

Part Four:

Policy Options

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Policy Options

Refusal to accept the inevitable shortcomings of any society is responsible for a good deal of what is best in political life.

—Peter F. Drucker

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12.

Policy Options

A large number of factors affect the success of technological applications in the area of disabilities. Among the most influential factors are Federal policies. This chapter discusses possible changes in those policies. Some involve legislative changes. Others are oriented to actions of the executive branch, but would involve congressional oversight or encouragement. None of them are recommendations: OTA does not recommend any particular course of action. They are options for congressional consideration. The options are not, for the most part, mutually exclusive. The adoption of one option within a category does not necessarily mean that the others are inapplicable. On the contrary, better effect can often be had by a careful combination of options.

Many of the generic problems that exist in this area range from a lack of financial incentives for manufacturers to produce devices for disabled people, to a lack of evaluation and evaluation criteria, to inadequate information transfer systems. These types of problems could be alleviated by a concerted effort involving public agencies, private organizations, and consumer and citizen participation. However, many of the other prob-

lems are so deeply rooted in complex financial circumstances that it might take substantial changes in reimbursement policies and in the public-private sector relationship to bring about significant improvements.

Some of the problems are based in social and psychological attitudes that cannot be changed simply by appropriating more money or by reorganizing Federal agencies. Federal policies can have some effect in changing attitudes, but any substantial change may depend as much or more on disabled persons themselves. Opportunities for changing attitudes, however, can be enhanced by Federal policies and administration that assure employment and education activities, thus changing the amount of interaction that takes place between disabled people and nondisabled persons.

The options below are presented by issue areas. Despite this division, which is for the purposes of presentation, it is important to bear in mind the extremely important interactions that occur both among the stages in the lifecycle of technology and between technical issues and resource or social issues.

PRODUCTION, MARKETING, AND DIFFUSION OF DISABILITY-RELATED TECHNOLOGIES

ISSUE 1

How can the Federal Government increase the probability that technologies will reach the people who need and desire them?

In as many cases as possible, commercial viability should be one of the goals sought in technology developed using Federal funds. A critical issue is how to alter the currently inadequate state of marketing efforts and processes.

As discussed in chapters 8 and 9, one of the most critical and yet currently inadequate stages

in the lifecycle of technologies for disabled people is the movement of technologies from development to use. Production and distribution are weak links in the process of technology development and diffusion. *The production, marketing, and diffusion of technologies are steps that are most often appropriate private sector activities, and yet a number of factors work against that sector's willingness and ability to engage in those activities.* Research and development (R&D) organizations have typically placed a low priority on production, marketing, and diffusion activities. The National Aeronautics and Space Administra-

tion's (NASA's) activities in technology transfer illustrate an exception. In general, however, the ultimate commercial production and distribution of technologies being developed with Federal funds have not been given sufficient attention.

There are several market-oriented factors that work against the involvement of the private sector. The difficulty in projecting the markets for disability-related technologies increases the risks of a commercial venture, as do the often small populations in question. Also, disabled individuals traditionally have had low average earnings or funds at their disposal. * The financing and reimbursement policies of the Federal Government and the States also contribute to the uncertainties of the marketplace for a firm considering the production of a technology. (this problem is covered under the option area below on financial barriers to the acquisition of technology,)

OTA finds that the key problems in the production and marketing area are the following: 1) lack of attention to production and marketing during the R&D and evaluation stages (this is covered under the option area below on research, development, and evaluation of technologies); 2) absence of adequate data on potential markets and on the needs, desires, and capabilities of people in those markets; 3) lack of organizations that could provide such data in the form needed by potential production and marketing firms; 4) greater than average risks related to entering the disability market; 5) Federal fiscal and regulatory policies that do little to reduce such risks; and 6) inadequate mechanisms for funding the purchase of devices (especially those seen as "not medically necessary").

OPTION 1A

Congress could amend current legislation to create a consistent and comprehensive set of

*As indicated earlier, figures on the average earnings of disabled people may be deceptively low due to the fact that many such estimates are derived from people in assistance programs. Disabled people who are not enrolled in such programs are often not counted, and, presumably, these people have higher earnings than the estimates for the average disabled person. The perception of earnings levels of disabled people, however, are still based on such possibly deceptive average estimates and therefore may negatively affect the willingness of firms to take marketing risks.

fiscal and regulatory incentives encouraging private industry to invest in the production and marketing of disability-related technologies.

This option would require a substantial effort on the part of Congress to identify and review relevant sections of many statutes and regulations. Amending fiscal, monetary, and regulatory policy to create a consistent package of incentives will not be an easy task, nor, perhaps, one that can be accomplished without much compromise.

Nevertheless, this option recognizes the current confusing and often detrimental collection of competing incentives set up by such laws. It implicitly is based on several ideas: 1) that a great many technologies, though certainly not all, could be serving far more people than currently; 2) that some, perhaps many, technologies' development and subsequent distribution depends less on further research than on the willingness and ability of private industry to develop, produce, and market them; 3) that policies of the Government greatly affect private industry's willingness and ability to produce and market these technologies; and 4) that current legislation and regulations do not create adequate positive incentives for those firms to do so.

This option is more applicable to hard technologies such as devices than to soft technologies such as counseling methods, planning or educational techniques, or service delivery systems. Nevertheless, firms or other organizations that might potentially develop and market soft technologies should also benefit from any changes in fiscal or regulatory incentives.

Fiscal incentives are created by policies that reduce the financial uncertainties associated with risk-taking in the disability field. Their objective would be to allow private investors and firms to make more reliable estimates of potential returns on investment *and* to increase the probability of a satisfactory return on investment. The principal type of policy that creates fiscal incentives is taxation policy.

Regulatory incentives seek to accomplish the same objectives as fiscal incentives but do so through methods less directly connected to financial factors. Patent and licensing policies are ex-

amples of areas where regulatory incentives might be created. Another example would be changes in the penalties for noncompliance with Federal regulations regarding the hiring of disabled people or the provision of appropriate technologies to disabled people. This type of incentive would increase the demand—and therefore the potential market—for technologies, as well as more fully utilize the skills of professionals and technicians who happen to have disabilities.

