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MENTAL RETARDATION AND OTHER DEVELOPMENTAL DISABILITIES, 1969

MONDAY, NOVEMBER 10, 1969

U.S. SENATE,
SUBCOMMITTEE ON HEALTH
OF THE COMMITTEE ON LABOR AND PUBLIC WELFARE,
Washington, D.C.

The subcommittee met at 9:30 a.m., pursuant to call, in room 4232, New Senate Office Building, Senator Edward M. Kennedy presiding pro tempore.

Present: Senators Kennedy (presiding pro tempore) and Dominick.

Committee staff members present: Robert O. Harris, staff director; James Babin, professional staff member to the subcommittee, and Jay B. Cutler, minority counsel to the subcommittee.

Senator KENNEDY. The subcommittee will come to order.

Today, the Senate Subcommittee on Health begins 2 days of public hearings on legislative proposals dealing with mental retardation and other developmental disabilities.

It has now been 6 years since Congress enacted the basic Federal legislation in this area. We know from the rising level of public concern over this major national problem that the scope and funding of our present efforts are far too narrow to provide the services and facilities that are needed.

In the course of these hearings, the subcommittee will receive testimony from public officials, private citizens and the representatives of a number of organizations and institutions familiar with the needs and aspirations of the retarded.

The legislation pending before the subcommittee is S. 2846, the "Developmental Disabilities Services and Facilities Construction Act of 1969," which I introduced in the Senate in August, and which is cosponsored by Senators Yarborough, Williams of New Jersey, Nelson, Mondale, Eagleton, Cranston, Hart, and Javits.

The text of the bill, along with my remarks at the time I introduced it, shall be printed at this point.

(The bill S. 2846 and introductory remarks follow:)

(I)

Dr. BOGGS. I would like to start out by paying tribute to this Senate committee. It is responsible for at least half the Federal funds—and when we think of the funds that are used for maximum leverage it is more than three-quarters of the funds—that affect the well being of the mentally retarded in the programs of the Department of Health, Education, and Welfare.

This Senate committee has during the past decade brought forth legislation of enormous benefit to the handicapped. The provisions for education of the handicapped developed since 1965, the recent modifications of the Vocational Rehabilitation Act, and the greater priority to construction of rehabilitation facilities have been especially significant.

I think I should add that, in many instances, this legislation bore the stamp of the committee much more than of the administration that proposed it. Nevertheless, a number of these programs tend to gravitate toward short-term solutions. They tend to provide assistance for those pupils or those clients or those patients who are considered to "profit most," who can be trained or treated and then discharged as self-sufficient within a limited period of time.

The exception to this statement is the legislation which is before us, the predecessor act of which addresses itself to all the mentally retarded without any such distinction.

The advances which have been made under the legislation I have cited, and the objectives that I quoted of returning people to the mainstream of society, are extremely important and have been vigorously supported and promoted by our association.

Nevertheless, we in NARC cannot overlook the fact that there are children who are still excluded from public schools because of the severity of their retardation, young adults denied the benefits of rehabilitation at public expense because it is thought it will not make them employable within 2 years or less, and older retardates who are placed in residential institutions of doubtful quality because the necessary supportive services in the community are not available.

We are also aware that the severely disabled but mentally alert child or adult who does need a specialized living environment may be denied even that to which the retarded are entitled under State law.

For the most destitute of the adults disabled in childhood and for those deprived of previous support from an employed parent, Government does provide minimal "income maintenance" under public assistance and social security, but the resources, the services which could maximize their human condition are often not there, for love or money.

This is true of medical resources; it is even more true of nonmedical resources.

It is true for those from well-to-do families as well as for those on "welfare," and it is even more true for that in large but mostly unstudied group who have very modest means but are not indigent.

It should be noted that Congress has an inclination to define programs so as to bring limited benefits to the largest number of people. Even "medicare" will not cover a continuous stay of more than 100 days in an "extended care" facility; "maximum benefit" is a polite phrase for easing children out of a State crippled children's program after the most dramatic part of their treatment is over, leaving parents

to face the long haul by themselves; the seriously disabled may have "up to 18 months" of evaluation (by grace of the Secretary) under vocational rehabilitation; and, even in this committee, Federal stimulation of long-term sheltered employment opportunities for these same people has been much talked of but never acted upon.

The present Mental Retardation Facilities Construction Act follows suit, for its Federal assistance for staffing any facility must decline rapidly and terminate entirely within 51 months.

The victims of all these subtle and not-so-subtle discriminations are most often those with serious lifetime disabilities.

It is to them, to what they need and have not received from other programs, important as they are, that we believe you are primarily directing this new imaginative piece of legislation.

We see this as an interstitial bill—a bill whose benefits should flow around and between existing programs, filling both the large gaps and the smaller crevices which divide the major elements of the present system of Federal aid to States and communities in meeting the needs of handicapped children and adults.

The Developmental Disabilities Services and Facilities Construction Act of 1969 should supplement and enhance—and certainly not duplicate—such programs as those now authorized under title V of the Social Security Act (Maternal and Child Health and Crippled Children), under title VI (Education of the Handicapped) of the Elementary and Secondary Education Act, under the Partnership for Health and Vocational Rehabilitation and Medical Facilities Construction Acts, or under programs of social services to welfare recipients.

It will be necessary to conserve the resources of the new program to focus maximally on those needs of handicapped children and adults which have fallen between the boundaries of existing programs.

It should be pointed out here that when we speak of these needs we have reference not merely to the fact that some people don't qualify for some of these programs, but that many people qualify only part of the time or for a partial program.

