

Appendix D.—OTA Public Outreach Survey

Introduction

Effective development and use of technologies for disabled people require the extensive involvement of disabled people themselves, as well as others who research, develop, produce, provide, and pay for the technologies. In practice, however, such involvement does not always occur. This finding became clear early in the OTA study and was refined and confirmed throughout the course of the project.

Similarly, it is generally recognized that the identification and analysis of problems and opportunities related to Federal policies that affect the development and use of technologies require input from those directly using, marketing, and providing the technologies—the “public.” This principle is particularly salient when applied to areas related to disabled people. The need for public input is primarily due to the great influence of technology in nearly every aspect, from personal to societal, of the lives of disabled people and those around them. A complete understanding of issues which shape and, in turn, are affected by policies can occur only when personal experiences are examined.

Thus, from the beginning of this assessment, OTA sought to involve the broad public interested in issues relating to technology and disabled or handicapped people. The objective was to reach beyond the world of the *experts on making policy* affecting disabled persons to the world of *experts on experiencing the effects of the policies*. OTA hoped to learn more about the real problems and opportunities which currently exist and obtain suggestions for policy options to present to Congress.

Methods

After determining the objective of the public outreach effort, the next step was defining the “public” to be reached. As established in the objective, the public did *not* include disabled or nondisabled public policymakers, practitioners, or academic experts on disability-related technology development and use. * It *did* include disabled people not in those categories. However, as noted throughout the assessment, there is an enormous variety of disabled individuals, with differing needs, desires, impairments, disabilities, handicaps, abilities, attitudes, and resources. True representation, therefore, was beyond the capabilities of the project.

*It is standard policy at OTA for these type of individuals to provide input to assessments by serving on the study advisory panel, by providing information for staff analysis, and by reviewing drafts of the report. This process is further described in app. A.

A feasible alternative for the outreach survey was determined to be contacting as many organizations dedicated to assisting different “types” of disabled people as practical.

The remainder of the public consisted of people directly involved with some stage of technology development and use. As does the group of disabled individuals, this group includes individuals and organizations with a wide range of functions and a wide range of attitudes and perspectives. It includes parents, teachers, researchers, manufacturers, physicians, allied health professionals, rehabilitation counselors, institutional providers, State agencies, third-party payers, and many others. Again, true representation was beyond the capabilities of the project. However, OTA hoped that by contacting professional associations, rehabilitation facilities, manufacturers of devices, and insurance companies, input could be obtained from many of the key perspectives of this sector of the public.

The third step was developing a method to obtain the public input. Although several forms of personal contact were seriously considered (e.g., a national public forum or a series of public meetings across the country), a mail effort was selected because of time and financial constraints. First, a concise description of the entire assessment was developed; this description is attached as addendum A to this appendix.

Next a survey method was selected. In order to avoid limiting or steering responses to particular categories of problem statements or options for change, OTA decided against the use of a questionnaire. Instead, a request for *specific* information on *problems* and missed *or potential opportunities* was presented in a general letter that stated the purpose of the assessment and of the outreach effort. This general letter, attached as addendum B, was modified according to the type of recipient.

The third step was compiling the actual list to which the request letter and project description were to be sent. Four categories were selected to encompass the public as previously defined. The first and largest included “advocacy groups.” OTA defined advocacy groups broadly to include organizations devoted to the various interests of different disabled people as well as associations of and for parents, teachers, providers (e.g., physicians and allied health professionals), program administrators and others who affect and are affected by the lives of disabled people. A list of 197 organizations and associations was compiled; the two sources which provided the bulk of the list were the 1980-81 edition of *Directory of Organizations Interested in the Handicapped* (176) and the *Directory*

of *National Information Sources on Handicapping Conditions and Related Services* (61).

The second category included medical rehabilitation facilities. From the 1980 membership directory of the National Association of Rehabilitation Facilities (NARF) (155), the alphabetically first facility offering medical rehabilitation services listed under each State was selected. Not all States had such a facility. While it was understood that the sample was not representative of all facilities in the country, * it was hoped that geographic variation allowed a wider range of perspectives to be represented. The final list of 41 also included several facilities that had heard about the assessment and contacted OTA. The third category included companies that manufacture devices for disabled persons. This list of 36 companies was not designed to be even loosely representative of all product manufacturers. Instead, it was compiled by using names of companies participating in seminars and workshops attended by OTA project staff members. Finally, the fourth category included 10 insurance companies whose benefits include coverage of some technologies for disabilities. The companies and people within them who were contacted were suggested by a member of the Insurance Rehabilitation Study Group, a group of 50 insurance company executives who are actively engaged in rehabilitation and medical administration.

