

Appendixes



Appendix A.— Method of the Study

This assessment of "Technology and Handicapped People" was preceded by a 3-month planning effort that identified areas to concentrate on and established a tentative study approach for the full study. The planning phase took place from July to September of 1980, and resulted in a study proposal for the full assessment. That proposal described the plan to examine the processes of research and development, evaluation, diffusion and marketing, and delivery and use of technologies for disabilities and to develop a conceptual framework for decisions made regarding these processes. The proposal also presented examples of possible case studies.

The full assessment began on October 1, 1980. One of the first tasks undertaken was the selection of the advisory panel. Most of the studies undertaken at OTA rely on the advice and assistance of an advisory panel of experts. The advisory panel for a particular assessment suggests source materials, subject areas, case studies, and perspectives to consider; assists in interpreting information and points of view that are assembled by OTA staff; and suggests possible findings conclusions based on the accumulation of information produced by the study. The panel members review staff and contract materials for accuracy and validity, discuss policy options of the study, and present arguments for and against the options and conclusions. They do not, however, determine the report's final form and are not responsible for its content, direction, or conclusions.

The advisory panel for the current assessment consisted of 18 experts with backgrounds in rehabilitation medicine, sociology, innovation, economics, industry, ethics, law, health policy, rehabilitation engineering, psychiatry, consumer advocacy, and state level disability program administration. The panel was chaired by Daisy Tagliacozzo of the University of Massachusetts. One member of the OTA Health Program Advisory Committee, Melvin Glasser, also served on the advisory panel.

The first panel meeting was held on January 14, 1981, in Washington, D.C. (the site of all three panel meetings). Panel members discussed the overall study plan of the assessment and helped OTA staff refine the goals for the project. The panel examined the project boundaries and definitional issues and was key in sharpening the study's focus. The panel was also helpful in reviewing the primary issue areas to be covered and in providing suggestions of individuals and organizations to contact for information and assistance. Case studies of specific technologies or disabling conditions were discussed, and the panel provided ideas of possible cases as well as criteria for final

case study selection. The case study approach was intended to illustrate problems and opportunities found in the various stages of the development and use of technologies for disabilities or impairments.

Following the panel meeting, a draft of a status report was prepared. This draft was distributed to panel members and to over 50 additional reviewers who provided comments. The status report contained only descriptive information; analysis and policy options were not included.

The second panel meeting was held on May 1, 1981. At that meeting, the panel provided comments on the revised draft status report and reviewed the progress of the study. Considerable time was spent discussing ways to analyze and synthesize the material that had been collected and to develop policy options. In addition, the panel identified strengths, weaknesses, and omissions in the work to that point. Finally, the panel explored modifications in the emerging conceptual approach of the project. The final version of the status report was issued in June 1981 to the Labor and Human Resources Committee and other selected Members of Congress.

Two subprojects were conducted during the spring of 1981: 1) a public outreach effort, and 2) a workshop on "Attitudes, Handicapped People, and Public Policy." The public outreach effort, which is described in appendix D, was undertaken during April and May.

The workshop on attitudes and public policy was held in Washington, D. C., on May 11 and 12. The goal of the workshop was to explore the ways in which the attitudes of and toward disabled people affect public policy on resource allocation and technology development and use. There were more than 70 participants from the academic, legislative, and program implementation communities. The workshop provided OTA with a number of specific options for changes in programs and policies affecting disabled people.

Two preliminary workshops were held in preparation for the May 11 and 12 workshop. One was a general strategy or planning session and one was on legislative issues and disabled people, attended by lawyers specializing in civil rights. Also in preparation for the workshop, several background papers were written by experts in different fields relating to attitudes of and towards disabled individuals. Proceedings of the May workshop, including the papers and a summary of conclusions reached by participants, will be available through the National Technical Information Service. Copies for congressional use will be available from OTA. Authors of the papers are listed at the end of this appendix.