Thus there are gaps in the services to an individual even though he may be eligible some of the time for some of the help.

We hope, we surely must expect, that the history of this bill will show that it is your intent that its benefits focus on the gaps and lacks and that it should not be used as a source of interagency rivalry on the part of people who have been suggesting that this would duplicate other legislation.

The machinery for coordination and planning that the bill provides and subsidizes should, under appropriate guidance from HEW, help to complete the jigsaw puzzle of "comprehensive" planning at the level of greatest critical responsibility, in State government.

The bill also assures—through its stipulations for a National Advisory Council—that voices from the State and local level, as well as those of "consumers" will be heard in a coherent way by the Secretary.

These provisions should strengthen communication among interested parties at all levels.

There has been quite a bit of discussion in these hearings already as to what is meant by "the developmentally disabled."

Candor forces me to say some of the remarks made yesterday reflect failure to read the language of the bill. Certainly it focuses on those who have a substantial continuing handicap.

Many minor physical disabilities or physical handicaps which originate congenitally, for example, do not constitute a significant continuing disability into adult life. Many are remediable by appropriate efforts in childhood.

We are in favor of utmost remediation, and in many instances this can be provided under crippled children's services or under vocational rehabilitation services now available.

We wish to point out, nevertheless, that there still exists a group of people who, because of the chronicity of their disability, continue to be shoved aside because they do not seem to show such a dramatic response to treatment.

Our best information about those with disabilities originating in childhood which continue into adult life can be found in the data gathered over the years by the Social Security Administration relative to its so-called adult disabled child beneficiaries.

Although we would not wish to limit eligibility for service under S. 2846 to those whose disability is severe enough to meet the social security test of disablement, we do believe that those meeting the intent of the definition of developmental disability in section 102 of the bill—amending section 401 of the act—will have many comparable characteristics.

In terms of the recent social security survey of disabled adults—which was not confined to those eligible for disability benefits—we see S. 2846 targeted on adults who are, and children who are likely to become, either "severely disabled" or "occupationally disabled," with less attention to those who have or will have a "secondary work limitation."

In mental retardation lingo, the functional definition of continued impairment and "substantial" handicap must subsume most, if not all, of the moderately, severely and profoundly retarded, and a significant subgroup of the mildly retarded.

On the other hand, those young people who are classified—or misclassified—as "educable" in school and who are among those who "disappear" from the ranks of the retarded by becoming socially and economically viable adults on leaving school are not primary beneficiaries of this bill although they will continue to need the best efforts of special educators and of vocational rehabilitation and manpower personnel.

By the end of this year about a quarter of a million adults will be receiving "adult child's benefits" under social security. Of these about two-thirds or more than 160,000, are mentally retarded, with or without another neurological impairment. Some 15 percent are epileptic or cerebral palsied, with or without mental retardation. Psychoses of childhood and adolescence account for another 9 percent. Altogether these disorders account for more than 80 percent of the total.

Sensory disorders, polio crippling, and a variety of other diagnoses account for less than 1.5 percent each. Although the social security sample is not a "random" one, since beneficiaries are only identified on the death, retirement, or disablement of the supporting parent, there is reason to believe that the diagnostic composition of the group

is typical of all adults similarly disabled in childhood. The same is true of the finding that more than 85 percent have a disability originating before their first birthday, a figure that rises to 90 percent by age 6.

About 28 percent are in institutions. This figure should probably be adjusted downward to 25 or 26 percent for the adult disabled group as a whole to compensate for the higher average age of the beneficiary group, because the beneficiaries are on the average somewhat older than the total adult disabled group.

Combining a variety of data we estimate that there may be as many as 3.5 million developmentally disabled adults and between 3 million and 4 million children.

On the basis of the foregoing data it seems reasonable to assume that, of the group to which S. 2846 is directed, about two-thirds are retarded and almost all the rest have neurological disorders or severe mental illnesses originating in childhood with poor prognosis for recovery. This latter group includes the typical cases of "infantile autism."

This subject of definition has been brought up because of the fear that the broadening of the coverage of the act as compared to the present act would dilute the attention and focus for the mentally retarded.

We would concur that there is a danger in this respect and we would like to comment on that point.

You will note that section 134(b) (4) of the bill specifies that the State plan must "(A) provide for the furnishing of a range of services and facilities for persons with developmental disabilities associated with mental retardation, (B) specify the other categories of developmental disabilities which will be included in the State plan, and (C) describe the quality, extent and scope of such services as will be provided to persons with mental retardation and other developmental disabilities;"

We understand this to mean that the State plan must include provisions for the retarded and may include or phase in services to others with developmental disabilities other than retardation.

We believe, that in light of present circumstances this proviso is only fair and realistic. The legislation which this act will replace is limited to the retarded. Their interests should be protected in any broadening of the group to be covered.

Moreover, as a practical matter, it will be impossible for the States to revise their existing State comprehensive mental retardation plans for fiscal 1971 in time to cover additional disabilities under the new legislation in a meaningful way.

This thought should also reassure the Federal agencies which are called upon by the bill to promulgate applicable regulations by March 1, 1970.

We believe the Congress should expect that, for example, the State construction plans required under the act for 1971 should conform with what might have been required under part C of the expiring legislation, with significant changes first becoming apparent in 1972.

In connection with the anticipated phasing in of additional categories of the developmentally disabled under the State's own timetable in accordance with the option offered in section 134(b) (4), we wish to speak approvingly of the provision in section 132(a) (2) which would

require the Secretary to take some cognizance (in his formula for allotment to the States) of the inclusion or exclusion in any State's plan of persons other than the retarded.