The letters to the advocacy groups were mailed at the beginning of April 1981, and the letters to the other three groups were sent out in groups at weekly intervals. Recipients were requested to respond within 3 weeks so that their views could be fully considered. However, although many of the responses arrived between 2 to 4 weeks later than the requested deadlines, all responses were utilized in the preparation of the draft and final reports.

*The membership of NARF is not necessarily representative of rehabilitation facilities in the country. Furthermore, the code used in classifying the services offered were likely to be used to mean different services by different institutions. OTA proceeded, however, as though "medical rehabilitation" meant the same services for each facility

Once received, the written responses and notes on telephone responses were circulated among the staff. A summary of issues, problems, and suggestions for change was prepared for internal use; each staff member received a copy. This summary was used in drafting the body of the report and in the revision process. Perhaps equally important, though, the summary was carefully reviewed as the findings and policy options were developed. In a number of cases, the respondents were contacted for followup information.

Response

Of 283 requests sent, 8 were returned unopened, and 61 responses were received. Table D-1 presents the response rates by group. The overall and individual response rates were surprisingly low, particularly for the advocacy groups at 18.2 percent. Because issues relating to disabled people have become increasingly visible in part because of publicity developed by advocacy groups, OTA had anticipated a greater response. As noted earlier, true representation of the "public" was not an objective of the outreach effort, although the low response rate diminished the amount of representation that would have been possible. An examination of the respondents produced no pattern in the type of organization responding. A possible exception to this **was** the multiplicity of responses from organizations concerned with visually impaired persons and with hearing-impaired persons, although there are more of these organizations than those with other concerns.

Despite the low response rate, the responses received were generally quite helpful to OTA. Most appeared to have been carefully considered. As a whole, the responses served several important purposes. They confirmed problems described in the literature relating to all stages of the technology lifecycle, including research and development (R&D), evaluation, marketing and production, and delivery, use, and financing. Perhaps more important, though, they provided spe-

Table D-1.—Response Rates of Public Outreach Survey

Category	Number sent	Number returned unopened	Number responses received	Percent responses received of requests reaching destination
Advocacy group	196	4	35	18.2 ⁰⁰
Medical rehabilitation facilities	41	1	11	27.5
Product companies	36	3	11	33.3
Insurance companies	10	0	4	40.0
Totals	283	8	61	21.20/0

SOURCE Office of Technology Assessment

cific examples of problems found in the process of technology development and use. Often, these examples were of actual experiences at the local level. Furthermore, while there were no policy alternatives provided, there were several examples of changes that might be made at various points in the technology process. Several of these were used at appropriate points in the report. Finally, the responses helped to emphasize the importance of certain problems over others because of the frequency with which they appeared. Owing to the lack of a representative sample, the frequency of problems was used only as a rough guide of their prominence.

An examination of the responses by category—advocacy groups, medical rehabilitation facilities, product companies, and insurance companies—revealed more similarities than differences in the problems that were stated most frequently and in the areas of the technology lifecycle that were discussed. For example, inadequate and inappropriate finding of technologies, particularly devices, was the most frequent problem cited in each group. And, in each group, with the exception of the insurance companies where there were the fewest responses, there were problems cited with research, evaluation, production, marketing, delivery and use of technologies. Also, while most organizations discussed only device technologies, several respondents specifically utilized OTA's broader definition of technology in their discussions.

As noted previously, the responses were used in all stages of the preparation of the report. Presenting them separately in great detail would involve unnecessary repetition of the report. In addition, as noted above, the responses differed little by category. Still, in order to illustrate the results of the public outreach effort, highlights of problem statements and suggestions found in each category will be listed below. The order is not significant.

Advocacy Groups

- Support for programs employing disabled people or enhancing their opportunities for employment is an essential expenditure of funds and should not be decreased even in this era of budget cuts.
- There is a lack of adequate and appropriate funding for technologies for disabled people,
- Information developed by researchers, which could assist disabled people, does not reach them often or systematically. It is essential that this gap be eliminated.
- There needs to be more input by disabled people in research and services delivery in order that they may determine the course of their own lives. In addition, consumers of technologies, particularly devices, need to be actively involved in evaluation and testing of new technologies.
- There is a lack of coordination among public and nonpublic programs, causing a waste of resources to society and a lack of necessary services to some individuals.
- Policy makers need more and better data on disabilities and handicaps.
- There is a lack of trained personnel to apply technologies to disabled people.
- Research funding is often for complex devices, and there is too little for necessary, but less complex, ones.
- Federal research funds are generally awarded to established researchers. Thus, the "basement" researcher with ideas developed from experience is often unable to receive support.
- The existence of different definitions of disability for program eligibility impedes coordination of services and may cause families to undergo multiple assessments.
- Groups supporting people with particular disabilities (e.g., visual impairments, hearing impairments, or certain diseases) urged an appropriate focus on their constituents.