A full study of the possible incentives and their potential interactions and results might be necessary before this option could be implemented. The following potential fiscal and regulatory mechanisms for creating incentives should be included in such a study:

- accelerated tax writeoff of equipment and other capital investments;
 - allow individual tax deductions for devices that are not covered by insurance or other payment programs;
 - expanded efforts in guaranteeing markets to potential producers of a technology (e.g., through the Veteran's Administration (VA), vocational rehabilitation programs, or education assistance programs);
 - modified capital gains taxes on investments in firms designated as producers of disability-related technologies;
 - extended carryover of losses for designated firms;
 - tax credits against profits for designated small businesses for a specified number of years;
 - other tax reduction policies for investors or firms engaging in the production or delivery of relevant technologies;
 - strengthening and clarifying of rules for compliance with Federal laws concerning non-discrimination in hiring, employment, etc., and concerning the reasonable accommodations that must be made by employers, schools, etc., to allow the participation of disabled people (this mechanism acts to increase the productivity and well-being of disabled people and to increase their ability to afford technologies, thereby increasing potential markets);
 - facilitating the awarding of grants and contracts to small, profit-seeking businesses for the development and testing of relevant technologies;
 - cooperation with State and local governments in providing low-interest-rate loans, direct subsidies, or guaranteed markets/purchases for small firms;
 - expanded coverage under Federal health insurance and service provision programs to include those technologies which, though not viewed as strictly "medically necessary," increase the capacity of disabled persons to function more independently and productively;
 - modification of the present patent system to allow small firms (which make up the majority of firms in this area) to secure patents in less time and at less expense (e. g., through Federal subsidies for patent expenses); and
 - clarification and greater standardization of Federal policies in regard to the granting (to firms that might produce needed technologies) of exclusive or nonexclusive licenses to Federal patents.
- In designing a package of fiscal and regulatory incentives, Congress should consider a range of factors that play an important role in the willingness and ability of organizations to produce and market technologies. Some of these factors are:
- the difficulty of obtaining *venture or risk capital* for the production of a technology, whose future success is subject to the higher than average uncertainties of the disability-related market;
 - uncertainty about patent rights for products developed with Government funds;
 - uncertainty about whether the technology will be covered by insurance companies or Government programs;
 - the possibility of product liability costs;
 - the difficulties of "selling" the merits of a product to intermediaries (e. g., insurance companies, the VA school districts, Medicare) as well as direct users; and
 - the need to spend more time and fun& than the average on market analysis, prototype development and testing, and training of

consumers and others in the maintenance and use of the product.

The implementation of this option would have both benefits and costs, all of which would share some of the uncertainty inherent in this area. On the benefit side, revenues to the Federal Government might be increased as a result of the larger corporate taxes paid by firms and the increased taxes paid by disabled people who would receive technologies that allow them to lead more productive lives. Revenues would be reduced by the amounts of any tax reductions embodied in the fiscal incentive structure. Federal costs would be diminished by the reduction in funds spent on income transfer, health insurance payments, etc., due to disabled people's being able to leave Federal and State programs. A prime social benefit of changes in incentives, however, is one that would be very difficult (perhaps impossible) to put into dollar terms-i. e., the increases in well-being (psychological and economic) of the disabled people who would benefit from the distribution of helpful technologies.

OPTION 1B

*Congress could legislatively charter a private organization to provide marketing and production-related services to both the private and the public sectors. **

The Federal Government, through Congress, has occasionally granted an official Federal charter to an organization when Congress has felt that such an organization would serve the public welfare. An example is the charter granted to the National Academy of Sciences. Chartering can be accomplished by an act of incorporation passed by Congress and signed by the President. A federally chartered organization, though not a Federal agency, is or may be considered a public organization for such things as compliance with civil rights legislation.

The initial funds and the operating expenses for such an organization would come from the non-public sector, with perhaps a small startup grant

*Much of the discussion under options 1B and 1C were suggested by and drawn from a paper by Tom Joe, "The Application of Technology for the Disabled: A Joint Public-Private Venture" (Center for the Study of Social Policy, University of Chicago, 1981).

from the Government. After startup, however, the organization would be expected to operate on its own revenues. For purposes of taxation, it would be considered a nonprofit organization. An organization of this type would be eligible to receive funds from any source, including Government agencies, philanthropic foundations, voluntary agencies, industry, estates, and gifts or donations.

The goal of the organization would be to provide technical assistance, analysis, and other services related to the production, marketing, and diffusion of disability-related technologies. In return for fees, it could perform marketing surveys and help put together market strategies for private firms who are considering entering a new product on the market. It could serve as a liaison between firms or Government agencies and ultimate consumers. It could develop and manage demographic and product data sets.

The success of this type of organization might depend on three items: the quality and reputation of its staff, its ability to deliver helpful services, and its ability to cope with what might be a large demand for its services while it is still young and growing. One of the goals of a Federal charter, in fact, would be to give the organization the prestige to attract qualified staff members. The organization would be eligible to receive Federal and other governmental grants and contracts. The National Institute of Handicapped Research (NIHR), its rehabilitation engineering centers, the Rehabilitation Services Administration (RSA), VA, NASA, the National Science Foundation, the National Institutes of Health (NIH), and other agencies should be encouraged to use the organization as *appropriate*. An organization of this type must be very careful to represent itself as being able to deliver only those services that it can (which will change as the organization grows and builds expertise and data) and only within the time frame that it can handle.

The proposed organization might be able to do technology evaluations, either directly or by managing evaluation projects that others are actually carrying out. However, this function should be added to the list of the organization's activities only if it can be clearly and cleanly separated from

the functions of assisting the marketing of products. Conflicts of interest could prove very harmful to the organization and its goals.

One potential advantage of the proposed organization is that it is designed to carry out an important and currently inadequately performed function; another is that it is located in the non-public sector. Potential disadvantages lie in the possibility of conflict of interest and in the nature of the tasks assigned to the organization. In order to consistently attract private and public funds, the organization would have to deliver valuable but extremely difficult services.

One crucial point is that the proposed organization should have broad representation of many different groups and constituencies. Consumers and marketing and production experts would be essential. Demographers, taxation and fiscal experts, the general public, analytical experts, technologists and researchers would also be very important to the organization's success.

Canada has an organization similar to the one of this option. Technical Aids and Systems for the Handicapped, Inc. (TASH) was established as a nonprofit corporation by the Canadian National Research Council and the Canadian Rehabilitation Council for the Disabled. It provides marketing, supply, and maintenance services, especially for devices that are not widely available. The experience of TASH should be examined closely before any decision about establishing a similar domestic organization is made.

OPTION 1C

Congress could establish a joint public-private corporation to provide marketing and production-related services to both the private and the public sectors.

This option has goals similar to those of the previous option and seeks to accomplish them through somewhat similar means. The principal difference between the two options is the legal authority under which the proposed organization would operate. The organization proposed in the previous option would be considered a private corporation for most purposes; that proposed in this option would be as quasi-governmental entity. The entity could be a nonprofit corporation

existing to serve the public good by acting much as a private sector organization. Analogous organizations are the Overseas Private Investment Corporation, the Tennessee Valley Authority, and the Federal National Mortgage Association.

An example of a similar organization is the Communications Satellite Corp. (COMSAT). COMSAT is a private firm, owned by its shareholders, with a board of directors who are not officials of the Government. It is not a public corporation, nor has it been granted a Federal charter of incorporation. Three of COMSAT'S directors, however, are nominated by the President and confirmed by the Senate. Even though COMSAT is a wholly private organization, it is considered to be performing a service that is in the best interests of the public and has therefore been given special status (e.g., it is by Federal statute designated the organization that represents the United States in the International Telecommunication Satellite Organization). COMSAT, therefore, illustrates another possible method of aiding the establishment of an organization to provide needed services.