In view of the data cited above indicating that about two-thirds of the developmentally disabled are retarded, we would expect that the Secretary would augment any State's allotment by an amount up to and not to exceed 50 percent additional when, and to the extent that it encompasses a range of services to eligible persons who are not retarded.

This provision means that a State does not have to penalize its retarded citizens by trying to stretch its allotment to cover more disabilities. The provision thus offers an incentive in the right direction.

On the other hand, this provision could work a serious hardship on all concerned if the President and Congress do not provide sufficient additional funds so that the allotments are not only proportionally (to others) but absolutely enlarged as the scope increases.

If appropriations are not provided in 1972, and thereafter, to cover increased activity projected by the States, as well as the increment which should be expected in funds for mental retardation alone, then we would expect the Secretary to exercise powers available to him under section 139 to limit the "categories of persons for whom such services may be provided" so that expansion to new categories does not take place at the expense of those already covered.

Now the Administration yesterday was taking the position that they could not possibly provide these additional funds that would be necessary and, therefore, the legislation should not proceed in this direction.

Mr. Chairman, we think this is a very shortsighted view. The purpose of substantive legislation which comes before this committee, as distinct from appropriations legislation, is to set the pattern of growth in a logical way for the future.

We do believe that it is important to develop legislation stage by stage in a logical way and to lay the basis for future programing.

The fact that we have what we all hope will be a temporary stringency with respect to funds should not be used as an excuse for scrapping the foundations of a good program and failing to build toward the time when we will have more ample funds to carry out a logical and appropriate program.

We believe that we need a transitional phase in this legislation which will move us toward the concept of a functional definition of the group which is in need of similar—not identical but similar—services, services which will be similarly organized, and that we would in any event (even with ample funding) need to have a period of phasing of the newly covered groups. This has to be done in an orderly fashion and in a fashion which gives the States some latitude in adjusting their complex groupings of services which have some impact on the disabled.

To go backward, to disregard the progress that has been made in the last 5 years, and to act as though the effort which the States have, in response to the Federal request for planning, put into organizing State agencies so as to address themselves to needs—to act as though this had never happened and to go back to the project grant approach which was appropriate in 1962 and 1963, would in the opinion of many of us be a very sad backward step.

We want to point out that S. 2846 reposes more trust and discretion in State administration than does Public Law 88-164 which it will replace.

Whereas the provisions of the present act delineate specific solutions to one presupposed problem (the need for specialized facilities for the retarded), the Kennedy-Yarborough bill describes a problem area and invites the States to propose within broad guidelines, solutions which are most adapted to the manifest needs and to the context of existing programs within each State.

Such latitude would have been premature in 1963, when the mental retardation legislation (to which S. 2846 provides a successor) was enacted; we believe, however, that it is not only timely but fitting as we approach the 70's, to make this transfer of responsibility.

The program is getting larger and more complex and the idea that the Federal Government is the repository of all knowledge in these matters and that it can carry on a dialogue with local agencies and tie its strings around every \$20,000 grant is just out of date.

It is important in this area that local initiative be encouraged and that the money reach the people in the local communities. I think the language in this bill makes it clear that it is intended to do that, and that the States can be expected to respond, as they have heretofore under 88-164, in that regard.

Thanks to intense State planning activity in mental retardation in the past 5 years with Federal assistance, and to the growing public understanding and voluntary agency activity on behalf of the handicapped, States and communities are now ready to respond to the kind of Federal initiative and incentive proposed in S. 2846.

The State comprehensive planning in mental retardation, when considered in conjunction with the State planning required and stimulated by other State-Federal programs referred to earlier, constitutes an adequate point of departure for the broadened target group contemplated in this bill, S. 2846.

We have listed in our prepared testimony a number of other provisions in the bill before us which we regard as real improvement over the present act.

I will refrain from touching on all of them but I wish to call attention to a couple. In the first place, there is a requirement that there be some State financial contributions in the implementation of the plan and some limit on the extent to which purely local or private funds may be substituted for the States' share.

Under the present act there is really no requirement that the State government put up any money excepting for administration.

We believe that the requirement for State contribution will strengthen the program and strengthen the State-local partnership.

We want to point out that there is a requirement that the States give special consideration to areas of urban and rural poverty and that it give special financial and technical assistance to those areas.

We also agree with the administration that these areas should receive more favorable Federal matching for construction. The figure cited has been up to 90 percent.

This is in fact considered by us to be part of S. 2846 for the reason that the provisions of S. 2846, if enacted, will be governed by the specifications as to the Federal share which are contained in title IV of the existing act as it may be amended.

It is proposed by the community mental health centers bill which is pending, S. 2523, to change that Federal share in the direction that we have just indicated and the administration supported that change when it testified on the mental health bill. If, for any reason, this increased Federal share for poverty areas is provided for mental health by a mechanism other than amendment of section 402 of Public Law 88-164, then a corresponding provision should be included in S. 2846.

Therefore, if this committee in its markup—which we anticipate shortly—of the mental health bill follows its own advice and that of the administration it will automatically provide for a revised and more favorable Federal share for areas of urban and rural poverty in respect to mental retardation construction.

Of course, if part C is allowed to lapse without extension or substitution, that won't be the case. Your bill provides a new part C; a substitution.

Finally, I want to mention and reinforce that the bill provides for the substitution of a concept of "services in the most appropriate setting" for the much more limited concept, that of "staffing of the facility".

The express inclusion within this definition of a number of important services heretofore not given express sanction for Federal support in this context is to us very important.

