Robert E. Cooke Oral History Interview—JFK #1, 3/29/1968

Administrative Information

Creator: Robert E. Cooke **Interviewer:** John F. Stewart

Date of Interview: March 29, 1968 **Location:** Baltimore, Maryland

Length: 23 pages

Biographical Note

Cooke, Chairman of the Medical Advisory Board of the Joseph P. Kennedy, Jr. Foundation and a member of Science Advisory Council of the Children's Hospital Research Foundation, discusses the creation of the National Institute of Child Health and Human Development, the President's Panel on Mental Retardation, and debates over where the research emphasis in the field of mental retardation should lie, among other issues.

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Suggested CitationRobert E. Cooke, recorded interview by John F. Stewart, March 29, 1968, (page number), John F. Kennedy Library Oral History Program.

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Robert E. Cooke—JFK #1

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First of Two Oral History Interviews

with

Robert E. Cooke

March 29, 1968 Baltimore, Maryland

By John F. Stewart

For the John F. Kennedy Library

STEWART: All right, let me ask you then, how did you get involved with the Kennedys,

with Mrs. Shriver [Eunice Kennedy Shriver] before 1961? What was your

relationship?

COOKE: Well, I think it was about 1958 that I was approached by Richard Masland,

who was then the Director of N.I.D.B. [National Institute of Neurological Disease and Business] with the request to develop some kind of a proposal on

a mental retardation research center here at Hopkins [Johns Hopkins]. I did so and it seemed to be interesting to the Foundation [Joseph P. Kennedy, Jr. Foundation]. And so Mr. Shriver [R. Sargent Shriver, Jr.], Mrs. Shriver, and a small number of consultants came to visit. From that first visit, other visits followed. Then there was a mutual exchange of correspondence and a working out of an agreement between Hopkins and the Kennedy Foundation. The person who played the most active role in that exchange was Sargent Shriver, and to a lesser extent Eunice, and Ted Kennedy [Edward M. Kennedy] was involved a bit, too. After that contact with the family in about '58, they tended to use me more and more as a consultant. Then I was appointed to the Medical Advisory Board of the Foundation, the Scientific Advisory Board, and I've been there ever since. I have gotten to know them more and more, and they still seem to count on my advice.

Now, about the middle of the summer of the campaign year—I've never had a memory for dates, that would be...

STEWART: July of 1960.

COOKE: ...July of 1960—I was asked by Eunice to send in ideas to the President, John

Kennedy [John F. Kennedy], ideas on the health and welfare needs of

children. I did send in some suggestions, which, I think, were used in part in

the campaign, certain programs that might be attempted for retarded kids and normal kids as

well.

STEWART: There was nothing terribly specific about mental retardation that he

mentioned, was there?

COOKE: No, that's right, not at that time, there was very little, and it was mostly in

terms of improvement of child health services and one thing and another.

And then, between his election and inauguration, I was asked, I think a call

came from Wilbur Cohen [Wilbur J. Cohen], to serve on a Task Force on Health and Welfare. That then was really my more formal entry into Administration thinking. My job in that particular task force was to write up soma specific programs for advancing child health. It was at that time that the proposal was made for the Center for Child Health. That recommendation went on then to be designated as the Center for Child Health which then led to the a creation of the National Institute of Child Health and Human Development [N.I.C.H.D.].

STEWART: Going back just a little bit, during the campaign or even before when it was

known, of course, that President Kennedy was going to run for the presidency, was there any reasonably definite talk within, or among, the Kennedy people

as to what they would do in the field of mental retardation if the President was elected?

COOKE: Well, I don't know of any specific things. I have vague recollections—

certainly no well defined things at all—I think just an occasional comment

that there might be more that could be done, and so forth, but no specific

programs. The idea of a National Institute of Child Health and Human Development—I don't know if you want to have this sort of thing—but my own notion was that this was a reaction to the antipathy which the National Institutes of Health had at that time to any sorts of programs oriented around the very young individual.

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There was a change in the policy of the National Institutes of Health to the support of training in the field of pediatrics, much put it in a very minor role. Doctor Harry Gordon [Harry H. Gordon], who is now the Dean at Einstein [Albert Einstein College of Medicine], and I went to see Shannon [James A. Shannon, Assistant Surgeon General], and Shannon indicated that as far as he was concerned, pediatrics was essentially playing the role of the

grandmother and not any great value. There was also, at the same time, some new clinical research centers being developed in medical schools. The decision was made that children and adults ought to be thrown together, which was a backward step, at least in our minds. So this resentment of the action of the N.I.H. led to the suggestion of a center for child health, so that we'd have some focus within the research institute. So it was basically a reaction to a poor government policy which had been developing in a previous administration.

STEWART: Why don't we follow whole thing through to the actual creation of the

National Institute for Child Health?

COOKE: Right.

STEWART: Had this been proposed before in a serious way, or was there a good deal of

pressure for the establishment of the new institute...?