Medical Rehabilitation Facilities

- Although deinstitutionalization is a stated policy under several programs, the services and funding available often do not support it.
- The research performed is not always appropriate; there is a need for many more functional devices.
- There is a need for uniform standards to assist in client evaluation of products.
- Programs that pay for technologies often do not cover technologies that might cost more in the short run but cost less in the long run. The total amount of funding is inadequate.
- The type of personnel licensed to prescribe technologies is not always appropriate. Further, there is a shortage of all trained personnel.
- Rehabilitation centers have particular difficulty in obtaining funds for the R&D of new technologies.
- There is a need for better organization of services to assist disabled people.
- There is a need for more centers to evaluate and train clients in the use of devices.
- Regulations governing institutional providers are often unclear.

Product Companies

- Too few large firms produce technologies for disabled people. The small firms that do are often created out of the founder's personal involvement with disability. Small companies need relief from regulation.
- There is a great need for data on the disabled population to assist in research as well as marketing.
- Information transfer between researchers and companies and between companies and users about devices is often a problem.
- Medical and social service personnel are often resistant to new technologies. In addition, there are too few well-trained people to prescribe the technologies.
- Federal money goes into R&D but not beyond. The risks of production of technologies for a small, undefined market are often too great for the private sector.
- It is difficult to move technologies from the R&D stage to the market.

- There is a need for marketing/sales-oriented people to be involved in the peer review process of awarding research grants.
- There is inadequate third-party funding of devices.

Insurance Companies

- The availability of funding for technologies influences their availability to disabled individuals.
- There is a lack of information on the availability of specialized equipment.
- There is a lack of general information on centers that apply specialized equipment for disabled people.
- It is essential that the needs and desires of disabled individuals be balanced against the economic costs and benefits of those needs and desires.
- There is often a lack of adequate information for users on the upkeep and available service for many of the complex pieces of equipment funded by insurance companies.

Addendum A

Project On

TECHNOLOGY AND HANDICAPPED PEOPLE

Office of Technology Assessment
Congress of the United States

At the request of the Senate Committee on Labor and Human Resources, the Office of Technology Assessment (OTA) is conducting a comprehensive assessment on "technology and Handicapped People." One purpose of the project is to examine the policies and specific processes through which technologies are developed, evaluated, diffused, delivered, and used. Another purpose is to examine the broader issues related to providing an appropriate fiscal and technical fit between technologies and users.

Project Focus. Policies concerning technologies and handicapped people must take into account a large number of technological possibilities, organizational factors, resource allocation demands and complexities, individual and societal attitudes, and various (and often competing) levels of decisionmaking. OTA believes that a unifying framework for analysis is needed in order to develop and evaluate policies that might fulfill the goal of an appropriate match between the needs, desires, and capabilities of handicapped people and the nation's ability to develop and deliver the needed technology. This concept of appropriate development and use of technology will guide the study.

Appropriate technology implies an organized way of matching resources to problems or opportunities. Appropriateness cannot be defined unless its context is specified, and that context will always involve social values as well as technical considerations. Thus, OTA is tentatively defining a technology as appropriate when its development and use: 1) are in anticipation of or reaction to handicap-related problems or opportunities, 2) are compatible with resource constraints and occur in an efficient manner, and 3) result in a favorable or acceptable ratio of desirable outcomes to negative effects and resources consumed. In the above, problems, opportunities, resource constraints, desirable outcomes, and acceptable ratios must be defined and valued by appropriate parties-at-interest.

Policies, processes, problems, and opportunities associated with elements of the technology life cycle will be examined from the perspective outlined above. In particular, OTA is developing or synthesizing specific information regarding: 1) research and development of technologies, including identification of needs and priority-setting; 2) evaluation of the effects of technologies, including performance, efficacy, safety, economic and social consequences; 3) diffusion and marketing of technologies, including incentives for private sector involvement; and 4) delivery and use of technologies, including methods of payment or financing.

Definitions and Boundaries. It is necessary to decide on study boundaries while remaining aware that many distinctions will be drawn artificially. Throughout the study, decisions on scope and boundaries -- in effect, decisions on whether to include or exclude specific types of handicaps, technologies, or policy issues -- will have to be dictated by pragmatism.