I refer here, for example, to protection services, to information and referral services, to specialized aspects of generic services which are often carried on elsewhere than in facilities for the mentally retarded.

We also hope that the Secretary will make sure that in interpreting the meaning of the term "a range of services" he will include diversification of both residential and nonresidential services at all age levels.

Mr. Chairman, title II on university-affiliated facilities is to us of extreme importance. You heard very eloquent testimony on this subject yesterday. We support the extension and expansion of that provision, part B of the present act, and support the testimony which was given by the people closest to that problem, the directors of the university-affiliated facilities.

I'd like to stress two aspects, however. First, we find shocking the refusal of both the Johnson and Nixon administrations to request any funds in fiscal 1970 for construction of university-affiliated facilities even though there are approved and approvable applicants. This is compounded by the failure of this administration to give any assurances that these applicants will be given the slightest consideration under its proposals outlined yesterday. (Indeed if it does fund any such facilities out of its proposed current level of funding of Public Law 88-164, it would cause further serious curtailment of the community programs.)

We find this behavior shocking and disturbing because it means that the leaders in HEW are prepared to consider expendable the time and energy already invested by literally hundreds of key professionals in the short-staffed field of mental retardation and related impairments. These are the men and women who have been, in good faith, developing exciting new plans in response to the Federal leadership that seemed to be so clear after Congress gave unanimous support to the UAF idea in 1963 and 1967.

A "now you see it, now you don't" approach to this issue will have a very disquieting effect on the already strained relations between the Federal Government and the universities.

Many millions of private and State dollars have been invested in planning programs and facilities and in assembling the initial interdisciplinary staff in anticipation that the Federal Government meant business. It may be argued that the Federal Government is giving lip-service to controlling expenditures while it contributes to inflation by causing dollars spent at other levels to be wasted.

The same observation applies also to the structures and plans brought into being at the State and local levels, in response to the inducement offered under part C.

Thank you.

Senator KENNEDY. That is very comprehensive testimony, Dr. Boggs. I want to express our great appreciation for your comments this morning, and for your help in the past in developing many of the ideas in this field.

You have shown once again this morning why both President Eisenhower and President Kennedy exercised such fine judgment in expressing their confidence in your guidance on the problems of the retarded and on our youth.

Let me express our appreciation to you.

I believe you heard the administration's comments yesterday on S. 2846 and the formula grant approach. Can you give us your own feeling about your reaction to this?

Dr. BOGGS. Frankly, Mr. Chairman, listening to the administration testimony yesterday was one of the most discouraging experiences I have had in 10 to 12 years in dealing with Federal legislation.

It was really—well, let me symbolize it this way: This morning I went to pick up a copy of MR68 which is last year's report of the President's Committee on Mental Retardation.

I found the pages were stuck together. Somebody had spilled a glass of water on it. It was symbolic to me. Cold water has been thrown upon the hopes that we have entertained for the Federal commitment to the mentally retarded and the pages were stuck together. The report was closed. It could not be further read, further heeded.

Yesterday's was a very discouraging experience. It was discouraging because I could not help but feel that this administration was making policy hastily at a level in the administration, at a locus in the administration, where there is obviously little understanding of the true problem.

It seemed to me that this was a careless brushing off of a need which has taken a long time to make itself manifest and visible. It was a careless way of abandoning any attempt to build on the impressive State level commitment and technical competence which has been nurtured, in the past 5 years especially, by the Federal Government.

It was inconsistent in its approaches to the Federal-State relationship. It was a way of saying to the State agencies and the Governors and the legislatures, "The Federal Government is a fickle acquaintance; it is not a solid partner; don't count on anything we say or tell you because 2 years later we may change our mind."

The administration witnesses said they would guarantee under this project grant approach that each State would get at least as much as

it would get in 1970 under the construction provision which, according to the administration's request, is the magnificent total of \$8 million for construction for the entire Nation (an amount that is about what it takes to build one good-size office building), and that this amount is going to be distributed among all the States. It means that 27 States can count on getting \$100,000 and those who get a little more are proportionately very underfunded.

It means that California can only be guaranteed one-fifth as much per capita as the neighboring State of Nevada.

It means that a poor State such as Mr. Black was pleading for yesterday, for example the State of Mississippi, can be sure of \$9,000 more than Nevada, which I also cited, or for that matter, \$9,000 more than Alaska.

Of course, to be fair to the administration, what they mean to do is to take additional money and parcel it out as they see fit, without any assurances, but if you are doing State planning you need some guarantee and what I just described is all the guarantee they would get under the administration proposal.

It says to me that an administration which has been in office for 11 months and has had excellent review machinery supplied to it, already in being in the Federal structure, provided by previous administrations ; which inherited a President's Committee composed of the outstanding people in the Nation, that this administration is now saying, "Oh, gentlemen, we should look at this program; give us time to study it some more."

This is a very discouraging experience for those of us who have been in the field.

Senator KENNEDY. I suppose it is particularly discouraging, since we know that the present program is going to expire next year. It is not simply a question of whether we start on such a program de novo today.

There must be some kind of machinery that tells the Federal agencies that certain legislation is going to expire.

Dr. BOGOS. This is true of all the health legislation and particularly true of this. I don't think it is any secret that the outgoing administration had the good grace to draft legislation in this area and leave it on the desk.

This is not a partisan area. The only real crunch issue was, how much could we authorize, how much money could we spare ?

This, as experience has well shown, is an issue that confronted President Johnson and President Nixon alike.

This effort, this ongoing effort of the Federal machinery has been available since January, but no attention was paid to it.