COOKE: Actually, it was almost zero. I'm told by Martha Eliot [Martha May Eliot],

that in the early days of the Children's Bureau, it was recommended that there be developed some kind of institute concerned with research in child health as

a part of the Children's Bureau. It died evidently, and to my knowledge there was nothing going on at the time. It's a rather interesting story how we managed to got this thing going. The Wilbur Cohen task force made this recommendation, I think, within the first ninety to a hundred and twenty days. The President did—I guess the legal end of the White House looked into—the constitutionality of creating, you know, whether it's legal, I don't know what the exact term is...

[-3-]

STEWART: Creating it without...

COOKE: ...whether the executive branch had the authority to create an institute, and

there was some question to whether or not this was possible. I can remember

meeting with Wilbur Cohen, and I believe the impression I got was that it was

probably within the authority of the President to do it, but it was controversial enough so that it seemed to make sense to create legislation, rather than to attempt to do this by administrative act. The Center could be created, and the Center was created. It was essentially a paper organization completely. I don't believe it ever did a thing, but it simply established a kind of pre-institute status.

Now it's very interesting that there was considerable action against the creation of an institute. The reaction of the head of the National Institute of Health, Jim Shannon, who is a terrific guy, but his reaction at that time was against the proliferation of institutes there. He didn't believe that cutting research on an age basis was an appropriate way to do it, that the traditional approach was to look at things in terms of systems—something wrong with a heart, or something wrong with a nervous system, or something else, and this was the traditional way of looking at it. To have something that cut across all these with age time as the variable was a new way of looking at the support of research, and he was reluctant to do

this. There was also some question of whether an institute could be concerned with normal processes. This was a radical departure as well. And when the decision was made that this was within the authority of the original legislation to set up the National Institutes of Health, that it could be concerned with, in a sense, health as well as disease, then the decision was to have an institute which was concerned with a span of life, and to get the normal concept in, human development. So it ended up with that title. Now there was a great deal of jockeying as to what the name ought to be. My suggestion originally was that it be called the National Institute of Child Health. Jim Shannon didn't want that. He felt that it was too narrow, it didn't fit in the concept of normality. He wanted this known as the National Institute of Human Development. Then Human Development and Child Health was suggested. I just kept insisting. I don't know who finally made the decision in the government, but the decision was made the there was a little more appeal to the public to call this Child Health and Human Development, and so it was left in that order.

[-4-]

Now it was very interesting in trying to corral support for this. There was resistance among professional groups, and an almost total apathy in other areas. I can give you a little pamphlet which we put together that attempted to marshal the arguments for the Institute. It was widely distributed among parents' organizations, various semi-professional groups, and the like. There was resistance from the obstetricians which was of interest. The obstetricians—I don't know if you know the structure of N.I.H., but there are review groups which are called study sections. They evaluate projects, pass on their recommendations to the councils, and the councils then issue what is really, to an extent, rubber stamps approval of the actions of the study sections. Well, there was a study section created a number of years before, entitled Human Embryology and Development. It was originally conceived of as a way to review grants that were concerned with human reproduction, with the development of babies, their wellbeing, and the growth of children. This was originally set up in the early Eisenhower [Dwight D. Eisenhower] period as a kind of balance between pediatrics and obstetrics. Through some political maneuvering it became almost solely obstetrical. When the organized obstetrical groups of the country heard about the creation of the new Institute, I think they were concerned they were going to be left out, and their balance of power was going to change a lot. So they actually tried to marshal some kind of ineffective opposition to this. There were a series of meetings with the obstetricians to try to got them to not oppose this in the congressional hearing. They kind of went along in a sort of lukewarm support, stating that this was okay, providing it really covered obstetrics as well.

STEWART: Was the opposition within H.E.W. [Department of Health, Education, and Welfare], within N.I.H., serious enough to cause any back door approaches to Congress on this?

COOKE: Well, Jim Shannon saw this as an opportunity to get what he had been wanting for some time in the way of elevation of the, what then must have been a Division of General Medical Sciences to institute status. I think the

deal that was made between whomever was handling this within H.E.W., and I'm not sure whether it was Wilbur Cohen, or not. The deal was to have the legislative package include both the creation of the new Institute and the elevation of the Division of General Medical Sciences to institute status. That package, I guess, satisfied Shannon.

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STEWART: They both passed at the game time?

COOKE: They supported it. Well, right. It was in the same piece of legislation...

STEWART: Oh, it was.

COOKE: Yes, and I think this was the deal that he must have made to support the

National Institute of Child Health and Human Development. Now it's interesting as one looks over the testimony that the official government

position was almost entirely on the National Institute of General Medical Sciences. Most of the non-governmental testimony was on the National Institute of Child Health and Human Development. There was a whole series of recruitments of people to testify. I think it was really about the first time that a case for mental retardation was stressed as an important issue. I think you've got all the testimony and so forth, so there's no value in my repeating it.

