adopted was the incidence of developmental disability as reflected by the proportion of the population in the State under age 18. This age was substituted for the age 21 factor used in the former mental retardation program formula, because it corresponds to the age criterion in the definition of developmental disabilities in the Act. The data for measuring need utilized after the first year came from the Social Security Disability Applicant Statistics published by the Social Security Administration and updated periodically. The actual data selected are the number of beneficiaries in the State under the Adult Disabled Child Program ans an index of relative need of the State for services and facilities for the developmentally disabled. It is the Department's belief that these data are the best that are available. Suggestions for alternative need data, or for definition of need to determine the extent of need for services and facilities for persons with developmental disabilities for State allocation purposes, are solicited during the comment period.

Following the comment period the final regulations stated in the preamble that:

Seven inquiries were received commenting on the use of data from the Adult Disabled Child Program, Social Security Administration, for determining "need for services and facilities" in computing the allotment to the States (§ 1386.10(b)). Suggested sources of information included data from the Bureau of Education for the Handicapped, the number of beneficiaries receiving assistance under the Supplementary Security Income, and others. Another suggestion was that additional weight be given to rural States. The Department will look into these matters and others and issue in NPRM its suggestions for changes at a later date.

Lack of funds and other resources precluded the study.

The new law (95-602) deletes the reference in prior legislation, Sec. 132(A)(2), which provides that:

(2) In determining for purposes of paragraph (1)(A)(ii), the extent of need in any State for services and facilities for persons with developmental disabilities, the Secretary shall take into account the scope and extent of the services specified, pursuant to section 133(b)(5), in the State plan of such State approved under section 133.

Sec. 133(b)(5) of the prior Act is all inclusinve for the provision of services and facilities to be provided to developmentally disabled people. The present referenced section 133 (b)(2)(B) is directed only to other Federal/State programs. Therefore, it is limited to what the States are/and to do for developmentally disabled people.

The situation is still pretty much the same as in previous years. With the revised definition of a developmental disability, it is expected that an unknown number of additional handicapped individuals will be eligible for service. Also, the other Federal/State programs are not required to be identified. Their client population according to the definition of a developmental disability as applied in P.L. 95-602. This makes the task of counting and identifying most difficult. The problem is further complicated by the fact that there is no reliable criteria available which can be used for determining the "extent and scope" of those programs serving the developmentally disabled.

Alternative Solutions :

(1) Use the present system, except increase the age range from age 18 to age 22 (Sec. 1386.10(b) of existing regulations).

Pro: This will have the least effect upon the States for allotments at this time.

Con: Some States may object because they believe another fact is more objective and they will be benefitted by using that factor.

(2) That a study be initiated for determining how best the information can be obtained and utilized.

Pro: Indicates that the Department is aware of the problem and is attempting to resolve it.

Con: Another bureaucratic move in hopes the problem will go away.

Con: Take too long to be of help to the States since the legislation is good for three years.

(3) Seek legislative relief in deleting the factor from the formula.

Pro: Same as 2 above.
Con: " " " "

Recommendation : #3, if can be accomplished immediately. If not, #1 with a study (#2) to be done within six months.

Issue Paper

Subject: Consumer membership on the State Planning Council

Issue: One half the SPC membership is required to consist of developmentally disabled persons and immediate relatives or parents or guardians of persons with mentally impairing dd. At least one third of this half must be persons with dd, and at least one third immediate relatives, parents or guardians with mentally impairing dd, one of whom shall be an immediate relative or guardian of an institutionalized person with dd. Should the remaining portion be regulated?

References: Sec. 137a(2)(A)(B) and (3), of P.L. 95-602

(7)). The members of the State Planning Council of a State shall be appointed by the Governor of the State from among the residents of that State. The Governor of each State shall make appropriate provisions for the rotation of membership on the Council of his respective State. Each State Planning Council shall at all times include in its membership representatives of the principal State agencies, higher education training facilities, local agencies, and nongovernmental agencies and groups concerned with services to persons with developmental disabilities in that State.

"(2) At least one-half of the memberships of each such Council shall consist of persons who-

"(A) are persons with developmental disabilities or parents or guardians of such persons, or

"(B) are immediate relatives or guardians of persons with mentally impairing developmental disabilities,

who are not employees of a State agency which receives funds or provides services under this part, who are not managing employees (as defined in section 1126(b) of the Social Security Act) of any other entity which receives funds or provides services under this part, and who are not persons with an ownership or control interest (within the meaning of section 1124(a)(3) of the Social Security Act) with respect to such an entity.

"(3) Of the members of the Council described in paragraph (2)-

"(A) at least one-third shall be persons with developmental disabilities, and

"(B)(i) at least one-third shall be individuals described in subparagraph (B) of paragraph (2), and (ii) at least one of such individuals shall be an immediate relative or guardian of an institutionalized person with a developmental disability.".