The goal of setting up a public-private corporation such as that proposed in this option is to support the performance of services deemed to be in the broad public interest through the use of primarily private funding and private sector managerial techniques. One possible and potentially very important element of such a corporation's mandate could be the inclusion of a formal requirement that the corporation subcontract with consumer groups or a single consumer organization for the testing and evaluation of technologies. The consumer groups could be chosen competitively, on the basis of criteria established by, for example, the board of directors of the corporation. The corporation need not be limited to consumer groups for its subcontracting, but such groups should play a significant *role* in its operations. As in the previous option, the corporation should only be allowed to perform evaluation services where no conflicts of interest exist.

Because of the possibility of conflicts of interest, Congress may wish to establish two separate public-private corporations (or two separate chartered organizations) to perform the two functions of

providing marketing and production-related services, and evaluating technologies and disseminating the results. If so, it would be desirable to have some mechanism to coordinate the activities of the two organizations (e.g., a joint board of directors). It might also be desirable for the two to share a data system, both to ensure compatibility and standardization of information and to avoid much potential duplication.

OPTION ID

Congress could mandate the collection of market-related demographic data by an interagency group led by the Bureau of the Census.

This option would be an attempt to reduce some of the uncertainty that accompanies decisions to develop or market products to be used by disabled people. It would also be useful to the public sector, because the data generated might be very helpful in the setting of research priorities and the allocation of funds for the applied engineering and diffusion stages of technology's lifecycle.

Current activities of Federal agencies are primarily oriented to the collection of data by etiological categories of impairments (and sometimes by disabilities). Less frequently do agencies collect data concerning limitations on functional abilities. The information that might be gathered from individualized plans (see ch. 3) is not seen as a source of raw material for the development of marketing-related data bases. Especially absent in data collection efforts are data on handicaps—i. e., disabilities turned into handicaps by an interaction of the disability and the physical and social environments. If data were available on the demographics (e.g., age, income, sex, other characteristics) of populations divided by types of functional limitations, the task of projecting the needed characteristics of technologies and the potential market for them would be made somewhat, perhaps considerably, easier. Such an outcome might be beneficial not only to the economic health of the private sector, but also to the public sector and the Nation as a whole.

Chapters 2, 3, and 11 discuss the issue of data based on functional limitations in more detail.

One important point in regard to the collection of such data by the Bureau of the Census is that the design and testing of the surveys should be done with the substantial advice of disabled people, Government program administrators (especially of R&D activities), other data collection agencies and experts (e.g., the National Center for Health Statistics (NCHS)), and industry representatives. Alternatively, an agency with more experience in the disability field, such as NIHR, might coordinate the data collection and analysis efforts with the assistance of the Bureau of the Census and NCHS. The key point here is that one agency should have the responsibility for national data on disabilities in order to achieve uniformity of definitions and measurements, but that agency must draw on the pertinent technical resources of other agencies. Although it might be possible for a private organization to perform these functions, an advantage of using a Federal agency is the ability of the Government to access the medical and other records from which many of the data would come.

The Federal Government recently conducted a substantial planning effort for a very similar data collection activity. An interagency committee (including, NCHS, the Bureau of the Census, and NIHR) was established and pretested a survey instrument for the Census Disability Survey. That survey, using 100,000 disabled people and designed to collect information on functional abilities and disabilities, was to be a follow-on to the 1980 census. If the survey had been funded, and if it had been successful, it would have provided a substantial portion of the information needed by Government agencies, industry, and other groups. Lack of funds was cited as the reason for the project's not taking place.

The costs of option ID would vary considerably, depending on how extensively the current survey techniques and activities of the Bureau of the Census would have to be modified or expanded. It might be possible to create a mechanism whereby the private sector, including industry, advocacy groups, and foundations, could contribute funds to the effort. Another dimension along which costs would vary is the extent to which new data are collected as opposed to old

data analyzed to provide new answers. A recent study of national sources of data by the Bureau of Social Science Research (BSSR) concluded that the current sources in regard to disability data do not lend themselves to making national estimates. According to BSSR, the data from these sources exhibit numerous inconsistencies. However, because of the cost of designing and implementing new surveys, a second best alternative to gathering new data might be to establish an adequately

funded effort to reevaluate existing data to get more accurate and more useful information. This alternative might be a fiscally easier first step.

A critical aspect of the success of this option would be the effectiveness of the dissemination of the generated data. Methods would have to be developed to allow all relevant parties to easily learn what would be available and how to gain access to it.

INVOLVEMENT OF DISABLED PEOPLE AND OTHER CONSUMERS

ISSUE 2

How can policies and programs be designed to encourage or assure the effective involvement of disabled people and other consumers in the development and delivery of technologies? In addition to providing information, consumers should themselves be part of advisory and policymaking bodies to the maximum extent feasible.

In theory, assuring maximum effectiveness, efficiency, and relevance in the development and application of technologies requires the extensive involvement of those who will use the technologies—the consumers. In practice, however, there is fairly little involvement.

There is no “correct” amount of consumer involvement, and there is no easy way to achieve effective involvement. OTA found the area of consumer involvement to be one filled with much irony. Consumer involvement is one of the most talked about aspects of the disability-related policy area—and everyone seems to believe in the concept—but few satisfactory schemes to improve the situation were suggested to OTA and few people or agencies appear to be taking aggressive steps to put the concept into practice.

OTA found a number of reasons for inadequate consumer involvement. One major reason is attitude. Although it is possible that, as a group, people working in the disability area are less prejudiced against disabled people than are other people, it appears that prejudice still plays a significant role in the willingness and desire of people in this area to interact with disabled people.

Another major reason is simply a bureaucratic one. Program administrators or service delivery individuals naturally seek to simplify their functions; adding another source of review, oversight, or advice is not usually compatible with the bureaucratic outlook.

A third reason for lack of involvement is the outlook of disabled people and handicapped people themselves. Despite dramatic changes in their view of themselves and their abilities, many people still are reluctant to consult to, or get involved in the administration of, programs addressing disabilities. When people do not see themselves as having something to contribute, they are less likely to be asked to do so.

A fourth reason is the difficulty of identifying “consumers.” Should a program seek any disabled person? A “representative” person? A representative from a consumer organization? From a coalition of organizations? How handicapped or disabled does the person have to be? One irony in this area is that the more articulate and mobile a disabled person is, the less *handicapped* (as defined in ch. 2) he or she likely is. Some people with disabilities may not be “handicapped,” since they can perform life’s functions substantially as well as a “nonhandicapped” person. Does this make them less representative? Not necessarily, but it makes the selection of consumers more difficult. Furthermore, consumers can include parents of disabled children, physicians and other providers, bus riders (both disabled and non-disabled), etc. Do parents always represent the needs and desires of their children and others’ children?