STEWART: The factor of waiting for the panel to finish its work wasn't a consideration in

setting up the Institute, was it?

COOKE: No, it wasn't. In fact, it's interesting that you bring that up. When we came to

make the final recommendation from the panel.... The Panel was created

before the final legislation was passed. But it was, I think, that the Panel was making the final recommendations and putting them into the report about the time that the bill was to be—it was after the hearings, I believe, but before it had been introduced, before it had been voted on. I remember saying at the last moment practically, well, why don't you at least put in one of your recommendations the support of the creation of the National Institute of Child Health and Human Development. There was no disagreement, but there was a passive resistance to this ever getting into the report. It was curious that people just walked around it, as there were a number of people on the President's Panel who visualized this as overemphasis of the biological aspects of retardation. I'm sure you've developed that theme already, but this was the major conflict within the President's Panel. It

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ran through it, and it s still going on—that MR [mental retardation] isn't a medical problem, it's an educational problem. And so the educators on the panel were reluctant to come out for the N.I.C.H.D., since the significant part of the support for that would do something about the MR problem. And then there were some basic scientists on the panel, who felt that the way to solve the problem was not through something oriented toward child health, that it was

better to put the money into the Division of General Medical Sciences, and so forth. It was interesting, that there was a kind of a passive resistance to even mention the fact. I got the feeling that legislation went through without any question because the President was taking somebody's word for it that there needed to be a focus on child health within the Institutes of Health. The documentation that prior to that time there was almost nothing going on in the field is pretty good. And I think that you can get that right out of the records. But in the child health area, for example, we did some calculations, and the grants programs the intramural program was zero for children. They had a few kids in the Cancer Institute that was being rather poorly cared for. There was not a single doctor with more than a year of training in pediatrics in the whole institute caring for whatever kids they had. It was a pretty bad situation. If you had that in a general hospital you'd be thrown out as an accredited hospital with that little coverage. And the grants program was just minuscule on the whole child health field. So there were a lot of reasons why they—well, we'll get on to some of the subsequent legislation, but congressional reaction to all of this was highly favorable. I think Mills' [Wilbur Mills] committee referred—was it Mills' that had that first go around with the institutes? Yes, I think the sub-committee was—Roberts was the chairman of the subcommittee at that time.... Kenneth Roberts [Kenneth A. Roberts]...

STEWART: That was the—Oren Harris.

COOKE: It was Oren Harris, right.

STEWART: It was Oren Harris of Interstate and Foreign Commerce and the public...

COOKE: Kenneth Roberts was the sub-committee, and Oren Harris was the chairman

of the main committee. And they were remarkably sympathetic toward the

whole thing.

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STEWART: Let me ask you a few questions. Were you in on the discussions that led to the

establishment of the panel, in January and February of 1961?

COOKE: Do you have this as the origin of the panel? Did anybody tell you how that got

started?

STEWART: Not really. Well, as far as the people, I haven't actually talked to anyone who

was involved in it at that stage. In going through what records we have, I see

notes of various meetings, but I have no absolute indication about just how it

got started.

COOKE: Well, I'll give you an idea.... Let me tell you how I think it got started. This

may be denied by some people, but I can recall at one or two meetings with the Shrivers discussing the question of how attention could be called to the problem of the retarded on the national level, and how the President could use the authority of his office to call this to the attention of scientists, and important people of various disciplines as well as the general public. I remember very clearly the statement that Eunice made when she talked with her father [Joseph P. Kennedy, Sr.]. Her father said they ought to use an approach similar to that of the Hoover Commission, and he was the one who made the suggestion for a President's panel. I didn't hear him make that statement, but Eunice said, "My father said we ought to create something like the Hoover commission, and call it a President's Panel." And indeed, Eunice and I went up to see Herbert Hoover and talked with him before the creation of the panel to try to get some idea of what sort of an organizational structure was needed to have a commission like this. What ought to be the subsequent actions of following the report, et cetera, et cetera. President Hoover was very sympathetic and rather helpful actually. And I think the origin of this was with the President's father.

STEWART: That's interesting, that Herbert Hoover did.... Did he have any specific suggestions on the type of panel, or was he at all knowledgeable about this problem?

COOKE: No, no. I think that I was interested, delighted,

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very pleased to have Eunice come to seek his help. What his suggestion was, I remember, the one I remember specifically was in regard to implementation of recommendations. He talked about the development of a non-government organization structure that would continue to, in the sense almost lobby for the recommendations. It would be a rather widespread national citizens committee that would see to it that in each state, and in each locality, and then on the federal level as well, that the recommendations might be implemented. Interestingly enough, that was never done. There was never a strong follow up mechanism of a citizen group to assist in the implementation, but I think it was a good idea. I think the Hoover Commission had such a system, how much it accomplished I don't really know.

STEWART: Where did it go from there, as far as you were concerned?

