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SUMMARY OF THE TECHNICAL ADVISORY COMMITTEE MEETING

"STUDY OF THE POTENTIAL IMPACT OF THE DEFINITION
RECOMMENDED BY THE NATIONAL TASK FORCE ON THE
DEFINITION OF DEVELOPMENTAL DISABILITIES"

H.E.W. CONTRACT NO. 105-78-5003

SUMMARY OF THE TECHNICAL ADVISORY COMMITTEE MEETING
Ramada Inn, Rosslyn (Arlington), Virginia
February 5 and 6, 1979

Present:

Members: E. Boggs; F. Bowe; J. Dempsey; J. Drage;
M. Fithian; R. Gettings; A. Halpern; S. Katz;
M. Kirkland
Staff: E. Gollay; S. Jacobson; K. Lapidus; W. Morgan;
V. Nelkin; A. Spindler; E. Beard
Federal: K. Rogge; R. Pelton
Interpreters for F. Bowe: N. Bouvier and A. Raffel
Absent: N. Lourie, member

The meeting was chaired by Elinor Gollay, Principal Investigator for the project. A number of important topics were discussed at the first meeting of the Technical Advisory Committee. Some of the issues were resolved satisfactorily, while others remain open to further discussion and debate. The key topics discussed are summarized below.

1. Background of the DP Program

After the introduction of project staff, technical advisory committee members, and other preliminaries, an historical overview of the Developmental Disabilities program and definition was provided. The discussion of the history of the DD program helped to clarify the probable impact of the new definition on the states. A summary of the discussion may be found in the Appendix.

2. Project Purposes

The TAC spent considerable time discussing the purposes of the project. The lack of clarity with respect to the precise purposes of the current project has resulted from the confusion that has existed over whether or not the project is part of the congressionally mandated study or is an independent (and perhaps parallel) effort. Because the study was originally designed before P.L. 95-602 was passed, the original purpose was an examination of the potential impacts of introducing a new definition into the field, with the expectation that the analysis would point the way toward a smooth implementation. However, with the passage of 95-602, the pressures to implement the new law immediately, and the congressionally mandated study regarding the impact of the new definition, it became necessary to alter the purposes of the project. However, these purposes were altered within the same basic framework as had been developed originally.

Assuming that the project is not the congressionally mandated study, then its primary purposes are to (1) provide population estimates based upon the new definition; (2) study the process of introducing the new definition in selected states to determine what types of impacts are being experienced by the states; and (3) make specific recommendations which can be useful at both the state and national levels to facilitate the future use of the new definition. However, if the project is the congressionally mandated study, then it is important that baseline information be gathered along with a design for gathering and analyzing data in the future. The lack of resolution about the role of the project with respect to the congressionally mandated study caused considerable concern among TAC members. In addition, the concern was expressed that the project's primary mission should be the provision of information which would be directly useful to the DD Bureau as it works with the states.

By the end of the discussion of what the purposes of the project were, the following specific purposes were suggested by the TAC:

1. Study the process of introducing the new definition into the DD field to determine its impacts in four major areas: Population; DD program operations; Broader program context; and Costs.
2. Recommend specific ways of facilitating the introduction of the new definition and mitigating negative impacts.
3. Assist in operationalizing the new definition so that it can be more readily used.
4. Lay the groundwork for the longitudinal study mandated by Congress.

The last purpose, the TAC agreed, is one which the project ought to be undertaking, but it is not clear whether it falls within the contract's scope. Following the advice of the TAC, MMS is seeking further clarification of this point from RSA.

3. Specific Issues

Over the course of the two days, the TAC discussed a number of specific issues and concerns which it had regarding the definition, its introduction into the field, and the way in which this introduction should be studied and facilitated. Some of the points made by the TAC are:

- The institutional environment which the DD program operates should be examined. In different states different administering

agencies were selected for a variety of reasons. With the shift in the focus of the DD program (in terms of population and services), it will be important to see whether this institutional environment is affected, and if so, how it is affected.

- The impact of the new definition and its meaning to disabled people and parents is crucial. Some effort should be made, if possible through this project, to facilitate the interpretation of the new definition to consumers. They want to know directly how the new definition will or will not make a specific difference to them. Since many of the people now covered are not familiar with the program (because they were previously excluded from coverage) they will often need to have basic aspects of the program explained to them, not just the definition.
- The new definition should be explored in terms of its implication for national data collection. Currently, national statistics vary widely and are in great need of improvement.
- Careful consideration needs to be given to identifying the potential users of the definition, and those to whom the meaning of the definition most needs to be clarified. Planners, administrators, parents, disabled individuals, service providers, and trainers all have different needs regarding the definition. The audience needs to be clarified.
- Consideration needs to be given to the extent to which the DD system can tolerate variations in interpretations of the new definition. A recent study by RSA of the definition of "severely disabled" as used in the rehabilitation field indicated that there were hundreds of interpretations that varied with different circumstances. Can this type of variation be tolerated? Are there some advantages to variation, or should every effort be made to ensure maximum uniformity of interpretation?
- There is a tension in the system which results from the different needs and perspectives brought to the situation by service providers, clients and administra-

tors. Administrators want definitions for accountability purposes; service providers and clients are more interested in providing or securing services in an integrated fashion.

The crucial criterion perhaps should be understandability rather than uniformity of interpretation. We can test whether or not people understand the new definition. We know for sure that it is causing confusion in some states. We need to recognize that there may have been a false understanding of the old definition due to the listing of categories which people (such as legislators) could grasp and understand.

We need to examine the political ramifications of the new definition, particularly at the state level.

There is a difference between a legislative construct such as the definition of developmental disabilities in P.L. 95-602, and the reality with which the state needs to deal.