It is for this reason that we so welcome the initiative of this committee which, as I said earlier, has on several previous occasions come to the rescue when the administration has failed in its responsibility.

I am not speaking in a partisan sense here. It has happened several times.

Senator KENNEDY. One of the responses in Mr. Black's testimony is that some \$585 million is already being spent on the retarded. This figure certainly startled me. We received some background information in a lengthy report which was made a part of the record yesterday.

What is your reaction to this statement? They say we are already spending \$585 million. Therefore, they said, the dollar figure in S. 2846 is unrealistic, especially with our current fiscal problems.

What is your reaction to these statements?

Dr. BOGGS. This is like saying medicare provides services to people. It does provide services to people but only those over 65.

The money being spent by the Federal Government on mental retardation is of great value; it is like medicare, it is important, it addresses itself to the problem, but it does not address itself to all the problems in the field of mental retardation.

There are gaps in this system. But let me speak to that \$585 million figure. That, as I understand, came as a shock to you and members of the committee. However, this is a figure we have been familiar with for some months because we are very much interested and concerned that all the agencies of government address themselves to the mentally retarded in a fair and equitable way. More often than not, the retarded have been screened out of programs to which they are entitled as citizens.

We have spent the past 10 years making sure that educators educate the handicapped and that health people look at the long-term disorders as well as the acute conditions, and so on.

We believe that the mentally retarded should get their share within the whole range of existing programs and that the special agency—the Division of Mental Retardation—should deal primarily with those problems which were either interagency in nature or did not fall naturally in the responsibilities of the other agencies.

Now, for that \$585 million of expenditures for 1970. Mr. Black said we ought to look at his \$20 million for Public Law 88-164 in the context of this \$585 million. I ask you to look at this \$585 million in the context of the total HEW program.

This \$585 million includes not only the regular appropriations for the Department but also the trust funds that are expended for the retarded who are entitled to social security. That means that \$585 million is part of \$69 billion. That is what it is—less than 1 percent—and yet Mr. Black will cheerfully tell you that 3 percent of the citizens of this country are mentally retarded.

So I am not so impressed by \$585 million as being that much of a commitment. Furthermore, I think we need to analyze this figure a little bit.

Incidentally, Mr. Chairman, the figures that Mr. Black quoted are obviously the same as were given in the testimony of the Secretary before the House Appropriations Committee earlier this year and I have taken the liberty of duplicating the table on three pages out of that testimony which summarizes these programs.

Senator KENNEDY. We will make that table a part of the record.

Dr. BOWS. Good.

(The table referred to follows:)

Dr. BOGGS. Also, there is another breakdown of the same sum. I am going to address myself to that, too. In this excellent annual publication called "Mental Retardation Activities of the Department of Health, Education, and Welfare, January 1969," there is a breakdown of this same \$585 million according to activity.

(The material referred to follows:)

OBLIGATIONS FOR MENTAL RETARDATION PROGRAMS BY ACTIVITY DESIGNATION, U.S. DEPARTMENT OF HEALTH EDUCATION, AND WELFARE, FISCAL YEARS 1968-70

[In thousands of dollars]

Activity	Fiscal years—		
	1968 actual	1969 estimated	1970 estimated
Services:			
Health Services and Mental Health Administration.....	2,661	1,738	0
Office of Education.....	38,089	53,218	69,438
Social and Rehabilitation Service.....	81,359	148,272	200,014
Total.....	122,109	203,228	269,452
Training of personnel:			
Health Services and Mental Health Administration.....	2,291	2,688	870
National Institutes of Health.....	12,476	13,066	12,449
Office of Education.....	9,000	10,129	10,150
Social and Rehabilitation Service.....	16,386	18,807	23,507
Total.....	40,153	44,690	46,976
Research:			
Health Services and Mental Health Administration.....	644	630	625
National Institutes of Health.....	22,588	24,492	25,637
Office of Education.....	948	1,225	2,120
Social and Rehabilitation Service.....	6,293	6,335	6,361
Total.....	30,473	32,682	34,743
Construction:			
Social and Rehabilitation Service.....	17,546	27,941	14,003
Total.....	17,546	27,941	14,003
Planning:			
Social and Rehabilitation Service.....	1,394	0	0
Total.....	1,394	0	0
Income maintenance:			
Social and Rehabilitation Service.....	55,000	65,000	75,000
Social Security Administration.....	109,800	133,700	144,300
Total.....	164,800	198,700	219,300
Other:			
Health Services and Mental Health Administration.....	52	52	0
Office of Education.....	0	90	90
Total.....	52	142	90
Secretary's Committee on Mental Retardation ¹	(128)	(160)	(160)
President's Committee on Mental Retardation.....	577	580	605
Total.....	577	580	605
Grants and services.....	212,304	309,263	365,869
Income maintenance.....	164,800	198,700	219,300
Grand total, all funds.....	377,104	507,963	585,169

¹ These amounts are shown as non-add items since they are derived from funds available to several agencies of the Department of Mental Retardation activities.

Dr. BOGGS. The first sheet represents the way it was presented to the Appropriations Committee. The second is broken down differently. Both of these are important in the way they reveal the thrust of funding.

Now Mr. Black looked at the bottom of that long sheet (first table) and he said \$365,865,000 of this goes to what he called services and grants. That excluded the so-called income maintenance provision.

He said this was \$56 million more than last year. Let me just show you where that \$56 million comes from. In the first place, \$25 million of it comes from a phony line item called medical assistance. I will explain that if you ask me. It is the line item called "Medical Assistance grants to the States, \$100 million."