COOKE: As far as I can tell, with the suggestion of Mr. Kennedy, Sr. to Eunice or to the President. I'm not sure exactly what the routing was, there was then the decision to go ahead and create such a panel. And I was asked to serve, and suggest names of various people. One of the problems, of course, was who ought to be the chairman. There was a good deal of discussion and a number of us had had close contact with Leonard Mayo [Leonard W. Mayo], through his job in the Association for the Aid to Crippled Children. Mike Feldman [Myer Feldman] played quite a role. He was sort of the intermediary in this whole business between the Shrivers and the President and some of us. He was responsible, I think, for a number of suggestions. I don't remember exactly. What it amounts to is a lot of different people sending in lists of suggested individuals, and then they get screened in a completely haphazard manner. It sort of gets boiled down to this: somebody

says, "Well, Josh Lederberg is a great scientist, and so we'll ask him," and so forth. Lederberg had been invited earlier in the Wilbur Cohen panel, and...

STEWART: Yes, I remember.

...he had made the suggestion of an Academy of Medical Sciences, which has COOKE:

> still not been implemented. That was part of the task force report which, of course, has not bean implemented. It is the only part that's still brewing.

> > [-9-]

STEWART: As far as the basic decision to set up the panel, or a commission, I think it was

called a commission originally, who else would have been involved in this?

Was it made totally by Mrs. Shriver in consultation, say, perhaps with you and

one or two others, or....

COOKE: I wish I knew. I got the feeling that once the idea had come from Mr.

Kennedy, Sr., Eunice got it. Probably the President got it at the same time.

There was then a lot of discussion back and forth with Mike Feldman, and I'm sure informal discussions between Mr. Shriver and the President. And somehow, somebody then said, "Okay, let's start recruiting for this panel." But what the substance of those other

discussions were, I don't know.

STEWART: Because weren't there certain negative factors involved? Wasn't there some

reason why a commission wasn't a good idea, at least at this time?

COOKE: Well, I don't know about that. I got the feeling that H.E.W. wasn't very

enthusiastic about it; that this was almost a device to short circuit their usual

approaches to a problem, which was to develop some legislation and make

their own studies, and so forth, and to get an outside group in of civilians. So I go the feeling that there was sort of passive resistance in H.E.W. towards this whole idea. So it was largely worked out in the absence of any H.E.W. participation; worked out through Mike Feldman pretty much as the White House Special Assistant. I don't even recall any suggestions coming from H.E.W. as to the make up. Now how is the panel made up, you asked me. Well, the panel was made up, as I say, by this kind of hit-or-miss sort of suggestion lists, but there was some structure to it in that, at least in discussions with Feldman and the Shrivers, we attempted to get some coverage of the critical disciplines that were involved. It's worth pointing out one particular omission which bothered me a great deal, and that was that labor was omitted from the panel, which is sort of getting ahead of the story. But I can remember our first organizational meeting at the White House, in what was then called the Fish Room when they were asking for comments there was some overview of what we were supposed to do, and they asked for comments about certain questions that the members had. I can recall asking

why it was that there was no coverage from labor. And somebody came and gave me a little note, that said, "Right after coffee break can I chat with you?" Then the coffee break occurred right at that time, and someone from the White House staff, I think it was Mike Feldman, spoke to me and something like, "Well, I wish you wouldn't say anymore about this. We're a bit on the spot, because there's nobody in labor that we would trust except for the one or two top men, and they don't have the time to give to this." This was an interesting reaction. But it's very true that the range of the panel's recommendations and deliberations and its future—the implementation of the panel—has been seriously handicapped by the fact that labor was not involved in the original activities. One of the stumbling blocks in the whole employment issue of the retarded, is the demand that these people be active full time union members on the same wage scale, et cetera, and not competitive with organized labor. This puts the retarded in a very unfavorable position. Membership on the panel by labor would not necessarily have solved that issue, but I think it would have allowed us a more realistic look at the real problems of employment and the handicapped.

STEWART: Then you're saying this was simply an oversight...

COOKE: No, I think it was deliberate. I was told there was no one in labor, with the

exceptions as mentioned, who they could count on at that time to serve on this and to speak for labor. I didn't quite understand what this was all about

this, and to speak for labor. I didn't quite understand what this was all about.

And I still don't exactly know what they meant, but I think, it was an intentional omission of labor from the panel, because, as I say, when I asked why isn't labor here, I was told essentially to keep quiet about the whole thing.

STEWART: What were some of the other problems that may have come up in the selection

of members? Was there, for example, any need expressed by anyone to have a certain number of lay people represented on the panel, or people who weren't

professionals in the field, but who...

COOKE: Well, the approach to the panel, I thought, was highly non-political. I'm trying

to think of whether there was any.... Did we have any Negroes on the panel?

STEWART: I'm not sure, I've seen...

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COOKE: I don't think so.