Much work has been done by others on the definition of a “handicap” or “disability” and on estimating the numbers of handicapped individuals in this country. Despite this prior work, the situation is confused. By one estimate, there are at least 41 definitions of “disability” or “handicap” used by federal programs. Similarly, many estimates of the number of handicapped people suffer from various deficiencies such as lack of measures of severity, double-counting, or under-reporting. However, the OTA study is not intended to identify populations to receive entitlements or other services. Therefore, it will not attempt to develop a preferred or recommended definition, nor will it focus on the development of estimates of the numbers of handicapped people. Instead, it will cover the importance and the implications for policy of methods by which the functional limitations of individuals are identified.

OTA defines technology broadly, as the application of an organized body of knowledge to practical purposes. Under this definition, technologies include physical objects, such as voice synthesizers, as well as processes, such as vocational rehabilitation or reimbursement systems. As a practical matter, the study will focus on those technologies designed for and used directly by individuals (as opposed to populations) with the intent of eliminating, bypassing, or reducing one or more of the individuals’ functional limitations. Thus, for example, medical devices, prostheses, modifications of automobiles, and techniques or programs for vocational training are within the study’s focus. Technologies designed to address and be applied to population-oriented needs, such as transportation systems or educational systems as a whole, are generally considered outside of the study’s focus.

Other Elements of the Project. To support the core elements of the project, several additional activities are taking place. An analysis of the role of the courts and the judiciary in the implementation of federal legislation relating to handicaps is being conducted. This analysis will also cover the general issues of rights and entitlements and the potential for proposed legislative initiatives to effect change in the present situation. OTA is also developing information about the attitudes (of society and of both handicapped and able-bodied individuals) that affect processes and policies relating to the development and use of technology. This issue will be examined in a workshop to be held in May 1981. A third additional activity is the examination of methods for developing individualized rehabilitation or education “plans.”

Several case studies will be conducted. Case studies are designed to provide both specific information about the technologies or areas of disability being studied as well as information that informs the more general issues being examined. Ones in progress include: techniques for “mainstreaming” in early childhood and elementary school; employment technologies (techniques); technologies for severe speech impairments; the impact of federal legislation on a state government; knee and hip implants; and learning disabilities. Ones under consideration include: individually scheduled van service for handicapped individuals; rocker shoes; incontinence; and toys.

The assessment began in October of 1980 and is scheduled for completion at the end of 1981. It is being conducted by the Health Program of OTA. If you have any questions, or would like to contribute information or suggestions, please call the Project Director, Clyde Behney, on (202) 226-2070, Or write to:

Office of Technology Assessment
U.S. Congress
Washington, D.C. 20510

Addendum B

March 27, 1981

2

Dear 2 :

As you may know, the Office of Technology Assessment is conducting a comprehensive study on "Technology and the Handicapped" for the Senate Committee on Labor and Human Resources. A brief narrative description of the project is attached.

The purpose of the assessment is to examine the specific problems and opportunities found in the development, evaluation, and use of technologies. Its purpose is also to examine the broader issues associated with providing an appropriate match between the technology needs, desires, and capabilities of users and the fiscal and technical ability to develop and deliver the technologies. The assessment will present policy options for Congressional consideration. These options may cover all aspects of the research, development, evaluation, diffusion and marketing, delivery, and use of technologies.

While the responsibility for the project rests with OTA staff, the advice of our advisory panel and numerous other individuals and groups in the private and public sectors is essential. We know that you and your organization have a particular perspective that would be helpful to us in our investigation of technology-related problems and opportunities. Could you review the attached description of our project and suggest, from your perspective, specific information on problems and missed or potential opportunities? We request and welcome your ideas. As mentioned, the final report of the OTA project will include a series of policy options for the Congress. If you have suggestions for needed actions, we would appreciate seeing them.

We have purposely avoided the use of a questionnaire in our request because we do not want to encourage or discourage particular categories of problem statements or options. Indeed, we hope that your response is constrained only by the boundaries of your expertise in this area. Please do not restrict suggestions for solutions to those that require legislative change or even to those involving the public sector.

We ask that your response be sent to us by April 22nd in order to lessen the possibility of omitting key issues from consideration. Please send it to me at the following address:

Health Program
Office of Technology Assessment
Congress of the United States
Washington, D.C. 20510

We look forward to receiving your response and thank you in advance for your time. If you have any questions, please do not hesitate to call me or Anne Kesselman Burns at (202) 226-2070.

Sincerely ,

Clyde J. Behney
Project Director