That is an estimate if ever there was one. I just want to tell you that 90 percent of that money is a well disguised revenue-sharing grant to the States. It is replacing State money that has been spent for the retarded heretofore. Very little of it is upgrading services for the retarded. Therefore let us take the \$25 million increase for that out of the \$56 million overall increase claimed by Mr. Black. That leaves \$31 million.

Now, Mr. Black didn't tell you, in presenting this material, that this material was developed and presented to the House Appropriations Committee before the Nixon budget cuts came along. So let us take off \$11 million total for Nixon budget cuts. This is composed of \$6 million out of the retarded's share of vocational rehabilitation and \$2.2 million out of the training programs of the university-affiliated facilities that you heard about yesterday, \$1 million out of the \$3 million earmarked for research in the NICHD and another \$1 million of unearmarked money for research in two of the institutes and a half million of vocational rehabilitation training money. All these were cut from the \$585 million by the President.

I am taking these as the proportion attributable to the retarded, not the total cuts of these programs. Then there is another half million dollars or so of miscellaneous cuts in libraries and community services, and so forth. That makes at least \$11 million that the Nixon administration took out. That takes this \$585 million down to \$574 million and it takes the \$56 million "increase" down to \$20 million.

Now, there is a \$15 million increase over last year in vocational rehabilitation which is mandated under the legislation this committee prepared. There is \$11.5 million new amount for vocational education of the handicapped which is also mandated by this committee. This is a total of \$26 1/2 million that is in this 1970 budget that was not in the 1969 budget, as a result of the mandate in vocational education and vocational rehabilitation that this committee enacted. If you subtract that from Mr. Black's phantom increase you get a minus number. You are down to minus \$6.5 million, an overall reduction in what is available for service, and training in mental retardation, other than in vocational program.

Another way to look at this is through the two page table you have there (second table) ; you will notice that \$585 million covers research, training, construction, services and so forth.

Research, we in NARC have supported research diligently. Training is tremendously important and our testimony in support of title II should indicate that. But when you talk about what is happening to the retarded who are here and now, you have to get down to the service area.

In the second table, at the top you will notice that \$269 million is listed for services. If you take out the \$100 million phony money I spoke of, that gets you down to \$169 million.

Most of that is education and vocational rehabilitation. Both vocational and rehabilitation funds are funds we have fought for. We want them, we need them, but they don't do everything for the mentally retarded of all ages. They don't reach very many preschool children and they don't reach the retarded over 30.

So there are lots of unmet needs when you take that service figure. That is what title I of this bill is addressed to—provision of service.

Senator KENNEDY. What about the relation of the State plan required in S. 2846 to all the other so-called "comprehensive" plans this committee hears about? Should we make this State plan consistent with the State partnership for health plan, for instance?

Dr. BOGGS. We certainly hope that the State plans for those with developmental disabilities will be seen as being coordinated with, rather than subordinated to, any other major State plans in health, or mental health, or education, or rehabilitation, or welfare, because the developmental disability plan is related to all of them but cannot be subsumed entirely under any one of them.

Those two tables we just discussed, particularly the first one, indicate that the mentally retarded are identified and served in vocational rehabilitation, in maternal and child health and crippled children's services, in special education, in public assistance, and also in a few adult health programs. I expect that Dr. Ganzer, when he testifies later, will be able to show you that quite a few retarded children and adults get psychiatric services in mental hospitals—40 or 50,000, maybe. The position of NARC has always been that the mentally retarded should as far as possible get their health services from health agencies, their social services from our social agencies, their education from public and private schools, and so on. But some of their needs are too specialized and for one reason or another fall outside the competence or mission of the generic agencies. And all the pieces have to be brought together in a planned way from the point of view of the retarded, individually and collectively. No one agency can do it all.

We would recommend that the committee make clear that the State plan for the developmentally disabled should specify what is being done or will be done for the target group under other major State-Federal plans and how the DDSFCA plan will complement, rather than duplicate any of those plans. However, we would not favor a Federal requirement for multiple agency clearance of individual projects within the State plan.

Of course, there already is a general requirement for clearing construction projects with metropolitan and other physical planning bodies, which would have to be respected.

Senator KENNEDY. HOW about leveling off this program at \$20 or \$25 million as Mr. Black suggested yesterday, in view of the amounts that are being spent in the other programs?

Dr. BOGGS. "Leveling off" is a very arbitrary idea. It takes no account of the history of a program, of its maturity. It's like saying to a family "As of now, and henceforth, each member will be allowed no more to eat than he had to eat last year" without regard to whether the person is 6 months or 6 years or 60 years old. Our program is a toddler who should be growing. The nearest comparable program, the community mental health centers program, has had a head start (due to various historical accidents); its staffing funds first became avail-

able in fiscal 1966 and have grown every year since; the first mental retardation staffing grants were awarded only at the very end of 1969. So leveling off for both programs is premature, but in mental retardation it is a disaster. Actually, it isn't even leveling off; it's reduction that is proposed.

As I've indicated already. This program is not interchangeable with others affecting other aspects of the problem. It zeros in on unique needs not otherwise addressed by the Federal Government.

Senator KENNEDY. In its reports "MR68" and "MR69" the President's Committee made a number of recommendations in terms of improving services and facilities. Is the administration's position consistent with the recommendations in these reports?

Dr. BOGGS. MR68, reaffirmed by MR69, focused on three main priority areas. One of these is the mentally retarded in poverty areas. Mr. Black made some references to that. I think his interpretation of the situation showed a lack of understanding of the problem but he did quote that finding of the President's Committee.