Discussion: The intent of Congress is clear: that persons with the problem shall have an effective voice on Council. Also, with the broadening of the definition, more varied interests must now be accommodated.

a. Present requirements:

1/3	2/3
DD* persons parents or guardians	State, local, and private agency representatives

*Includes only mental retardation, cerebral palsy, epilepsy, and autism

b. New requirements

	1/2	1/2
a.	1/3 at least-persons who are d.d.*	Same as above plus higher education training facilities and others concerned with services
b.	1/3 at least-relative or guardians of mentally impaired dd persons	
c.	?	

*Includes many additional conditions

Governors, who appoint the Council members, will need guidance in changing the make-up of the Council.

Solutions:

Option 1: Require in regulations that the unspecified portion consist of some combination of a and b.

Pro: Simple to explain. Meets the intent of the law. Probably not controversial.

Con: May leave some interests unrepresented. (See below.)

Option 2: Require in regulations that any vacancies in that portion be filled by relatives or guardians of young children with physically impairing developmental disabilities.

Pro: The dd persons on Council will be adults. Their interests may not include services for young children. The relatives or guardians specified must be representatives of mentally impaired persons. Thus they may not be concerned with services for physically impaired children.

Con: Possibly unnecessarily restrictive. People can be assigned to represent interests other than their own.

Option 3: Allow in guidelines States to fill vacancies in that portion with persons who have milder forms of the disabilities (i.e., are not technically eligible for services, but are cognizant of the problems).

Pro: Provides more latitude to the States. Recommended by at least one Council.

Con: Contrary to Sec. 137(a)(2)(A) and (B).

Option 4: Combine 1 and 2.

Pro: Allows maximum flexibility within the law, while reducing ambiguity otherwise caused by failure of regulations to specify make-up of part of Council.

Con: Goes beyond the law. May not be needed.

Option 5: Refer in regulations to guidelines, which will suggest that groups covered in 1 and 2 be included on Council.

Recommendation: Option 5 accepted

Pro: Provides assistance to Governors without being restrictive.

Con: Physically impaired children's interests may not be guaranteed representation.

Technical assistance and guidelines should protect their interests in most cases.

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Issue Paper

Subject: Rotation of Membership on Councils

Issue: Should regulations specify tenure of Council chairman and consumer members?

References: Section 137(a)(1)

"The Governor of each State shall make appropriate provisions for the rotation of membership on the Council in his respective State."

House, Senate, and Conference reports do not directly address the rotation issue. They mainly address their intent that consumers and their representatives shall be maximally involved.

Discussion: The new definition adds many conditions whose interests must be taken into account, without reducing services to the previously defined population.

The primary concern here is consumer representatives. (The providers present less of a problem. Many are ex officio and should not rotate.)

It is patently infeasible to try to include on the Council representatives of every "eligible" condition, since they would be far too numerous.

Thus, rotation required by Sec. 137(a)(1), is the way, over time, for additional groups to be represented on Council. But we do not, at the present time, have information about all the groups who may want to be on Council. Until we do, we should not try to be specific about consumer members.

With the formerly limited number of groups to be represented, the Department did not address the matter of tenure on the Council. It is necessary that we do so now.

Experience has shown that at least the Council chairmanship should, as closely as possible, coincide with that of the Governor. A lame-duck chairman is in a weak position.

It is, of course, necessary to allow time for a new Governor to make new appointments, but it should be clear that the chair's tenure will end soon after a new Governor's inauguration.

To provide continuity, however, it is desirable that most members of the Council have Council experience, which can be achieved by rotating membership.

Thus, rotation serves two purposes: to increase the variety of concerns addressed, while maintaining continuity and stability of the Council.

The question is how specific the regulations should be.

Solutions:

Option 1: Do not specify in regulations tenure for anyone. Do not regulate groups to be represented. Leave it to the States, with guidelines provided.

Pro: Provides flexibility for States.

Leaves representation to initiative and resourcefulness of the groups in the State who wish to be included.

Con: Makes Governor subject to pressure from groups and individuals.

Excluded groups may complain to the Department.

Option 2: Specify in regulations that chairperson's term coincides as nearly as possible with that of the Governor. Leave other members' tenure unspecified in regulations, with suggestions provided in guidelines.

Pro: There are many factors which need to be taken into account in determining tenure: size of Council; number and strength of organized groups concerned with DD; etc. We do not have information as yet on which to base more specific regulations.

Con: The newly eligible groups will want regulations to assure them equal opportunity with the previously included groups.

Recommendation: Option 2.

Decision: Do not specify chairperson's term.
No decision on members' tenure.