STEWART: ...some correspondence suggesting, well, various people, various possibilities.

I'm not sure that any were actually selected. It must have been a

consideration, at least by someone.

COOKE: Well, I'm sure that someone did have these considerations, but the selection

ended up being those individuals who had great stature in science or in some

aspect of retardation, or, who had demonstrated some exceptional ability, or some exceptional standing in the field itself. I thought it was about as free as any I've known and I've been on a number of these since, and they've all been highly political oriented, but this one wasn't. Nowhere did I get the feeling that somebody was on there because he represented an area of the country, or a power group of any sort. There was representation from the National Association for Retarded Children. It was there strictly because this person knew more about certain aspects of the problem of retardation than anybody else, and was highly motivated. That was Elizabeth Boggs [Elizabeth M. Boggs]. And it was highly representative of areas that would be of importance. It was really the first ecumenical look at the retardation problem, quite honestly. In the past, the MR problem had been one confined to departments of health or departments of mental hygiene, or to somebody in education, but never before had these various groups come together to try to do something, or even discuss the problems of the retarded. The educator, and this came boiling to the top from the very beginning of the panel, the educator said something like, "I'm the one who handles ninety percent of the mental retardation problem; it's really an educational problem. I don't recognize genetics. I don't recognize this and the other defects that you physicians talk about." The doctors had literally never talked before to the educators, and at the end they were still not talking with each other—they were talking to each other. But it was a terrific step.... It was a first step without any question.

STEWART: Looking at the whole effort, to what extent was the need for a commission like this brought about in order to get these proposals before Congress, give them a

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lot of publicity and get them passed and to what extent was it to seriously formulate these proposals?

COOKE: This was the most honest commission or panel that I can imagine. There was literally no legislation on the books at all, except the N.I.C.H.D. which had

preceded it. And, as I say, the panel didn't even support it very actively.

There was a nice thing or two said about it on the last day, but there was no legislation in the hopper to my knowledge. Whatever was developed subsequently by H.E.W., and whatever the Administration did, was a reaction to the panel's report. As I understand the process, and I'm sure you can get better verification than this, I think the panel report was given H.E.W. with the order to come up with some reactions to this in the form of legislation recommendations. Then there was a series of workings, on a very informal basis, with the legislative arm. But there was no intent, to my knowledge, to get this group together to give public support to some particular proposals that might be in the mill.

STEWART: Not that might be in the mill, but that would result from it? I guess what I'm asking is, could in fact the proposals of the panel have been anticipated, or generated within, say within H.E.W., or within the federal government in a much quicker, possible and a much smaller, with a much smaller effort?

COOKE: Yes. I think there's a difference between whether it could or would have been done. Yes, it could have been done, very definitely, because none of the ideas

were so world-shaking that if H.E.W. had called in a few of us we could have

laid out most of the recommendations. That it would have been done? I don't think there's any question in the world that it wouldn't have been done. H.E.W. had no capability and no interest in the area at that particular time. Now they might have had an executive order that said, look, get some people together and develop a real program on MR, and I suspect it might have been like that which the President's panel developed. For the amount, it was a relatively small amount of effort. I don't know what the final budget was, but it was one of the smaller investments that had, I think, quite a productive result. There was a lot of volunteer work.... I

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can't even remember whether anybody got paid. I guess they did—they must have. But there was an awful lot of effort that went into this that, I think, would never have been generated by just an H.E.W. request. You know when you consider the consequence of this.... I was reading a brief report, and you ought to have that. This was a historical review of Head Start, how it got started, and of course this is a direct output of the President's panel report. This is a rather neat review in this by Ed Davens [Edward Davens], who was one of the members of the panel. [Looking for review, trails off] These were some of the recommendations that he cites in here that were directly responsible for the Head Start development. I can get one of the girls to xerox this if you want. It's in the record in a sense, but there are a few references in there that wouldn't be in the record....

STEWART: Okay.

COOKE: He gives a little bit of the outgrowth. I think that the reason this, in part, was

successful was because there was no intent for this to be a ballyhoo operation.

They got excellent people on their own staffs, for example, to prepare material and the report was much more than simply the thinking of the panel members. I know in my own setup here, we had more than a half a dozen people who were strongly involved, very much involved with some of the problems. We were doing the prevention side of the whole

business. And this got a lot of people into the act. I think it was a very honest effort.

STEWART: To what extent was the Joint Commission on Mental Health a model for the

panel, or was there any thought, or was there any relationship in the thinking

of the people who were closely tied to the panel....