The second priority area was residential care. I don't think the administration's proposals address themselves in any substantial way to the problems in that area. I believe that S. 2846 can and should; it certainly is intended to cover both residential and nonresidential services and provide assistance in diversifying the range of living arrangements; the bill adds (to the definition of services) "specialized living arrangements" that focus on the need for so-called "alternatives" to the standard type of institutional care.

You bill, Mr. Chairman, addresses itself to these problems. The administration approach is a very spotty one at best. They didn't say a word yesterday that indicated to me that they appreciate the nature of this problem of residential care.

Finally, MR68 spoke to the manpower question. Probably the most important single tool that we have at present in the manpower picture is the university-affiliated facility idea. You heard yesterday what the universities are doing and the real changes that are being brought about, both in the training programs themselves and in the byproduct effects on the service areas, but this was brushed aside by the administration.

MR69 talks about building on the past, building and moving into the 70's. Let me quote their exact language.

It is

"Time to consider carefully and begin building the urgently needed programs for the retarded that must come into being during the 1970's. Time to renew our national resolve to bring the mentally retarded into full participation in daily life and work as their individual capabilities permit.

Time to press on in quests for ways of preventing mental retardation.

I don't think that the administration witnesses really address themselves to that either.

It is true that the Deputy Assistant Secretary for Health did mention prevention and I was glad to hear he was aware of this need. But prevention depends on research and on training of manpower.

Primary prevention is not a primary objective of title I of this bill. Secondary prevention is, because early services are important to secondary prevention.

Senator KENNEDY. What is your feeling about the administration's position that by project grants rather than formula grants, they will

be able to focus the limited resources in the areas of greatest need—for example, in poverty areas?

Dr. BOGGS. Let me say, first of all, that every major Federal program which involves activities which have to be carried on at the State and local level should, in our opinion, consist of both formula grant money and project grant money.

The reason there is no project grant provision in title I, I am sure, is that there already exists a broad—by that I mean broad in terms of its applicability—project grant authority available to the Division of Mental Retardation.

Senator KENNEDY. IS that under the Mental Retardation Act?

Dr. BOGGS. No, it derives from a special phrase added in 1968 to section 4 of the Vocational Rehabilitation Act. It was incorporated as an amendment proposed by Senator Hill. It makes possible project grants related to rehabilitation of the retarded without limitation to vocational rehabilitation.

Senator KENNEDY. HOW much money is involved?

Dr. BOGGS. For fiscal 1970, \$4.5 million has been requested. This year is the 1st year under which project grants will be funded under the "section 4" authority. This is called "rehabilitation service projects" in the table we have appended to our prepared statement. It does everything that the administration talks about except provide project grants for construction.

It provides all the other things, training projects, service projects, demonstration projects, and so forth. It is a very useful little thing.

What do they ask for? For \$4 1/2 million for projects for the entire country for 1970. That could be expanded without any more attention to substantive legislation.

Senator KENNEDY. They have not had a project grant authority before?

Dr. BOGGS. The Division had a project grant authority when it was part of the Bureau of State Services of the Public Health Service. It began in 1963-64 and was gradually built up to \$5.5 million in fiscal 1967. Then after the Partnership for Health Act, funds were no longer available specifically for mental retardation, and the Division was without general project authority and leverage in fiscal 1968 and 1969.

Senator KENNEDY. DO you believe that there should be a clearly spelled-out project grant authority in S. 2846?

Dr. BOGGS. While not absolutely necessary, such an authority would strengthen the bill if it were not allowed to diminish the basic formula grant provisions.

Senator KENNEDY. DO you believe that project grants are needed to reach the areas of greatest need?

Dr. BOGGS. Not necessarily, not federally administered project grants; with a properly structured formula grant, you can assist the States in doing the job in the areas they identify as high priority areas. Don't think the States don't know where these problems are.

In further response to your question, the important things are, I think, first, the fact that project grant authority alone is not enough; if the project grant authority were big enough to do the job in deprived areas, it should not be a project grant authority. Secondly, Secretary Black yesterday showed a lack of understanding of the nature of the problem in the so-called poverty area when he kept talking about the

necessity for putting facilities "in the places where 75 percent of the retarded are."

Now, in MR68 there was a map, on page 18, of St. Louis which purported to show, and I think did show to a considerable extent, that there is a correlation between the school enrollment of mildly retarded educable children and the existence of poverty.

It showed the proportion of all schoolchildren who are enrolled in special classes for the educable mentally retarded, by census tract.

It showed that the highest concentrations were in areas designated as poverty areas.

The majority of these people, the mildly retarded, don't need specialized facilities for the retarded. They don't need to have a building apart marked "institute for the retarded." They need to have specialized services, from specially trained people, services built into the neighborhood health centers, into the education system, into the social service systems, so that their needs can be met where they naturally come for service.

They do not need to get a big separate installation and a big label "mental retardation" placed on them in that way.

They need to be seen for what they are, if they are indeed mentally retarded, by the people who deal with them, who attempt to assist them professionally with their problems.

Let me digress for a moment and tell you that a recent followup study of the retarded in the public schools of New York City reveals a very interesting thing.

It showed that whereas the enrollment in special classes for the retarded in New York City of Negro children was approximately proportional to the total number of Negro children in the New York public schools, the enrollment of Puerto Rican children in special classes was double and the enrollment of other white children was half, in proportion to their enrollment in the public school system.

What this says is that Puerto Rican children are being identified as mentally retarded under situations that raise grave questions as to whether this is true mental retardation or whether this is the result of their failure to respond to the tests that we give them in a language foreign to them.