ISSUE PAPER

Subject: Adequacy of State Planning Staff

Issue: What number and qualifications shall the Secretary determine to be adequate?

References: Section 133(b)(1)(A) requires that the Secretary determine the personnel, their numbers and qualifications, needed to enable the Council to carry out its duties.

House testimony commented on the variability in staff size among the States, and the inadequacy in many instances. The House and Senate Reports are silent, as is the Conference Report.

Discussion: Previous law did not require the Secretary to set numbers and qualifications, so minimum standards were placed in guidelines. Suggested staff was a minimum of a full time equivalent (FTE) of a director, a planner, and a secretary. Testimony indicates that guidelines did not assure adequate staff. Nor do we have any valid study of the kind of staff needed to enable the Councils to carry out their duties. We will have shortly an indication of the relationship between staff size and completeness of the plan, but many factors are not controlled, so the findings are of dubious value.

Factors tending to vitiate any specifications included: size and population of the State; relationship between Council and State agency; amount of allotments (minimum vs. larger allotments); commitment of State agency to the DD program effectiveness of Council; etc.

A major deterrent to requiring a minimum staff previously was the size of the minimum allotment: $150,000. Now that the minimum is $250,000 (except for Territories), however, it would not seem unreasonable to require at least the FTE of a director, a planner and a secretary. This would usually cost less than $50,000.

Budget for Min. Allot. State	
Staff Council	$50,000
Council Expenses	15,000?
65% for services	162,500
Sub Total	$227,500
Balance for other purposes	22,500
Allotment	$250,000

(Territories receive $100,000. It is probably not practical to require them to spend half on staff. Indeed, they are legally required to EVERY CENT on services! The regulations must address this. See separate Issue Paper.)

Solutions:

Option 1: Leave specifications as they have been: 1FTE director, 1FTE Planner and FTE Secretary - in guidelines.

Pro: This maintains status quo. Strong councils can and do go beyond guidelines as they see fit.

Con: Analysis of staffs showed that guidelines have not served to obtain much staff for Councils in some States.

Option 2: Put these specifications into regulations.

Pro: These numbers and qualifications seem, by experience, to be minimum essentials.

Con: If there is objection, we will have little objective bases to justify these regulations.

Option 3: Put these into regulations, but say in Preamble that we will conduct a study to determine what criteria should be used in determining for each State what constitutes adequate staff.

Pro: Criteria can be published later and States can then be held accountable.

Con: Prior to conclusions from the study, it will be hard to implement requirements in recalcitrant States when we have admitted a lack of basis for the regulation.

Recommendation: Option 2

Issue Paper

Subject: What is meant by "The State Planning Council shall develop jointly with the State agency...the State plan?"

Issue: The DD amendments make some changes in Council/Agency relationships. The legislation deletes the specific language that the Council "supervise" the development of the State Plan and "approve" the State Plan. It now requires that the Council "develop jointly with the State Agency -- the State Plan --." The Conference Report makes reference to the Council's major role in setting broad policy, including development of the priorities for services and in plotting the course of the DD program in the State. It does not clarify what was intended by the word "jointly" other than to indicate that planning involves the two agencies working together.

References: Section 137(b)(1)

States that "Each State Planning Council shall develop jointly with the State agency or agencies...the State plan...

Conference Report - p. 107

House bill provided that the Council develop the State plan.

Senate bill provided that the Council advise regarding the plan, and supervise its development. Conference agreement states the intention is that the public, and consumers of services have input into development of the State plan to the maximum extent that is both possible and appropriate.

Discussion: Current conditions and approval provide for the Council to supervise the preparation of the Plan which includes a "design for implementation prepared by the designated Agency based upon the data, goals, and objectives pronounced by the Council.

However, the legislation did not prohibit grants-making by the Council, although it clearly identified the Council as a planning body. Nor did it prohibit the designated State Administering Agency from controlling planning although it was clearly recognized as the administering body to carry out the design for implementation.

In keeping with Department policy of limited directives beyond those specifically addressed by legislation, we were silent in regulations but suggesting Council/Agency working alternatives in guidelines.

The State Agency through its administrative program unit is responsible for:

a. developing strategies to achieve the goals and plan year objectives as documented in the State Plan; and

b. developing agreements with other agencies, public or private, and managing all funding and grants-making responsibility in order to accomplish the objectives.

The regulations remain silent on defining jointly. However, our concern is to assure the strength of the Council vis a vis the State agency.

Solutions:

Option 1: Do not define "jointly" in the regulations, but specify that the Council submit the plan to the Governor and the Secretary.

Pro: The Council represents the major programs in the State with resources and expertise to meet the priority needs of the DD's. The Council also consists of consumers capable of contributing to decisions on policies and priorities based on interchanges of ideas although representing a variety of needs.