COOKE: Well, I think in the Joint Commission on Mental Health, that the thinking was

just that the whole damn problem of retardation was left out. And this was one of the actual reasons for going ahead with the panel. It was so obvious that the

so-called professionals, at least in the area of psychiatry, totally left out the problem of the retarded, and left out the problem of the child. Now, I don't think it was much of a model. It may have been for Leonard Mayo and his organizational thing, but

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I doubt it. The structure was pretty simple. They tried to make an outline, and I can remember being involved in the planning of "what is the subject?" and then how do you parcel it out in groups. This was a fairly straightforward job of trying to divide up the assignments. Then the task forces and the panel did the same thing, divvying up the assignments. Now there were some parts of the panel activities which, as you asked, could have been done without so much fanfare. I suspect the trips to Europe were a bit of a waste of time. I don't know how much one gets out of that. I think the result of that was to see that the Scandinavian countries were way ahead of us in the organization of residential facilities and the panel got the feeling that the whole thrust of society there was towards service rather than production. This is something that we wrestled with, but don't know how to overcome the different orientation of the young people to be happy to do service things rather than be in production. The visit to England, which I ran, came up with one worthwhile concept, I think, that was imported through us to a large extent. This was the concept of the risk register, which never really got amplified in the final recommendations, but did get into the professionals' mind, at least. This is the concept of maintaining a kind of record of those individuals who before they're born had difficulties possibly that would make them more susceptible, more likely to have retardation. The concept of the handicapped register is still being developed now by the present President's committee. Those are two fairly major things that were imported by those visits, but I think even without those we wouldn't have done things too differently.

STEWART: As far as the time that the commission would be in existence, was the initial thinking always for one year, or was there any thought that possibly there should be a two or three or even a four year...

COOKE: Well, I can tell you our reaction at first was that the President couldn't be serious. Anybody that asked for this thorough a job in one year just couldn't know how complicated the field is. I remember when it was first said, you know, that it was going to be a year, that there was some whispering that this was just ridiculous, hat they just want a superficial glossing over. Well, it didn't turn out that way.

STEWART: Who actually decided on a year, do you know?

COOKE: I don't know. I think that—well, I do know that there

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was some discussion. I can remember Eunice saying something about the fact that her brother didn't want one of these things that just went on indefinitely.

This would have, at least, made people really get down and do something in a hurry, rather than just have a kind of open-ended, never-ending analysis of problems. There was definite pressure to get something out so that there could be a start of some legislative activity. I think that it was the hope that there would be some legislative product that could be marketed, and that was the reason for the year deadline rather than a much longer period. As it turned out that was enough.

STEWART: Then certainly there was no fear that if it was only a year and possibly another year, as it turned out, to formulate the legislation, there was no fear that progress would be delayed because the panel was still deliberating, so to speak. Was there?

COOKE: Well, let's see.

STEWART: Can you recall any specific things that people wanted to do, say in 1961 and 1962 that were put off until 1963 because the panel still hadn't finished its work?

COOKE: Well, I just have a vague recollection. I think the reason you gave of not having this go on in an open-ended manner helped develop one of the reasons that was advanced, that if you don't have the damned thing wrapped up, you aren't going to be able to do anything. Still I don't think there were any specific things in the hopper that would have been, that I can recall would have been held up while the panel was deliberating.

STEWART: Was there any talk, or much talk, among people in the field that—naturally the outcome of this study would be a series of major proposals—was there any talk that perhaps that maybe the field of mental retardation wasn't ready for such an expansion that would inevitably come from such a commission?

COOKE: I don't think that I ever got that message. In fact, I think the panel's existence and its deliberations were

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not too well known by the professionals in the field—you know, the majority of professionals in the field. Now we did have meetings around the country, but I can't say that, from my own experience, that there was a lot of concern on this score at all. I think the feeling I got was that anything would be a big improvement, things are such a mess. And I think some of the professionals had the feeling that directors of traditional, large institutions, who dominated the American Association on Mental Deficiency, were intentionally left out. I remember specifically a few names. But the idea was, well, we don't want the same people who have been doing such a miserable job in the last thirty years, doing this again. So there was almost no representation. I don't think there was any representation from what one would call the traditional MR organizations, except the parent's group, and that was more

specifically a person rather than a representative of the parent group. I never got the feeling on the selection of this panel that there was any intent to have representation, which is why it probably was good. They did try to pick areas and say who is the best man in that area, or to have organizations represented that was not....

STEWART: The setting up of the panel received a rather cool reception by the A.M.A.

[American Medical Association] and I assume, by certain other medical

groups....

COOKE: Did it?

STEWART: Yes. In fact, well, there was a very strong statement by, I forget who was

president at the time, which was later toned down, but seriously questioning

the need for such a commission. Do you recall that?

COOKE: I don't recall that. I do know that when I was on the task force, on the Health

and Welfare task force, I received a visit from representatives of the A.M.A.,

who sort of wanted to find out whether I was all there, because they couldn't

imagine a full fledged member of the A.M.A. and a physician coming out with such recommendations. This was largely in regard to the Medicare Act.

STEWART: Were you at all involved in changing or in increasing the figures that were in

the budget when the Kennedy Administration took office, specifically in the

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of mental retardation? There was a sizable increase, I think, in the Eisenhower budget that they inherited and that was before Congress, but that was later revised....