Another, very critical, reason for the inadequacy of consumer involvement is a lack of knowledge about how to design the advisory mechanisms that consumers would fit into in order to ensure effective involvement. In equal opportunity programs, in urban renewal, in education, and in many other policy areas, the country has sought to use consumer (affected party) involvement. Many of these efforts have been less than successful. That does not mean that they accomplished nothing, merely that they did not come close to meeting expectations or their potential contribution to policy formulation or implementation.

The tactical goal of consumer involvement is *realism*. Consumers and the groups or organizations they interact with should gain a more

realistic appreciation of the others' needs and capabilities. Designing a subway system that will handicap many disabled people is perhaps worse than designing a system with a plan for handling disabled people in a particular way, without the initial and continuing involvement of disabled people. Even so, the latter approach may not be the most effective or efficient way to make the system accessible and may also generate a priori resistance on the part of disabled people. Early, extensive involvement of potential disabled riders in planning for a new system might inject an element of realism: Subway designers and financiers, may gain a more realistic idea of the needs, desires, and capabilities of disabled people and be made aware of alternatives to their plan; *and* disabled people may gain a more realistic idea of



Photo credit" Association of Hand/capped Artists

Confined to a wheelchair by cerebral palsy, Neita May Kimmel of Catawissa, Pa., has appeared before high school, college, church, and club audiences to show and tell of her work and that of the Association of Handicapped Artists. She has written a book, "Reaching for the Stars," in collaboration with Dr. Raymond Treon

the design and financial constraints operating on the subway builders, thus allowing them to suggest possible alternatives within the constraints.

OTA found that R&D of technologies often proceeds with little input from potential users. When involvement is sought, it maybe perfunctory. The everyday, realistic needs of users very often do not find expression in the funding of R&D by the Federal Government. Nor are consumers represented very often on the groups that perform evaluations of technologies. (These shortcomings are addressed under the option area below on the research, development, and evaluation of technologies.

Consumer involvement is critical at each stage in the lifecycle of technologies. If Federal programs change their orientation from one of concern with simply the needs of consumers to concern with a mix of needs, desires, and capabilities (see ch. 2), the lack of consumer involvement will become even more critical. Besides R&D and evaluation activities, marketing, delivery, and financing programs need information that can best be provided by those directly affected.

The options provided below for the issue area of consumer involvement are organized by the degree of formality involved. This does not mean that they are necessarily mutually exclusive. More formal action may be desired in one area of policy (e.g., research project review, or consumer review of technologies for coverage under Medicare) and less formal actions in others (e.g., oversight hearings on compliance with individual education program (IEP) preparation and use).

OPTION 2A

Congress could mandate formal consumer involvement in any or all Federal programs or federally funded programs related to the development and use of disability-related technologies,

As mentioned above and in other parts of this report, Congress has already mandated consumer (“handicapped persons”) involvement through several Federal laws. The National Council on the Handicapped, for example, must have consumer representation, and the individualized educational program, individualized written rehabilitation program, and individual habilitation plan proc-

esses are designed to involve disabled people or their parents or other representatives in decisions about education or rehabilitation.

Under this option, Congress could expand the formal, statutorily based, requirements for the participation of disabled people in the policy development and implementation processes. Numerous agencies, including the Department of Health and Human Services (DHHS), the Department of Education, VA, the Department of Labor, and the Small Business Administration, could be required both to involve disabled people directly and to support consumer activities.

Direct involvement of consumers could be mandated in the process of R&D. (Option 3A also attempts to accomplish this.) Consumers would provide valuable advice to the process of setting research priorities, evaluating grant and contract proposals, and evaluating reports of progress on existing grants and contracts. The process of peer review would thus be expanded to include a more realistic appreciation of research needs and the usefulness of results.

Agencies that finance the use of technologies or that directly provide technologies to people with impairments and disabilities (e.g., VA) could set up panels, composed wholly or partially of consumers, to review technologies that might be included in reimbursement schedules or purchase lists. Alternatively, the Health Care Financing Administration (HCFA), NIHR, and VA could jointly fund a private nonprofit organization of consumers to review proposed technologies.

In general, this option could involve a program-by-program review to determine which programs could use the various mechanisms for establishing or expanding consumer involvement. As discussed above, effective consumer involvement is difficult to achieve. Thus, consideration should be given wherever possible to the use of flexible mechanisms—e. g., combinations of advisory panels, staff hiring, and contracts with consumer groups.

OPTION 2B

Congress could mandate an office of consumer involvement to monitor and provide assistance to other offices dealing with technologies, and Congress could encourage all

relevant agencies to expand consumer involvement,

Instead of legislatively mandating consumer involvement in specific instances, Congress could clearly encourage various agencies to expand their consumer involvement activities. This option provides the advantage of flexibility-flexibility to change as conditions change over time and as data on the performance of involvement methods become available. Congress could encourage specific actions through oversight hearings, committee reports, and other means.

The obvious disadvantage of this option relative to the previous one is the difficulty of gaining voluntary compliance by the agencies. That disadvantage is part of the rationale behind the creation of an office of consumer involvement to coordinate, monitor, and provide technical assistance regarding the involvement of disabled people. The legislative record, including hearings, committee reports, and the law itself, would serve as mechanisms for signaling the intent of Congress to encourage involvement. Further, the office could be required to submit annually to Congress a report on all relevant executive branch activities.

Another reason for the creation of an office of consumer involvement coordination and technical assistance is the desirability of *effective* consumer involvement. Achieving effective participation will not be easy; thus, providing agencies with an office that possesses expertise and experience in techniques to encourage such participation could be very helpful. It would be a small office with a modest funding level.

The proposed office, perhaps with the assistance of an interagency advisory or coordinating

committee, could monitor all consumer involvement activities, keep standardized records of these activities and any evaluations of their outcomes, maintain lists of consumer organizations and individuals who may be called upon, advise agencies on methods of increasing consumer activities, evaluate agency activities, and report on its own and other agencies' activities to Congress, the President, the National Council on the Handicapped, and any other designated groups.

The office could also be responsible for testing the feasibility of, and perhaps eventually implementing, a management information system based on data from individualized plans (as described in ch. 3) in order to evaluate and support involvement of consumers and consumer-generated information.

OPTION 2C

Congress could encourage agencies to increase consumer involvement activities.

If Congress wishes to signal a concern about the inadequate amount and quality of consumer involvement activities, it could do so through mechanisms less formal than legislation. These mechanisms include, as noted above, oversight hearings and records of hearings, and language in committee reports accompanying related legislation. Such informal, though official, encouragement has some potential to effect change. However, in view of tight agency budgets, bureaucratic inertia, and the difficulties inherent in attempts to achieve fully useful consumer participation, it is likely that this option possesses substantial disadvantages.

RESEARCH, DEVELOPMENT, AND EVALUATION OF TECHNOLOGIES

ISSUE 3

How can R&D activities be organized and funded to produce knowledge, techniques, or devices that serve the needs of disabled people and relevant providers in accordance with the magnitude of various problem areas and opportunities? How can evaluation of present

and emerging technologies be organized to provide consumers, providers, and policy-makers with adequate information?