This option also maintains the present working relationships that have been mutually agreed to by the Council and agency.

Con: This does not clarify any confusion caused in the States about the meaning of "jointly develop."

It does not strengthen weak Councils.

Option 2: Require in regulations that both Council and State agency sign the plan in a context which says this is what "jointly develop" means.

Pro: This option attempts to clarify congressional intent. When both parties sign, the inference is that there has been mutual agreement.

Con: Signing does not assure a joint undertaking.

Recommendation: Option 1, with strong emphasis on technical assistance through guidelines and other means to enhance cooperation and coordination.

Decision: Do not define in reg. Form used in submitting plan will have statement that the plan was jointly developed and both Council and State agency will sign.

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SETTLED

Had to do with expenditures on the two priority areas. (See attached.)

ISSUE PAPER

Issue:

What criteria are necessary for the Secretary to determine that the expenditures for the State designated two areas of priority services have reasonably met the need for those services in the State.

Reference:

Provision of Priority Services - Section 133(b)(4)(c)

Discussion:

Section 133(b)(4)(c) provides for a waiver to permit the portion of the funds which must otherwise be expended under the State plan for service priorities, as identified by the State, to be expended for service activities in additional areas of service priorities. In the absence of established criteria to be used in determining the merits for granting such a waiver, confusion among Federal and State government representatives will occur as to what constitutes a proper waiver, with State agencies challenging the possibly subjective and arbitrary decisions of Federal representatives.

In adopting the waiver provision, the conferees were addressing the particular situation which occurs in states like the State of California, which both because of its sizable state allotment (which makes it possible to devote 65 percent of the expenditures to more than two areas of service while still allowing a substantial commitment to each designated area), and its particular situation regarding its use of area boards to identify regional service gaps and priorities, which might be disrupted by the limitation, justified allowing some flexibility in the general standard.

Alternative Solutions:

(1) Develop no criteria and merely restate the wording that is in the amendments in the regulations. This approach would allow maximum flexibility to the states in requesting a waiver. This approach would, however, place the administering Federal agency in the position of making arbitrary decisions in approving or disapproving waiver requests.

(2) Develop and publish criteria for waiver approval in the regulations. This approach would certainly eliminate arbitrary decision making, but would allow no flexibility or take into account uniqueness or special circumstances that individual states may have.

(3) Develop program guidelines concerning waiver criteria and review processes in evaluating waiver requests, and not attempt putting criteria in the regulations.

Not an issue. Remain silent in Regs.

Issue Paper

Subject: Authority for State's Receipt of Funds

Issue: The legislation mandates the provision of an annual review of the extent and scope of priority services to be provided under the State Plan. The issue is what, if any, document should be submitted to the Secretary for receipt of funds for the second and third year of the approved State plan?

References: Section 133(b)(2)(B)&(C)

Discussion: The Developmental Disabilities Services and Facilities Construction Act of 1970 (P.L. 91-517) required States to submit annual revision to State plans in order to receive DD formula grants. This requirement continued until the present legislation (P.L. 95-602), which now mandates the States to submit a State plan every three years and annually provide for a review of the program, but does not stipulate how Federal funds are to provide in the second and third year of the plan.

The question that presents itself is whether or not the annual review should be part of the requirements to receiving funds and what type of report would be acceptable?

Solutions:

Option 1: Presently, a Program Performance Report (PPR) is due quarterly from the States. It is designed to describe the progress made in implementing the State plan according to the Design for Implementation (DFI). An analysis of the PPR will reflect the extent to which a State responds to the purposes of the Act.

This report, updated and revised to reflect P.L. 95-602, may be an appropriate review instrument. Since the PPR is already used by the States, it would eliminate an extra report by the States.

Pro: The PPR could be used to serve for the interim 2 year period to receive grants. An updated and revised PPR would reflect the State Plan progress throughout the three year period. Since the States already report through the PPR, using the PPR as the annual review will reduce paperwork and prevent the duplication of effort of reporting.

Con: The time frame to which the PPR adheres would reflect a three month lag in reporting State Plan implementation progress.

Option 2: Submit a separate report describing results of review.

Pro: Since the States are required to (a) review annually the extent and scope of services now or to be provided by DD and other Federal programs (Sec. 132(b)(2)(B) and (b)) review their priority services as to achieving results, this review could be submitted to the Secretary for this purpose.

Administratively needed. Documents that the State Council and agency have made the required review. Guidelines would make it as simple as possible.

Con: Annual review is not legally required to be written. This would add a requirement.

Recommendation: Option 2. Accepted

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Issue Paper

Subject: Prohibition of lobbying by Protection and Advocacy Systems
Sec. 508(113)(b) of 94-103

Issue: Shall lobbying be defined in regulations?