COOKE: In the health area?

STEWART: Right, and I think, well, there was, I forgot the exact amount, but there was a

sizable increase in the mental retardation, the total amount that was devoted

within, to mental retardation.

COOKE: No. You know, I think you have to look a little bit carefully at that. I've never

been very happy about the figures that H.E.W. was putting out at the time. If

you take the totals, it looks awfully impressive. If you subtract what represents

disability payments under the social security legislation, because there was an amendment about that time, and I'm not up enough to bother with that sort of thing, but if somebody looked at that carefully, I think they would see that the increment may well have been totally the result, almost totally the result, of a change in the social security legislation which led to payments to families whose social security holder died who had had a handicapped child. I think that was the increment. And it looks big, because that was.... I know H.E.W. put out

something for the panel, at one time, showing all the money they were spending on retardation. But when you took that component out, which didn't have a damned thing basically to do with retardation as such—it just happened to be that if you had a defective child, and you died—then there was going to be some social security money going to your family. Well, I think that was the increase, to my knowledge but I don't know everything that was going on. There was very little in the way of specific directions on the problem at that time. Now the parents' group [National Association for Retarded Children] had an important pressure group before the Kennedy administration, by a good deal. And they may have put enough influence to get a little bit going, but I think, the increase would have been really non-MR stuff, even though it could be listed for parents of the mentally retarded.

STEWART: In general, were there many serious problems in organizing the work of the panel? Maybe you're not that familiar with whatever decisions were made, but were

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there any serious problems, or serious alternatives considered? I think originally the work was broken down into research and services. The whole group was divided into these two areas, and than it was later broken down among the task forces that eventually came out. Did this work relatively wall, or was there....

I don't know. I wished you'd interviewed me several years ago. As I'm sure COOKE: any historian knows, the unpleasant things get dropped out of the mind. I do remember a couple of meetings where—I just thought this was the living end, that it was going just terrible. We were going absolutely nowhere. There was just one platitude after another being put on the table. We had one meeting in Baltimore, I think, and it was just horrendous. I know Mrs. Shriver's blood pressure must have gone up and down about a thousand times during that session. I remember talking with her in the middle of it, and she said something like, "We've just got to change this, you know, we're going absolutely nowhere, just talk, and nothing constructive," et cetera. It was a short while after that that Leonard Mayo must have been told, I'm sure he can tell the story better, that there had to be some change in the structure, because it was formless and we were going absolutely nowhere. Then when it got cut down to the task forces with specific areas, we began to make some progress. And this is sort of a good lesson, it seems to me, if you're going to tackle a big problem. The first job is to break it up into at least some specific areas. A few may get left out, but if you think hard you can cover most of it. Then have those areas, and parcel them out, rather than trying to work the whole global thing, it's just too much.

STEWART: Was the whole question of exactly what consideration should be classified under mental retardation, was this always a problem?

COOKE: It still is. Yea, well, the biggest debate in the whole panel was who is the retarded. One group maintained that these are the people who don't get educated properly. The other group said, that that is not retardation basically,

that it is under-education, and the real retarded are the people who have something wrong with the brain. This was the hassle, and it will always go on. If you take a definition, it's a quantitative definition, it's a relative definition, and

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whenever you've got a relative definition, why who they are depends on where you put the limits on this relative thing. So that.... But the nice part of it is that kind of approach permits some spin off to related things. When you talk about better prenatal care, you're able to talk about this under the framework of retardation, and it has some spin-off for other kinds of problems. Likewise, you talk about Head Start and it has some way of combating mild retardation. It has some spin-off for other kinds of individuals. So I don't think there's any great advantage to having a very narrowly defined subject for this sort of approach.

STEWART: I think it's 9:30, do you want to.... [tape turned off, resumed]

COOKE: I think one of the interesting things that we really haven't gotten into is the implementation of the panel's recommendations.

STEWART: Right, and I don't know how well you specifically remember the things that were in the report, but would it, for example, do you think it would be fruitful to go over, I have a list of the recommendations. Would it be fruitful to go over the ones in your area, the ones you were concerned with, and the ones that were controversial, or which you were worried about?

COOKE: Yes. I can tell you some of my remembrances about them, which may be sort of interesting and will give a little clearer picture. You know, one of the biggest things was this thrust in maternal and child health. It's very interesting how that came about. Our own task force was concerned with the problem of prevention, and we tried to decide, well, how the devil do you prevent this problem when you don't know the individuals it's going to hit? So the natural thing was then, to look at the groups that were having the largest number of individuals, or retardeds. This concept of the high risk group was helped by the visit to England as I said. Well, that made us focus then on the question of how to beef up the maternal care, and then that led to a meeting with Arthur Lesser, of the Children's Bureau. It was an interesting meeting, because here was a government bureau that had been set up for this responsibility and H.E.W. was so damned conservative that when Lesser presented this very good program of how to beef up maternal health and health of premature infants,

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and newborn babies, and the like, he was talking about increases of two, three, four, or five million, you know, the most conservative kind of approach which sort of reflected H.E.W.'s whole approach to the problem which is, well, if we give a little bit here that'll be plenty, you know. Arthur Lesser was at the meeting of our subcommittee, he had to be, in a sense, almost

coerced into saying, I could use fifty million, or I could use a hundred million very effectively. He was talking about five or ten, but I think it was symptomatic of the real lack of involvement that H.E.W. had with doing something in a big way. But it undoubtedly forced HEW to up its sights by a factor of ten, because they had, well....