R&D activities and related evaluations must be adequately funded, their potential contribution to the ultimate goals of technology application must be recognized, and their organization be

such that it support the attainment of those goals. In the area of disability-related technology, however, as discussed in chapters 6, 7, and 10, these needs for R&D and evaluation activities fall short of being realized.

Excluding the general health research of NIH, the amount of Federal funds spent on R&D related to disabilities is approximately \$66 million. (This figure includes education and vocational-related R&D, but not R&D in areas such as transportation or housing; even if these other areas were included, it is unlikely that the figure would be substantially increased.) In contrast, transfer payments alone to disabled people from Government programs total \$36 billion. Thus, R&D expenditures represent about one-fifth of 1 percent of the transfer payments. *If the other public and private sector expenditures for services to disabled individuals were added to the transfer payments, the R&D budget would be an even smaller percentage.* These comparisons are not meant to suggest that there is any way to identify a “correct” amount to spend on disability- or handicap-related R&D. (Total Federal health R&D is about 2 percent of total national personal health care expenditures—a figure that, at a minimum, is 10 times greater than that for disability R& D.)

Similarly, the level of evaluation activities is extremely low. No figures for the total effort in evaluation of disability-related technologies are available. However, it is clear that relatively little formal clinical or life-use testing takes place (see ch. 7). The reality of competition for funds certainly affects the levels of both R&D and evaluation activities. For evaluation, though, a perhaps equal factor is the lack of recognition given to the potential contribution of evaluation to decisions about the appropriate application of technologies.

The organization and directions of R&D and evaluation also contribute to the inadequate number of useful technologies from these activities. The peer review systems in effect at the start of the OTA study were not well organized (see ch. 6), although that situation appears to be changing. *Inadequate attention is paid to what will happen to the results of R&D once develop-*

ment is completed. The constraints and demands of marketing, production, and consumer acceptance and preferences continue to play a relatively small part in the R&D process, though that situation also seems to be changing—slowly.

Methods of evaluation and analysis remain underdeveloped. Recent work of NIHR and RSA seems to be moving in promising directions, but such work may not be a priority item for those agencies. Cost-benefit and cost-effectiveness techniques and modified forms of comprehensive technology assessment show potential in this area, but these methods are not being investigated thoroughly.

Complex, expensive technologies continue to receive a large share of NIHR's and other agencies' R&D funding. Complex, expensive technologies are not inherently more or less appropriate to concentrate on than simpler, inexpensive ones. R&D and evaluation funding should be apportioned among different technologies according to their potential for appropriate applications to the needs of consumers; such funding should not be apportioned on the basis of investigator interest or how fascinating or futuristic a technology may appear. The R&D process should be organized according to the needs it is designed to satisfy. More attention could be given to the apportioning of R&D funds by the potential payoff of various efforts in various technological areas. Some areas need more basic research, others need development funds, and others have technologies that need diffusion assistance. In short, attention should be divided according to the state of maturity—“readiness”—of the technologies and the nature of the population in need. NIHR and other agencies already have the authority to take many of the needed actions; they do not have to wait for legislative change. Agencies could, for example, allocate increased funds for low- or middle-technology fairs and contests. (Such fairs or contests should not become ends in themselves, but should be followed by publicity and publications summarizing the ideas generated.) Also, agencies could devote resources and attention to development and testing of methods of evaluation.

OPTION 3A

Congress could mandate that consumers and production and marketing experts be represented on R&D panels and evaluation panels.

This option explicitly recognizes that considerable involvement of the people and organizations who will play a major role in the subsequent usefulness and diffusion of technologies should take place early in the processes of R&D and evaluation. The objective of this option is the improvement of systems for conceiving new technologies, adapting existing ones to new applications, allocating R&D funds, and evaluating the results of current or past R&D. Congress has already indicated its desire that consumers and other groups be represented on the National Council on the Handicapped. The council is involved in setting or recommending directions and policy for NIHR. This body, however, cannot play a role in each R&D allocation decision; nor can it serve as the only source of consumer, production, and marketing input to the entire R&D and evaluation process. Further, its influence is far less extensive in agencies other than NIHR.

Implementing this option would require extensive thought on the most effective ways of avoiding tokenism and conflict-of-interest situations for private industry. Effective consumer involvement has often been a goal of many public policy areas, yet that goal is difficult to achieve. Questions have been raised, for example, about the effectiveness of consumer representation on the Food and Drug Administration's medical device classification panels. However, the addition of consumer, production, and marketing experts to disability-related R&D peer review and other groups may be somewhat more effective. Many aspects of the R&D process for technologies that will be used by disabled people are amenable to experienced consumer input. Consumers might inject a degree of realism to the setting of R&D goals and priorities; evaluation criteria might be set to more closely resemble the list of factors that lead to a technology's successful application. A consumer does not have to be a mechanical engineer to know that wheelchairs must fit through doors.

Production and marketing experts could help the R&D process in several ways. For example,

the simple presence of such people on panels could remind researchers and policymakers that the end result of R&D is supposed to be (in most cases) useful and cost-effective techniques and devices. Also, their experience and expertise would allow them to make suggestions concerning the evaluations that are necessary and the technological characteristics (reliability, cost to produce, ease of repairs, potential demand, flexibility) that should be sought. Such experts might help in the process of considering potential technologies, whether complex or simple, in relation to their eventual application and distribution.

Theoretically, no congressional actions are necessary for the adoption of this option. The executive branch agencies could implement it by themselves. If Congress finds that it is a desirable option, however, and agencies do not implement it on their own, Congress could amend relevant laws to mandate that R&D-related peer review and other advisory groups have such representation.

OPTION 3B

Congress could mandate demonstration projects for the awarding of "production stage" grants or contracts early in the R&D process.

The objective of this option is similar to that of the previous one. The ultimate goal of most R&D efforts is the development of technologies or techniques that will be effective *and* will be distributed—i.e., successfully reach their market. Small grants or contracts to nonprofit or profit-seeking organizations to analyze the potential market and to develop plans for the efficient production and diffusion of specific technologies *may* help. This option is oriented to only a demonstration effort because of the many questions that exist concerning the effectiveness of such a mechanism. Enough potential exists for the idea to be given consideration by Congress, however, and, if Congress believes it is warranted, for the idea's trial through pilot projects.

Congress could specify, either in renewal legislation or in appropriations language, its desire that NIHR (and perhaps NASA and VA) develop such a demonstration program.

One method of implementing the demonstration would be to select through a competitive

process a firm that is interested in the marketing rights, for a specified time or area, for a particular technology. That firm would use the contract funds to examine the most efficient ways to produce the technology under development. It could suggest changes in the technology or the populations for which the technology is being designed. It could aid in any evaluations of the technology. Essentially, this option is designed to set up a strong positive incentive for organizations to produce and market technologies.