Reference: P.L. 94-103, Sec. 113(b), paragraph 2 is amended to read (in part):

"No part of the money appropriated by an enactment of Congress shall, in the absence of express authorization by Congress, be used directly or indirectly to pay for any personal service, advertisement, telegram, telephone, letter, printed or written matter, or other device, intended or designed to influence in any manner a Member of Congress, to favor or oppose, by vote or otherwise, any legislation or appropriation by Congress, whether before or after the introduction of any bill or resolution proposing such legislation or appropriation; but this shall not prevent officers or employees of the United States or of its departments or agencie from communicating to Members of Congress, on the request of any Member or to Congress, through the proper official channels, requests for legislation or appropriations which they deem necessary for the efficient conduct of the public business.

Whoever, being an officer or employee of the United States or of any department or agency thereof, violates or attempts to violate this section, shall be fined not more than $500 or imprisoned not more than one year, or both; and after notice and hearing by the superior officer vested with the power of removing him, shall be removed from office or employment."
June 25, 1948, c. 645, 62 Stat. 792

Discussion: It is clear that the issue is not whether Section 1913 covers lobbying efforts outside of the U.S. Congress. OGC concurs that the law pertains only to lobbying efforts intended to influence Congress. Section 1913 does not, for example, prevent State P&A agencies from lobbying state legislatures, even if that lobbying effort involves the use of federal funds.

OGC has indicated as well, that Section 1913 does not prohibit th lobbying of Congress with funds obtained from State or private sources.

The issue that remains is:
How does one distinguish between efforts designed to influence Congressional appropriations or legislation and efforts to educat members of Congress on key areas related to protection and advoc

Solutions:

Option 1: Do not address in regulations.
(Only refer to "Sec. 1913 of Title 18 of U.S.C.")

Pro:	The P and A agencies are doing their own research on this. Let them carry the responsibility.
Con:	With the political heat already evident, regulations should address matter.
Option 2:	Quote Congressional or IRS definition of lobbying in the regulations.
Pro:	It is lobbying of Congress which is prohibited. Therefore, the Congressional definition should be used; and putting it in regulations will make it enforceable.
Con:	Beyond scope of legislation.
Option 3:	Assume the matter is adequately covered by Part 74.
Pro:	Standard Policy applicable to all grants.
Con:	Does not adequately define lobbying.
Option 4:	Quote Sec. 1913 in the regulations
Pro:	Saves referring to other documents. Easy for constituents.
Con:	Policy against copying material from other references. Does not define "lobbying".
Recommendation:	Option 3. Accepted

Issue Paper

Subject: State Planning Council - P&A System Relationship

Issue: What is the scope of activities precluded by Sec. 113(a) which states that protection and advocacy systems may not be administered by State planning councils?

References: Section 113(a)(2)(B)

Discussion: In developing the program regulations of January, 1977 the Department determined that Sub Part C - Protection and Advocacy of Individual Rights - should be written so as to allow States as much flexibility as possible in implementing their P&A systems, given the Department's lack of experience in the program. It was decided that more detailed regulations might be issued as the result of the experience of the Bureau of Developmental Disabilities in monitoring the P&A program.

Currently, there are two reasons for making the regulation more detailed in regard to the relationship between State planning councils and protection and advocacy agencies:

(a) the current act now stipulates that a State planning council may not administer a State P and A system.

(b) experiences in administering the program have shown that there are several ways in which an SPC may exert partial or even complete control of State's P&A activities without being the governor's designated agency:

(1) when staff to the SPC acts as staff to the P&A agency. (this is presently the case in one State).

(2) when the SPC provides funds to the P&A system under the developmental disabilities basic State grants program.

(3) when individual members of the SPC serve as members of the P&A governing board, but not in an official SPC capacity (as is the case in one State where the entire P&A governing board is comprised of SPC members).

Solutions:

Option 1: Prohibit in regulations any sharing of personnel in any way.

Pro: This would be clear-cut.

Con: It would rule out cooperation even to the extent of prohibiting P&A representation on Council.

Option 2: Prohibit in regulations any arrangement which gives to the Council control of any required activity of the P&A system.

Pro: Limits prohibited action to required activity of the system. Does not prohibit Council's support of other P and A activities, nor of P&A representation on Council.

Con: There may be some disagreement as to what is "required activity."

Option 3: In regulations state only language of the law. Put explanatory materials in guidelines.

Pro: Simple.

Con: Weaken enforcement.

Recommendation: Option 3 Accepted.

Problem

Subject: Review process for UAF applications.

Problem: Where should this review be done - Regional Offices or central office.