The big conflict is one I'm sure Leonard can give you better than I, and there's some interesting anecdotal material which he can supply more accurately, regarding the telephone call when he was in Turkey. Have you gotten that? Did he mention that?

STEWART: I haven't talked to him yet.

COOKE: Well, again, this is all secondhand, so you might get it more directly, but this

was towards the end of the panel report, and there was evidently an enormous

split between the basic biologists who said what is needed is support of

fundamental basic research and the more educationally oriented—Anne Ritter [Anne M. Ritter] was on that panel, and who has subsequently died. She was all for spending money in the applied side of things, so that services could be improved and educational things could be improved, and so forth. I think these two groups that were working on the research side of things just would not agree to anything, and they had basically two different reports. Leonard was in Greece or in Turkey, and he got a telephone call from Mrs. Shriver to try to resolve this. How he was supposed to do this in Turkey, I don't know. But he was awakened in the middle of the night to try to settle this battle that was going on. I think you ought to quiz him about that, because it's a rather interesting story. But, I think, at about 2 o'clock in the morning he got this call, and says, "Who is this," and was answered, "Eunice." He was half asleep and said, "Eunice who?" Anyhow, this was the biggest issue that kept cropping up all along. In every area, is this a medical problem; is it an educational problem; where should the real emphasis be; where should the research be? It's slightly better,

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but it's still a long way from resolution. I think, though, that the thing I was most involved in outside of the President's panel is a rather interesting one, because this again shows some of the resistance in the establishment. When the President's message on mental health and mental retardation came along, I remember getting a rough draft of this message. Eunice was absolutely crushed by the report, because she'd been over all these things before the President's panel, and it was H.E.W.'s suggestions, and to her it sounded so familiar that she thought it was just awful. She let Mike Feldman, and I'm sure, let her brother know that this just didn't seem to have any oomph.

STEWART: This is the President's message you're talking about?

COOKE: Yes, and she asked whether or not something new and different, something

else might be brought in. It was then that I wrote a paragraph or two on what turned out to be what we called then in that draft, the university-affiliated

clinical facilities proposal. It was to create these centers for training of people for service from multiple disciplines and I think the language I used then was that no longer would

students graduate from medical school without ever having seen a retarded, or cared for them, and so forth, and so forth. It was bought but I don't know who bought it. Eunice was enthusiastic about it. Mike Feldman seemed to be. Supposedly the President read it, and it sounded good to him—something that tended to be different from the usual. So it was included in his message. Well, that hit H.E.W. like a rock, because they hadn't reacted to the President's panel with this, because there's nothing in the President's panel about this particular aspect of things. So that when they were asked to come up with some legislative recommendations, they said they didn't have any money for it. I can remember going over to Mike Feldman's office. Wilbur Cohen and some of the other people were there, and it was essentially one of these things with grabbing people by the lapel and saying, "Look, you've got to find some sort of money." What was done was to pull some money out of some of the other programs. If a historian ever looks at the dollar amounts that were allocated, he would see very interestingly that the figures went to seventeen and a half million, or something like that, because it was two and a half pulled out of here, and twelve out of

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here, and then five out of here, and you get that funny kind of figures appearing. But H.E.W., they'd be damned if they were going to ask for any more money for this program. They were being forced really to pull it out of some existing ones, which was really after their planning had started. They planned strictly according to the President's panel. Well, I think the point I'm trying to make is that H.E.W. reacted to the report. They had none of their own thinking basically in the eventual message and in the eventual programs for the retarded. And something new introduced came from the outside completely. Well, this was a sort of tug-of-war on this particular one. It's been going ever since, because they have had a great reluctance to develop the support for it, and everything else. They had a tough row to hoe. It's still having its problems with its funding, because of, well because I really believe—because H.E.W. didn't create it.

STEWART: Were you reasonably satisfied with the reaction of the H.E.W. to the panel's recommendations? Or let me ask you, how closely did you follow, I assume you followed it fairly closely as to exactly what they were doing, and how they converted the proposals into action.

COOKE: Yes. I think that this was, as I recall, they reacted with proposals that were for increased maternal and child health, mental retardation centers, community mental retardation centers, and the university-affiliated clinical facilities was grafted on to that.

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