Now this issue has become a hot one in Los Angeles recently, because of the large Mexican-American population there, to such an extent that the Los Angeles city schools have forbidden the giving of so-called IQ, tests to first and second-graders lest the children get a label that they should not have, of mental retardation.

Now I am saying this to point out that when Mr. Black says clearly "75 percent of the retarded are in the poverty areas" he hasn't distinguished the mildly retarded from the severely and profoundly retarded.

In MR69 there is a map showing distribution, showing the number of identified profound and severely retarded persons in Los Angeles County overlaid with an indication of where the poverty areas are.

I think if you remove the overlay on the poverty areas here and if you take account of the density of population in the tracts which concentrate more in the center of the city, the very few people could look at that map and say, "Oh, well, I can tell from that map where the poverty areas are."

We don't deny that there is some correlation between the conditions of poverty and the conditions of severe mental retardation. There is some correlation because lead poisoning, for example, which is a very devastating cause of severe mental retardation, is more common in dilapidated housing areas than in the suburbs. There are other factors, also. But basically, the distribution of severely and profoundly retarded children and adults is not so very, very different in the different socioeconomic groups, and there is desperate need in all of them.

Now, if Mr. Black only knew it, we in NARC were among the first to point out to the administration back in 1965 and 1966 that the functioning of Public Law 88-164, for the reasons he outlined, was not resulting in facilities for the retarded being built in the poorer parts of town.

This had to do with the matching formula, the low Federal share in urban States, and with the laissez faire dependence on local private initiative, which was stronger in the more privileged areas, and it had to do with the lack of any visible means of supporting the program after it got going.

We have addressed ourselves to this problem in NARC. Mr. Black didn't tell you that half of the staffing grant money that was awarded in mental retardation, went into areas known to have urban and rural poverty.

Your bill addresses itself to this problem. I think I mentioned in my testimony that the bill requires States to give priority attention to the areas of urban and rural poverty. I also mentioned the proposal for increased Federal matching under the construction provisions in title IV of the act.

It should also be pointed out that many of the existing programs—other existing programs—can be brought to bear on the mildly retarded in the poverty area and should be brought to bear.

So this argument seems to me to have been distorted. It is clear that we need to get more facilities for the moderately, severely and profoundly retarded in the poverty areas. There is no question about it. Your bill would permit this to be done, would provide incentives for it to be done under a formula grant approach.

Another thing we might mention is that Mr. Black kept saying that the distribution of mental retardation is not equal among the States. If you assume mental retardation is more present in poor States than in wealthy ones, let me point out that the formula for allotting the funds gives attention to that. The per capita income in Mississippi is about half the national average and in Nevada it is about twice the national average.

Fiscal resources of the States are taken into account in the formula for allotting the funds under the present act which would be continued under your bill. I think this is not a good argument for an exclusively project grant approach.

Senator KENNEDY. What about the level and duration of funding under the bill. Do you think it is adequate?

Dr. BOGGS. I would say it is minimal. What we have been getting and are likely to get is less than minimal, however.

Senator KENNEDY. Is there any point in putting in an authorization which is above a realistic level that can be expected for appropriations?

Dr. BOGGS. Yes. I think the authorizing legislation should be the need realistically, not grandiosely, but realistically. The limits set in Public Law 88-164 could and can be justified.

For 1970 it authorizes \$20 million for part B, enough for six or eight facilities. In S. 2846 you ask for \$20 million a year for 5 years. If we could achieve this level we could fund one per State or one per 4 million people by 1975 and be at full production in training professionals by 1985.

For 1970, part C construction is authorized at \$50 million. This is the annual level that was proposed by the President's Panel in 1963. Allowing for the fact that we have put up less than 100 million Federal dollars in 5 years, for inflation and for population growth, a level of \$75 million rising to \$200 million just for construction and just for mental retardation is not out of line.

Costs of services quite properly outweigh construction. At present the States and counties are putting up more than a billion dollars a year for the care, training, and rehabilitation of the relatively small group—a quarter million—of the retarded who require residential care. If Federal aid is to give the desired lift and new directions to this program, more than token dollars will be needed.

On this basis alone, the \$100 million specified for 1971 in S. 2846 is a "barebones" statement of need for the retarded alone. Increases in subsequent years should reflect the expanding attention to needs of the retarded plus a markup, eventually reaching 50 percent, as other developmental disabilities are phased in.

Senator KENNEDY. HOW about duration; is a 5-year authorization too long?

Dr. BOGGS. Five years is none too long and 3 years is too short—too short to enable the bureaucratic machinery to revolve and produce results before we have to come back to you again to extend the program.

In my State, we used to have required automobile inspections every 6 months—and a jam-up. The law was changed to require annual inspections. The accident rate wasn't accentuated by the jam-up was eliminated. If Congress wants to *get* home before election day, it can do so by giving some of these programs less congressional oversight and more time on the road between inspections.

Senator KENNEDY. I want to thank you very much, Dr. Boggs. You have covered a number of different areas and it is extremely helpful to us.

Again, thank you very much. You have been a great help to this committee. The testimony you have given will be extremely valuable to us.

Dr. BOGGS. Thank you for your kind attention and courtesy and for sponsoring the legislation.

Mr. HAYES. Thank you very much.

Senator KENNEDY. Our next witnesses will be Dr. Robert E. Cooke and Dr. Arnold Capute from Johns Hopkins University. Dr. Cooke was trained at Yale in pediatrics and physiology. His first experience with the retarded was in 1944 at the Southberry Training School in Connecticut. He served under President Kennedy on the President's Panel for Mental Retardation, and was a member of the President's Committee on Mental Retardation under President Johnson and