The grants or contracts should not be so large that organizations would seek them without a real desire to eventually market the technology. The funds should be set at an amount that covers part or most of the cost of the activities in conjunction with the R&D process, as listed above. The hope for this option is that it will reduce the risk and the cost of deciding to market the technology, thus allowing a more intensive look at the appropriate potential applications of that technology.

OPTION 3C

Congress could appropriate specific increased funds for evaluation of technologies.

This option follows from the discussion of the relatively low level of funds and activities currently existing in the disability area. Although current economic realities naturally affect the viability of this option, it is important to remember that the current level of funding for evaluation is extremely low and that the number of technologies in need of clinical and other forms of evaluation is increasing constantly (see ch. 7). Especially pertinent is the probability of an acceleration of the number of technologies being developed. Many observers speak of the “explosion” in technologies for disabilities. Although the term “explosion” is a dramatic one, it is clear that advances in solid-state electronics, other communications developments, new alloys, and medical advances are producing numerous new technologies. Some of these may produce dramatic effects, others may turn out to be useless, but most will produce benefit under certain conditions—i. e., when applied appropriately in relation to their costs and risks. An increased amount of funds will be needed to adequately assess these new technologies as well as existing ones. The money, attention, and person-

nel will have to come from existing resources, which are already scarce in the disability-related R&D area, or from new funds specifically indicated for evaluation. Further, in the absence of increased funding—from whatever source—of evaluation, it is likely that program funds will not be spent in as efficient a manner as might be possible.

One drawback to this option is the immaturity of analytical techniques for comparing costs, risks, benefits, and social implications of disability-related technologies. The direct health-related benefits and risks can be estimated through relatively sophisticated techniques (using controls and statistical methods), but other effects are less amenable to current methods of evaluation. Thus, selection and implementation of this option may require that some initial attention and resources be devoted to the development of methods of analysis. Additionally, if this option is adopted, the very fact that increased funding, and therefore researcher attention, will be devoted to the area may mean that more work will be done on methods.

OPTION 3D

Congress could conduct oversight hearings with the Department of Education to determine why the dissemination of information on technologies remains inadequate,

OTA finds that the amount, usefulness, and accessibility of information on the characteristics, availability, and performance of technologies are not meeting the needs of users or potential users. Interviews with researchers, administrators, and consumers and with disabled people and nondisabled people; a review of the literature; and the results of OTA’s public outreach survey all reveal that dissemination of information is inadequate.

There are many partial explanations of the inadequate state of information flow that exists. One, for example, is that the National Rehabilitation Information Center (NARIC) is relatively new, and its ABLEDATA system is even newer. Also, these activities have not had significant amounts of funds appropriated. Thus, while ABLEDATA appears to be a potentially model system for disseminating information on assistive

devices, the number of devices about which information has been entered into the ABLEDATA system and the amount of data on each such device are still quite limited because of the small size of the staff. Another reason is the generally low level of information that exists. It is difficult to disseminate what is not available or is of poor quality, low relevance, or nonstandardized. This is one reason that option 3C would assist in improving the performance of information dissemination activities, particularly for evaluation information.

Furthermore, experts in the field disagree on the best way to approach the collection and dissemination of data on disabilities and technologies. Some people believe that a large, centralized data system for the collection of masses of data is not the most effective or efficient method. However, others believe that such a single standardized sys-

tem is necessary. The evidence available to OTA indicates that one system is not the answer, given the nature of disabilities and the disability field. There is a wide variety of parties who have a number of differing information needs. Disabled people themselves represent one of the largest groups of potential users of information. Yet the data needs of disabled people are as varied as the disabilities, desires, and capabilities they possess. Still, questions remain about the alternatives to a single system.

Before any specific legislative actions are taken, a number of questions could be addressed in oversight hearings. Such hearings could be designed to bring out more clearly the reasons for the current situation and the administrative reactions to that situation. Examples of questions that could be explored in oversight are the following: Why have agencies, especially in the Department of



Photo credit Barry Corbet Courtesy of North American Reinsurance Corp

Imogene Dickey of Buffalo, Wyo., uses a wheelchair for mobility. She and the chair ride on a Chair-E-Yacht or, for longer distances, a ramp-equipped van

Education, oriented their dissemination activities to professional research institutions and similar clients? What is being done to establish the criteria for the design of a system to make information available to disabled people directly? What effects might be expected from an increase in the funding levels for NARIC and, especially, ABLEDATA? Why has little effort gone into the standardization of evaluation and performance data on technologies? How will disabled persons not enrolled in public programs have access to information on technologies? Do agencies plan to expand their evaluation activities in regard to the

performance of any existing systems for disseminating information, including NARIC (and specifically ABLEDATA) and any non-Federal systems?

Oversight questions could also address the factors cited above that make dissemination difficult and explore what the agencies are doing to minimize the difficulties, or to compound them.

Depending on the results of any oversight hearings, Congress may then decide to take substantive legislative action or to encourage specific actions by the agencies.

FINANCIAL BARRIERS TO THE USE OF TECHNOLOGY

ISSUE 4

How can financial barriers to the acquisition of technologies by disabled people be reduced, within reasonable constraints? Can the levels and distribution of available funding be made more appropriate in relation to the level of the problems addressed?

Imperfections in the structure of delivery systems need to be minimized. Inadequate and sometimes illogical criteria for reimbursement or payment for technologies should be reviewed and where appropriate changed.

Despite eligibility for the public and nonpublic programs that may pay for technologies to assist them to function more independently and productively, *a number of disabled people are denied funding for particular technologies that are clearly appropriate.* As discussed in chapter 9, a primary reason for the denial of funding—especially under Medicare and Medicaid, but also under other programs—is that the technologies in question are not strictly “medical” in nature and are therefore not considered “necessary.” A connection needs to be made in these programs between paying for these technologies and the potential independence or productivity of disabled people. Another finding is that when device technologies are funded, services necessary to their proper use (e. g., fitting, training in correct usage, and maintenance) are often not included in the funding. Furthermore, OTA finds that decisions to fund certain technol-

ogies are sometimes based on the criterion of low initial, short-term cost. Use of such a criterion may fail to identify instances when a greater initial investment might result in decreased long-term costs and greater functional ability for the individuals involved.

While most indigent disabled persons are eventually able to receive some assistance towards meeting their needs, OTA finds that *acquisition of technologies in the period immediately following the onset of their impairment presents particular financial hardships.* Those individuals who must leave their employment because of their disability often lose the insurance coverage that would have funded the technologies. Eligibility for a Federal program may be established, but benefits are provided only after a number of months have elapsed. Earlier intervention through funded technology would often serve to reduce or ameliorate disabilities during the early stages and thus lessen the long-term disability.