References: P.L. 95-602, Sec. 122(c) requires that the Secretary establish a process for the review of applications for grants that will ensure that other agencies providing direct support review the applications. Since there is no discussion of this provision in the House Senate on Conference Reports, it is difficult to determine the rationale of Congress on this issue.

Discussion: UAF's generally are funded from two main sources, the Maternal and Child Health Program (MCH) Bureau of Community Health Services, and the Developmental Disabilities Program (DDO), rsa. The Bureau of Education for the Handicapped funds a number of UAF's but on a very limited basis. There is no consistent pattern for funding by the various offers, and no formal arrangement for review of all applications by all agencies. In the some cases the basis for awarding grants is not that the grantee is a UAF.

It is assumed that Congress intended the review process to include all agencies that provide direct support to UAF's participate in a joint review of all application; however, each agency retain its approval authority for programs for which it is responsible. Also it is assumed that "direct support" refers only to the UAF and not the entire university.

Current Conditions: Presently there are 44 UAF's receiving funding from the sources indicated. The funding cycles for these grants differ by programs and the approval process is also different. For example, MCH approves applications at various times; DDO applications are approved for 12 months beginning July 1. DDO applications are approved in the regional office, MCH are centralized. There is a UAF Interagency Coordinating Committee and it has met periodically over the past two years. MCH tried using it to review UAF applications for MCH funds, but concluded that this mechanism was not workable due to the length of the MCH applications and the lack of staff time available from the RSA and BEH representatives. An expanded version of the HEW-UAF Coordinating Committee did jointly review satellite proposals in 1977. The Committee felt it was quite effective in achieving a truly integrated review of those particular applications.

Although representatives of the programs meet regularly, there is no formal arrangement for review of all DD UAF applications by the other agencies, nor any for DD;s review of the others'.

Problem: DD UAF funds have been administered in the regions (with the exception of the funds for satellite centers and their feasibility studies), MCH and BEH UAF programs remain the responsibility of the central office staff.

The problem of trying to coordinate the pieces of the UAF programs has been recognized long before the '78 amendments. The matter was surfaced to OHDS early in 1977, but as far as we know, no disposition has been made.

Solution:

(1) funding cycles, (2) review and approval process, and (3) monitoring. This can be done either at the regional or central office level. Delegation of authority for approval would have to be issued by the respective offices.

Option 1: Leave approval of DD/UAF applications in regions; assure that OHDS policies are implemented.

This would give MCH and BEH an opportunity to have RO and/or CO staff participate in the review, in whatever way they choose.

Pro: RSA can make its own decision about process without getting involved with other agencies.

Pro: Especially with staff and travel restrictions, it is less expensive for RO's to monitor the UAF's.

Pro: RO's are more knowledgeable about needs of States and regions for UAF benefits. Disparaties among regions will be reduced when standards are promulgated.

Pro; RO's are in better position than CO to encourage cooperation between UAF's and State Planning Councils (SPC's).

Pro: Procedures for review are in place.

Con: Decentralization has made it difficult for BDD to be accountable for variations among regions.

Con: Coordination with other UAF programs is almost impossible.

Option 2: Place authority in CO. Use OHDS procedures.

Pro: Coordination will be greatly facilitated.

Pro: More uniform quality control can be exerted.

Pro: Utilize HEW-UAF Coordinating Committee for review.

Con: CO staff not presently available to monitor projects.

Con: RO's will find it more difficult to coordinate UAF's with SPC"S.

Recommendation: Option 2

Not a public issue. Administrative only.

ISSUE PAPER

Subject: University Affiliated Facilities Standards

Issue: How can we meet the legal requirement that University Affiliated Facilities (UAF) standards be established by regulation by May 5, 1979?

Reference(s): A. Title V, Section 122(a) of P.L. 95-602:

"(a) Not later than six months after the date of the enactment of the Rehabilitation, Comprehensive Services, and Developmental Disabilities Amendments of 1978, the Secretary shall establish by regulation standards for University Affiliated Facilities. These standards for facilities shall reflect the special needs of persons with developmental disabilities who are of various ages, and shall include performance standards relating to each of the activities described in section 102(10)."

B. Report of House Hearings on the DD Act, Serial #95-103, April 4 and 5, 1978.

C. H.R. 95-1780, Conference Report (on P.L. 95-602):

Standards for University Affiliated Facilities

House Amendment

The House amendment provided that the Secretary shall establish standards for University Affiliated Facilities within six months after enactment of this Act, and that in order to receive funding a University Affiliated facility must either be in compliance with the standards established or be making substantial progress toward complying with the standards and be able to achieve full compliance within three years of the date its initial application is approved or the standards are promulgated, which ever is later.