A current problem is how to respond to the states yesterday in terms of the new definition.

How can a developmental disability be measured in a way that it would be useful at different levels? Most behavioral measures that exist have been designed for use at an extremely micro level with an individual client. They are not readily aggregated for use at the administrative level.

How does the new definition affect the way in which the DD program fits into the broader context of other services for the population?

The issue of who is excluded from the current definition and the reasons for these exclusions should be explored.

Despite the fact that the definition is based largely on the extent to which a developmentally disabled person can not do certain things, it is important to focus on what the disabled individual can do.

Eligibility determination has been much less important a criterion in DD programs than in VR or Social Security programs.

Including additional diagnostic groups under the new definition may not add substantial numbers

to the total population due to low prevalence of many of the added disabilities, and concentration on the most severely disabled.

The states are varied in their utilization of funds; there may be more than one state administering agency.

- There was considerable discussion of terminology, with disagreement on such terms as "disability", "handicap", "impairment", and "substantial functional limitation".
- Historical and legal perspectives are needed.

4. Specific Reactions to Issue Paper on Explicating the Definition

The TAC spent considerable time discussing the contents of the Issue Paper on the Definition of Developmental Disabilities. Although some of the discussion was conceptual in nature, much of it related to specific issues raised in the paper and to specific suggestions for modifying the paper. Most of these suggestions have been included in the revised version of this issue paper. There were, however, some issues that were not adequately resolved in the discussion; they will require further exploration later in the project. These include:

- The precise definition of impairment needs to be explored, and in particular, the difference between an "impairment" and a "functional limitation" needs to be clarified.
- Further thought is needed on how to include two particular groups in the program: Those who are "at risk" of being developmentally disabled, and the "formerly" developmentally disabled.
- The issue of progressive conditions, particularly those which begin to manifest themselves prior to age 22, but do not result in severe functional limitations until a later age, needs to be explored.
- Age-appropriate limitations need to be further spelled out. Consideration will be given to using the functional limitations for levels of retardation at different ages used by AAMD.
- The issues of applying the new definition to specific aspects of the DD program have been raised, but not yet adequately addressed.

5. Summary

As a result of the discussions during the meetings, the following were agreed to by the group:

- The site visits will serve additional functions, more than originally conceived. In order to study the introductory process, the interviews should be conducted earlier than planned, and should be done in phases. In this way, they will be able to describe the process at various stages (before the regulations are issued; immediately after; and some time after the introduction of the regulations.) The site visits will also feed into operationalizing the definition, provide feedback for the implementation process, and background for a longitudinal study.
- We are seeking clarification on our role in the Congressionally mandated longitudinal study.
- The issue paper on population clarifies issues raised in the Congressional intent and the conference report.
- Due to many factors and constraints of immediate introduction, the definition has to be viewed in a broad context in relation to the Act.

The Technical Advisory Committee will meet two more times in the Washington area. The next meeting is scheduled for June 11 and 12, 1979. The third and last meeting is tentatively scheduled for September 17 and 18, 1979.

APPENDIX

HISTORICAL OVERVIEW

The original concept of "developmental disability" was introduced in 1969 by Senator Edward Kennedy. Although it was not intended to be categorical, the original definition as it emerged in the law listed three specific categories: mental retardation, cerebral palsy, and epilepsy. These three categories covered approximately 75% of the people who were on Social Security rolls as the result of a childhood disability.

(MR counted for 50-66%, CP for .7% and epilepsy for another 7%.) The original intent was to focus the program on people with severe, chronic disabilities originating early in life. The expectation, as indicated by the original authorization levels, was that the DD formula grant program monies would be spent primarily on services for the target population. However, when the funding level was in fact very low, it was decided that more impact could be made by spending the scarce funds on planning and influencing activities rather than on services. However, even the services were primarily intended to be gap-filling and demonstrative of the types of services which could and should be supported through other means for the population.

The new law, Public Law 95-602, returns the program to its original intent, but unfortunately does so with little increase in the funding level. P.L. 95-602 clearly requires that the states spend at least 65% of their formula grant on direct services. Again, these services are explicitly intended to be gap-filling services, to be supported only after other sources such as 94-142 and vocational rehabilitation funds have proven inadequate. This new requirement will bring all the states into the same basic pattern of expenditures. Up to now, states have varied widely; some have been spending as little as 5% on planning, and others as much as 100%. This diversity should still be preserved, reflected in the types of services funded by each state. The services funded in each state should reflect the specific gaps which exist in that state, as well as conform in general to the priority services identified in the law.

It is important to note that the DD program has always served, and undoubtedly will continue to serve or benefit directly and indirectly many individuals not specifically targeted by the program. This is because many of the specific services which are needed by the developmentally disabled population are best provided to a group of people that includes some non-DD people as well. To deny such services would be like saying, "that no one with a baby carriage could use a curb cut because they were designed for wheelchair users only." It is, therefore, important to distinguish between those people who would be declared eligible for specific services because they are developmentally disabled, and others

who would fall within the broader target group benefitting from the program. Again, this is one of the aspects of the DD program that differentiates it from many other programs for handicapped people. It is not an individual entitlement program such as vocational rehabilitation or Title XIX. Rather, it is aimed at a group of people.

The discussion of the history and purpose of the overall DD program is the key to understanding how the introduction of the new definition of developmental disabilities is likely to impact on the states. In particular, it is important to recognize that the change in the definition was accompanied by other important changes in the law. As a result, it will be difficult to disentangle the precise reason why certain changes are brought about in the program. For example, in looking at the congressionally mandated study and the impact of the new definition on the types and amount of services received, it is likely that there will be greater impact on the services from the new service priorities than from the new definition, while the new definition will have more impact on the types of individuals benefitting from the programs.