OTA finds that disabled people with enough resources to prevent their participation in programs that pay for technologies also face serious financial barriers to technology acquisition. *There are few available methods for financing the capital outlays that are often necessary, and those few that exist are available only in selected parts of the country.* Additionally, there is a need to expand the use of innovative ways to eliminate financial barriers to the use of technologies. One

such method that shows promise is pooling of devices by schools, voluntary health or disability organizations, hospitals, or similar organizations. This approach should be taken only with great care, however, since pooling of obsolete or simply “left over” technologies from other users could lead to inappropriate matches between the new user’s needs and the available pooled technologies.

OPTION 4A

Congress could establish a loan guarantee program with low interest financing (on an income-related sliding scale) to assist disabled people in device purchases.

This option would reduce or eliminate financial barriers to acquiring devices for individuals who have the capability to generate the funds to pay for the devices but who do not have the resources for the initial capital outlay. Either the amount of money available for the loan or its interest rate, or both, would vary according to the financial need of the individual beneficiaries. The rationale for such a program is straightforward—the loans would assist in the purchases of devices which, in turn, would assist the individuals directly or indirectly to function independently, work, and pay back the loan.

Pursuit of this option would likely involve a minimum of Federal dollars. The program could be State-administered, as is the program of federally guaranteed student loans for higher education. Adding this new program to a similar one for administrative purposes would minimize the funds spent on administration. The interest subsidies could be provided either by the Federal Government directly or by the lending institutions with tax incentives to do so. The actual Federal funds necessary for coverage of defaulted loans could be kept at a minimum as long as the beneficiaries of the program are selected to fulfill criteria that would increase the likelihood of their ability to repay the loans.

A significant implication of this option is the public-private partnership likely to occur if it were implemented. Such a partnership might be an important advantage in an era of pressures to constrain expenditures of public dollars.

OPTION 4B

Congress could conduct oversight hearings on ways to change criteria for reimbursement under the Federal health insurance programs with respect to technologies for disabled people.

This option is developed from OTA’s finding that disabled people eligible for coverage under one of the Federal health insurance programs are often denied payment for technologies that are not considered strictly medical in nature, although the technologies would improve the ability of the individuals involved to lead more independent, productive lives. The current patterns of reimbursement exist largely because of the history of these programs as assistance for acute medical problems rather than for the chronic problems faced by disabled people. The legislation for the programs does not expressly prohibit payment for “nonmedical” technologies such as communication, education, and rehabilitative aids. Instead, the denials usually occur at the State or regional level through regulation.

A significant effect of the current “system” is that in the short term, funds maybe saved, while in the long term, a greater amount of total funds is expended in, for example, income maintenance payments or institutionalization expenses. In addition to the cost-related effects, there are psychological effects on the individuals involved—the current system provides incentives for the dependence of disabled people on public programs. Changes enacted should provide incentives for independence.

Hearings on methods to change reimbursement criteria to foster independence and productivity would focus attention on the need to consider the implications of policies in one area on other related areas. Such hearings, if pursued, could include testimony by consumers and providers of disability-related nonmedical technologies as well as by representatives of HCFA, the State Medicaid offices, and the contractors. Theoretically, the hearings should provide alternative criteria for expanded reimbursement and suggested regulatory changes to accomplish that objective which HCFA and the States could then adopt. Congress could

then hold oversight hearings at a later date to determine the effects of any adopted changes. However, it is possible that legislative action may be required to assure expanded reimbursement. In that case, the actual law should include safeguards against abuse of the expanded opportunities for reimbursement. One method would be to detail the criteria for payment in the law directly.

Finally, OTA finds that reimbursement for an expanded variety of technologies should not be pursued without accompanying reimbursement for the services of those who select the technologies, those who fit them, and those who train the users in their proper use. A portion of the oversight hearings could address various criteria for assuring that these essential related services will be provided.

OPTION 4C

Congress could conduct oversight hearings on methods to improve health insurance coverage for persons leaving employment as a result of disability.

The objective of this option is to reduce the financial barriers to the acquisition of technologies during the period immediately following termination from employment due to disability. The option stems from OTA's finding that the systems for assistance are least able to assist disabled people during that time, although some form of early assistance may prevent or reduce assistance at a later time. Most people who leave employment lose health and medical insurance coverage formerly provided by their employers. Even if they are eligible for public or private disability income maintenance payments, they often do not have the funds to purchase private individual coverage. Since health and medical insurance programs are a primary source of funding for technologies for

disabled people, Congress could investigate ways to close these gaps and examine the resultant benefits and costs to society of any administrative or legislative action implemented.

One method that might be covered in oversight hearings is the provision of Medicare coverage during the 29-month period that individuals must wait for Federal disability insurance. This method should be used only for those people who do not have private insurance or other financial resources readily available to them. Criteria for providing Medicare coverage (e.g., a likelihood of having the severity of the disability reduced as a result of early medical intervention), or methods for measuring fulfillment of the criteria could be topics for testimony. Another method that might be covered is the provision of incentives to employers to provide health and medical insurance coverage to their terminated employees for 12 to 29 months following termination for disability-related reasons.

It is likely that legislative action will be necessary to implement any of the methods presented. Such action could range from changes in the Social Security Act to minor changes in tax deductions. The amount of Federal dollars will vary according to the source of the coverage (Federal or private), the amount of coverage extended, and the number of new beneficiaries. A potential drawback to this option is that it is not designed to improve coverage for those disabled from birth or those disabled later in life who are not working at the time of disability onset. Furthermore, unless changes in the criteria for reimbursement under the Federal health insurance programs are pursued as discussed in the previous option, there is likely to be an inefficient expenditure of dollars under any program arising from these hearings as long as appropriate technologies are not covered.

PERSONNEL ISSUES

ISSUE 5

How can Federal policies assure an adequate number of well-trained personnel at all stages

of the development and use of technologies? Systems for R&D as well as delivery of services should provide incentives for the cost-effective use of these personnel.

Although the actual number of professionals (disabled and nondisabled) working to develop and apply technologies to disabled people has increased dramatically over the last 40 years, there remains a shortage in a number of key areas. First, there are too few rehabilitation researchers and rehabilitation engineers. Although difficult to quantify, this shortage can be described by the primary reasons behind it. One, as discussed in chapters 6 and 10, is the relatively low level of funds spent on disability-related research in relation to the amount spent on general health-related research. Another reason, as discussed in chapter 9, is a lack of reimbursement for the skills of these professionals, particularly rehabilitation engineers. Together these reasons result in an unfavorable job market that may discourage prospective students from entering those fields. Second, there are too few allied health professionals, including physical therapists, occupational therapists, orthotic and prosthetic technologists, speech therapists, vocational educators, and rehabilitation counselors. As in the case of rehabilitation engineers, the size of the shortage is difficult to quantify, primarily because demand figures for these professionals usually include the needs of nondisabled clients as well as disabled persons. It is clear, though, that legislation such as the Education for All Handicapped Children Act, as amended, has served to increase the demand for allied health professionals. Furthermore, there is a shortage in these areas of professionals who are disabled themselves.