Senate amendment
No provision
Conference agreement
The Senate receds. pp. 110-111

D. 1972 Guidelines (Draft)

These are the only guidelines ever distributed. Regulations for UAFs were never approved for this program under P.L. 91-517, but were included in the January 1977 regulations.

E. Contract to Morgan Management Assoc.

Discussion:

Background: September, 1977, but before P.L. 95-602 was conferenced, BDD/RSA let a contract for one year to develop standards for UAFs. It is a complex matter to develop meaningful standards that can be applied to a variety of programs which differ among themselves because they address a variety of needs. The needs for the gamut of paraprofessional training cannot be met by any one model. Nor can the service needs for the entire range of the clientele be modeled by any one agency or institution. Just as there is a range of institutions of higher education for the general population, there is a need for a range of institutions to meet the manpower needs for the field of development disabilities, and a range of services to be demonstrated.

The problem has been to develop standards which can assure quality without losing the values of individual programs. This problem subsumes the problem of differing purposes and requirements imposed by or inherent in the differing funding sources.

Current Conditions: Because of this complexity, the contractor is not likely to produce, in time to meet the legal deadline, an adequate set of standards. Nor do we have staff adequate to develop the standards in the time allowed.

Furthermore, standards, once published in regulations, are difficult to change. In view of the complications described above, it would be unfortunate to incorporate hastily drawn standards in regulations.

Solutions:

Option 1: Include in the regulations whatever standards we have abailable.

Pro: This would respond to the clear intent of Congress.

Con: Congress would probably not like the product.

Con: Some UAFs that would not meet "final" standards may be able to meet these brief standards.

Option 2: Ask Congress for more time.

Pro: A reasonably good set of standards should be available in late 1979. They could be issued as regulations then.

Con: The House subcommittee made a point during the hearings that six months should be adequate. They would probably not be favorable to a postponement.

Con: We cannot be sure, at this stage of the contract, that the standards will be good enough to put into regulations.

Option 3: Make reference in the regulations to the latest version of standards to be issued by the Secretary.

Pro: It will nominally meet the legal requirement.

Pro: It will allow for revisions to be issued as needed.

Con: It may not meet the full intent of Congress.

Recommendation: Option 1 Accepted.

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3/79

WITHDRAWN

No issue. Had to do with what is satisfactory to the Secretary in re: assurances.

ISSUE PAPER

Subject: Professional Assessment

Withdrawn. We will address in guidelines. There is no need to deal with it in regulations.

#16
3-79

ISSUE PAPER

Subject : Standards for Services Provided to Developmentally Disabled Persons

Issue : What shall the standards be that the Secretary prescribes in regulations for services furnished and facilities in which services are furnished?

Reference : P.L. 95-602, Sec. 133(b)(5)(A)(i)

Discussion : Previous law, P.L. 94-103, also provided that the Secretary prescribe standards as to the scope and quality of services provided to persons with developmental disabilities, as well as standards for construction and equipment for facilities. (Sec. 109(1) & (4)). In addition, P.L. 94-103 mandated the Secretary to develop performance standards and quality assurance mechanisms for programs serving persons with developmental disabilities (Sec. 204, P.L. 94-103) and a report submitted to Congress including a review, evaluation and recommendations of the study.

Regulations, (Sec. 1386.17), do contain standards for construction and equipment for facilities that used Federal DD funds for construction. Since the admendments deleted authority for construction of facilities, these standards are no longer applicable and the regulations will be amended to remove the requirement.

However, standards for services, even though required since the initiation of the DD program, have not been issued. The reason for this delay was stated in the preamble to the NPRM, August 30, 1976,-and the preamble to the final regulations January 27, 1977 which says:

> "Two comments registered disappointment with the lack of standards for services for developmentally disabled people. The Department has let a contract to study this matter as mandated by the Act. Standards will be published in the FEDERAL REGISTER upon completion of the study, and acceptance by the Department, as indicated in the preamble to the NPRM on August 30. (See Appendix to this document)."

This study has now been completed and a report has been prepared for submittal to Congress. The Department is presently, by contract, arranging for the validation of the performance standards and quality assurance mechanisms. This study will field test the model standards and gain the support of other agencies involved in providing services to developmentally disabled persons among others. It is likely that standards acceptable to generic agencies will not be suitable to this specific population.

At the present time, the Joint Commission on Accreditation on Hospitals for Mental Retardation and Other Developmental Disabilities (JCAH) has developed a set of standards for accreditation purposes. These standards have been in use for about three years, but apply to programs specifically targeted on developmentally disabled people.

Alternative Solutions :

1. Accept the standards of the JCAH as those meeting the requirements of the Secretary for this purpose.

PRO (A): The standards developed by JCAH were done so in consort with experts delivering services to developmentally disabled persons and consumers of such services and involved groups concerned with developmental disabilities.