The initial, partial drafts of the main report were

reviewed by OTA staff, special consultants, and advisory panel members. In certain instances, outside reviewers were also asked to provide comments. The first complete draft of the report was then sent to the advisory panel.

The final meeting of the advisory panel occurred on October 2, 1981. The entire meeting was spent reviewing the first complete draft on the main report. The primary focus of the review was on the policy options for congressional consideration.

The draft was then revised by OTA staff based on the suggestions and comments of the advisory panel. This second draft was then sent for a further round of review by a much broader range of experts in a diversity of settings: Federal agencies, private and non-profit organizations, academic institutions, practicing health professionals, consumer groups, and other selected individuals. Altogether, more than 180 individuals or organizations were asked to comment on drafts of the main volume or individual case studies of this assessment. The final draft of the main volume of the report, containing the policy options, was reviewed by approximately 50 individuals. After appropriate revisions were made based on comments received, the report was submitted to the Technology Assessment Board.

The project resulted in a number of documents: the main report, of which this appendix is a part; a booklet that summarizes the main report; a status report to Congress on the project, issued in June of 1981 and fully encompassed by this main report; a series of background papers of individual case studies and issue papers; a background paper containing the proceedings of the workshop on technology, attitudes, and public policy; and a xeroxed bibliography (prepared for the workshop, by the Institute for New Challenges) on attitudes toward and of disabled people, which is available for inspection at the OTA offices,

The background papers containing the case studies and issue papers were prepared both to provide information and ideas for the main report and to serve as individual analyses of particular issues and technologies. The case studies, as well as the issues papers, were selected according to several criteria:

- *Area of policy covered.* Cases were selected to cover more than just health-related disability policy.
- *Several functional types of disability* should be represented, e.g., deafness, mobility limitations, speech impairment, and learning disability. In addition, there should be cases or papers which address issues generic to all or many forms of disability.
- *Physical form of technology.* Physical technologies (such as joint implants) should be included, as well as process technologies.

- *Complexity of technology.* Both complex and simple technologies should be represented.
- *Purpose of technology.* Prevention, treatment, diagnosis, and rehabilitation should be represented.
- *State of knowledge.* There must be sufficient data or information available for analysis.
- *Policy relevance.* There must be significant policy questions involved in the cases selected.

The case studies and issue papers commissioned by OTA are listed below with their authors. As mentioned, they are being issued in separate volumes and will be available through either the Government Printing Office or the National Technical Information Service (or both):

- "Passive Restraint Systems in Automobiles" by Kenneth Warner.
- "The Technology of Joint Implantation" by Dan Lawson.
- "Sheltered Workshops as an Employment Technology" by Jeffrey Rubin.
- "Learning Disabilities" by Candis Cousins and Leonard Duhl.
- "Telecommunications Devices for Deaf People" by Virginia Stern and Martha Reddan.
- "Assistive Communication Devices for Severe Speech Impairments" by Judith Randal.
- "Mainstreaming in Education" by Nancy Carlson.
- "Congress, the Courts, and Civil Rights for Disabled Persons" by Stephen Chitwood.
- "Technology and Disability Programs and Rights: A State Perspective" by Kent Hull.
- "Techniques for Resource Allocation Decisions" by Mark Ozer.

An additional background Paper, as mentioned above, will include the papers presented at, or included in the proceedings of, the May 1981 workshop on attitudes and technology. The topics of the papers and their authors are:

- "Cultural and Societal Views of Handicapped Individuals" by John Gliedman and William Roth.
- "Denial of Emotional Needs to People with Handicaps" by Irving Zola.
- "Communications Barriers Between 'The Able-Bodied' and 'The Handicapped'" by Irving Zola.
- "Values Informing U.S. Attitudes Toward Disabled Persons" by Ruth Purtilo.
- "Disability: The Policymaker's Dilemma" by Tom Joe and Cheryl Rogers.
- "Changing Structures in Society and Handicapped People" by Joan Costello.
- "The Media and Attitudes Toward Disabled Persons" by Harold Yuker.