Finally, there is a shortage of rehabilitation physician specialists, although the specialty has been in existence since 1948. Under the current reimbursement system, this shortage is often a key one, because it is often the physician who must prescribe a technology for it to be funded. OTA explored the reasons behind this shortage and found them to include a perception of the specialty as one with low status, a relative lack of control over the client's treatment due to the wide range of other professionals whose opinions must be considered, a lack of professional orientation towards the treatment of stable or deteriorating conditions, and a lack of training in the undergraduate medical education on the management of chronic disability.

Another key finding with respect to personnel is that *those providers who are permitted by the structure of the delivery and funding systems to select or prescribe technologies for disabled users may not be the most appropriate ones to do so*. Traditionally, physicians have prescribed most of the device technologies, partly because disabled people often receive their first services through the medical system and partly because the major third-party payers will pay only for items that carry a physician's prescription. For certain technologies, physicians are the most appropriate providers to make the best selection for their clients. However, for other technologies, particularly those that are not medical in nature, other providers are equally or better qualified to make the best selection. Yet if these other providers, including rehabilitation engineers, occupational therapists, and special education teachers, as well as users themselves, cannot obtain funding, their skills may not be fully utilized, and the overall costs to society may be greater. Changes in physician curricula as well as in reimbursement policies might alleviate this problem.

OPTION 5A

Congress could appropriate funds for the training of increased numbers of disability-related personnel, including rehabilitation engineers, rehabilitation medicine physician specialists, and allied health professionals.

The objective of this option is to alleviate the shortage of providers in the development and use of technology. The option is weighted toward the application end of the technology lifecycle, since it is likely that researchers trained in related fields could apply their basic skills to the disability field if funds were available for new projects. Schools eligible to receive the funds under this option would include schools of engineering with specific programs for rehabilitation engineering, medical schools that sponsor residency programs in rehabilitation medicine, and schools for allied health professionals. As under the existing programs for training assistance (including public health, nursing, and physician traineeships), the funds could be awarded directly to recognized programs but applied to educate specific individuals. This

mechanism allows nationally determined priorities to affect the selection of both the educational programs and the individuals in them. Funds appropriated for these programs might come from funds currently appropriated for physician training in specialties for which there is likely to be an excess according to the recent report of the Graduate Medical Education National Advisory Committee (102).

A corollary objective of this option is to encourage disabled individuals to become rehabilitation professionals, particularly rehabilitation engineers. As noted throughout this report, the appropriate application of technologies to disabled people requires input from consumers at every phase of the technology lifecycle. Because rehabilitation engineering is a blend of technology development and application, it is a key field in which to focus Federal efforts to encourage the training of disabled professionals. Mechanisms to encourage an increase in the number of disabled professionals trained include requiring or creating incentives for programs that receive Federal assistance to implement affirmative action programs.

This option will not be effective unless mechanisms for improving criteria for reimbursement for nonmedical technologies are developed, as discussed under options 4B and 5C. Currently, a lack of funding for nonmedical personnel who assist disabled people to function independently has made the job market undesirable for prospective students. Training more professionals for these positions would probably be an inefficient use of scarce resources.

Finally, an alternative to training more rehabilitation medicine specialists is training physicians in other specialties to become “managers” of the rehabilitation and habilitation of their chronically disabled clients. This alternative recognizes that physicians are likely to influence delivery and payment systems for at least the short-term future. Funding courses in medical schools or residency programs might assist other physicians to better help their disabled clients.

An additional need in this area is for the training of existing disability-related and general health professionals in the specialized skills necessary for the appropriate use of technologies.

OPTION 5B

Congress could encourage volunteer participation in assisting disabled people by modifying tax incentives related to volunteer expenses and charitable contributions.

As with the previous option, the objective of this option is to alleviate the personnel shortage in various parts of the technology lifecycle. This option suggests the use of volunteers to perform some of the functions normally provided by professionals, to enhance the services provided by professionals and to assist in implementing existing legislation that has, to date, not been appropriated enough funds for full implementation (e.g., the Education for All Handicapped Children Act). Although “volunteer participation” suggests that no compensation is provided, the incentive of reduced taxes is known as a relatively inexpensive method of providing compensation. This option assumes that the provision of such “compensation” will increase the supply of volunteers. Although tax provisions currently exist both for deduction of charitable contributions and volunteer expenses, strengthening these provisions might increase volunteer participation. For example, the current deduction of 9 cents per mile of volunteer travel by automobile might be increased (for business travel, the current deduction is 20 cents).

Specific examples of possible volunteer assistance are: serving as information resources and referral persons (a function often performed by several types of allied health professionals); assisting in planning and conducting education and training programs on the application of existing and emerging technologies (a function performed by allied health professionals when performed at all); assisting in the evaluation of new products and services (a function often neglected); conducting self-help groups for peer counseling (an activity best performed by disabled volunteers); and donating money or goods. Possible strengthened tax incentives are: tax credits (instead of deductions) for some portion of charitable contributions; deductions for more than 100 percent of expenses incurred in providing services that otherwise would not be provided because of budget cuts; deductions for expenses incurred by

families who provide services to disabled members of the family who would otherwise be served under a publicly funded program; and deductions for activities which might affect the environment of disabled and handicapped people in a positive way (e.g., an attitudes awareness campaign by a television station).

Because the expenses incurred under this option, if adopted by Congress, would be primarily in the form of lost tax revenues rather than direct outlays, few Federal dollars would be expended if volunteer activity were not increased. A potential drawback to this "solution" to provider shortages, however, is the lack of quality control over volunteer activities.

OPTION 5C

Congress could mandate the funding of demonstration projects to test reimbursement for technologies under Federal health insurance programs by the types of skills provided rather than by the types of providers.

This option is in response to OTA's finding that those providers who are permitted by the structure of delivery and reimbursement systems to prescribe technologies for disabled people may not always be the most appropriate ones to do so. In some instances, therefore, a client may not receive the proper assistance, or the skills of several providers (those able to prescribe and those unable to) may be employed at more expense and loss of efficiency than necessary or desirable. Another

problem is that services necessary for the proper use of prescribed technologies are often not reimbursed under the Federal health insurance programs (see option 4B) if they are not provided by a physician and are therefore not provided. So far, there has been no proven method established to solve these problems, although numerous suggestions have been made. A program of demonstration projects mandated by Congress is proposed under this option in recognition of the untested status of this potentially helpful solution.

Because reimbursement experiments are common under the Medicaid and Medicare programs, it would be logical that HCFA administer this demonstration program. Congress could provide the Secretary of Health and Human Services with the authority to issue waivers from current Medicare and Medicaid rules to demonstration project participants when it next amends titles XVIII and XIX of the Social Security Act.

In order to meet the objectives of providing more appropriate, cost-effective services and assuring that services are of an acceptable quality, Congress might want to limit the types of services eligible for the program in its authorization of the project. Alternatively, each pilot project might limit the types of services reimbursed by service to an area in which the project's sponsors had already demonstrated quality and effectiveness. The funds appropriated for the demonstrations should be sufficient to assure quality; the limits should be placed on the number of projects.