(B) The standards have been and are continuing to be tested in the field and are acceptable to a majority of those providing services.

CON: (1) The standards are relatively new and may be difficult for providers of services to meet at this time. Some flexibility should be allowed for compliance.

(2) The agency monitoring compliance may lack the expertise to judge whether the services being rendered do, in fact, comply with the requirements.

2. That the regulations remain silent on this issue at this t: A notice to be included in the preamble to the NPRM indica: that JCAH standards are to be used during the period covered by the model standards and quality assurance mechanisms now being validated.

PRO: This is a major policy determination by the Secretary affecting many programs within the Department and will need time before a judicious decision can be made and acceptance by all concerned.

CON: Another delaying tactic by the Department in issuing standards.

3. The Secretary issue regulations stating that standards developed by other Federal programs for services applicable to developmentally disabled persons shall be followed, e.g., Day Care Standards.

Pro: (1) Will avoid some duplication and overlapping between programs and allow States flexibility.

(2) Maintains the status quo and adds no additional burden on States.

Con: (1) This alternative circumvents the legislation in that, not all Federal programs available for services to developmentally disabled mandate standards, e.g., Maternal and Child Health Services.

(2) Services to developmentally disabled will continue to be provided in many instances by unqualified persons and rendered on an inferior basis.

Recommendation: #2 - Upon completion of the validation study, a decision will be made whether to accept the model standards and quality assurance mechanisms or adopt some other standards.

2/7?

ISSUE PAPER

Subject: Portion of allotments to Territories to be expended on priority services.

Issue: Several sections of the law require that the Territories (listed below) do either of two things which are not required of States:

a) either they must spend their entire allotment on priority services; or
b) they must qualify under clause (iii) of Sec. 133(b)(4)(B) by not reducing the amount expended for planning below their 1978 expenditure, and by expending "substantially the remainder on priority services.

References: Sec. 132(a)(2)(A) - allotment to Territories.
Sec. 133(b)(4)(B)(i) - requirement that at least $100,000 be spent on priority services.
Sec. 133(b)(4)(B)(iii) - "grandfather clause regarding amounts spent f planning.

Reports do not address issue.

Discussion: Secs. 132(a)(2)(A) and 133(b)(4)(B)(i) combined require the 5 Territories listed in Sec. 132(a) to spend their entire allotments on priority services.

It is our interpretation of Sec. 133(b)(4)(A)(ii) that the requirement to spend a certain amount on "priority services" does not take effect until FY81. A transition period is afforded States to move from their present funding plans to the new requirements.

To be able to expend funds on planning, however, the Territories would have to meet the requirements of clause iii of Sec. 133(b)(4 Accordingly, they would have to a) not increase the amount spent on planning, and b) expend "substantially the remainder" on priority service areas -- and this would apply tc FYs 79 and 80, as well as to 81.

It was probably not the intent of Congress to apply such discriminatc rules to the Territories. The intent seems to have been to require that 65% of the allotment be spent on priority services after a reasonable transition period. During this period, States which had found it advantageous to the program to spend more than 35% on planning would be allowed to continue at an unreduced level provided most service funds were funneled into the priority areas.

Solutions:

Option 1: Increase grants to Territories

Pro: Would make possible the expenditure of $100,000 on services.

Con: This would dislocate the the basis for all allotments, and cause a storm of protests and demands for special attention from other jurisdictions.

Con: It would increase the budget for the basic grant program not only for FY'79, but also for 80 and 81, unless the Territory met the clause iii provisos.

Option 2: Make an award for a special project to each Territory to cover the non-service costs.

Pro: This would adhere to the letter of Sections referred to (but not to others, such as administrative costs and planning staff sections).

Con: It would probably take at least $25,000 per Territory (for a total of $125,000 or more).

Con: Only by stretching Sec. 145(b)(8) could authority for such a use of Sec. 145 funds be justified.

Option 3: Exempt the Territories from the "whichever is more" proviso of the Act, and allow them to expend $65,000, or 65% of the allotment, on services on the same bases as States.

Pro: The minimum amount is usually referred to, in the House and Conference reports, in terms of the percentage, rather than the $100,000. It is reasonable to assume that the Territories' dilemma was due to an oversight in drafting the compromise, and that the intent was that 65 per cent of the allotment be spent on services.

Con: It would violate the "whichever is more" proviso.

Option 4: ASk Congress to amend the legislation.

Pro: It would be "cleaner".

Con: It might take so long to obtain the amendments and implement them that the Territories would have been foreclosed from participation in the program in FY'79. Meanwhile, they have been allotted funds at the FY'78 level.

Recommendation: Option 3 *Accepted*
Tentatively and in formally approved by GC.