Life is the art of drawing sufficient conclusions from insufficient premises.
—Samuel Butler
10.
Developing and Using Technologies: Conclusions From Part Two

The preceding chapters have discussed the process of developing and using technologies: A need is recognized or an idea for a technology arises, basic and applied research takes place, testing and evaluation occur, a marketing or distribution plan is developed and implemented, reimbursement or financing methods are determined, use of the technology begins and spreads, widespread use is attained, and eventually (perhaps) obsolescence or disuse sets in. This description of the process, as discussed earlier, is extremely simplistic and idealistic when compared to reality. Nonetheless, it is a useful and important way to examine reality and the performance of the system’s actors. The order and the exact content of each of the steps in the process are not as important as the conceptual and practical connections between the steps. These connections are as critical in reality as they are in the ideal.

OTA’s examination of the current situation leaves little doubt that the disability-related research, development, evaluation, diffusion, and marketing “system” suffers from a number of significant weaknesses. This system is capable of, and has produced, important contributions to disabled and nondisabled people. It definitely has had success stories, stories that frequently have been due to the dedicated efforts of individuals rather than to the thoughtful application of effective governmental or private systems of development and diffusion. Despite these successes, the system is, or could be, capable of a great deal more.

The high level of expectations that has been placed on this collection of public, private, and nonprofit organizations is not unreasonable. This system should be held responsible for reaching the goals that have been set for it. This is an area of high expectations for the simple and obvious reason that the technologies and services are critical to the consumers who use them. Very often, there are few or no alternatives.

OTA finds that there is a crucial lack of attention being paid to the concept of appropriate use of technology. This implies that research and development (R&D) often proceeds without an adequate appreciation of its role in assuring the existence and the diffusion of appropriate technologies. Appropriately used technologies can be simple or complex, manual or electronic, expensive or inexpensive. The key point is that they should be the appropriate technological response to a defined set of needs, desires, and capabilities, taking into account resource constraints. Whether the simple approach to analyzing the appropriateness of technologies as suggested in chapter 5 is the preferable or most effective way to move closer to appropriate development and use of technologies is not important. The critical aspect is that considerable attention needs to be given to the creation of analytical methods for determining and attaining appropriateness. The conclusions that are set out below regarding the more specific problems of the R&D, evaluation, diffusion, use, and financing processes emerge from this concept of appropriate development and use of technology. The discussions and conclusions on resource allocation that follow are similarly dependent on this concept.

The issues and problems discussed in the preceding chapters are not new, nor are they being pointed out for the first time, although the emphasis on a lifecycle approach to appropriate technology has received inadequate attention. In fact, one of the more perplexing and frustrating aspects of a review of the relevant literature is that the same problems reappear year after year in report after report, hearing after hearing, and seminar after seminar. The problems continue to exist despite the efforts of dedicated individuals and organizations and despite government reorganizations, new legislative mandates, new research plans, and the continued expenditure of substantial funds.
Money is, as always, a problem. In real terms, the Federal and State commitment of funds for disability-related R&D has been declining for the last decade. That trend is likely to continue. Funding is and will be an ever-present problem. Increased funding for R&D would definitely help, but at the same time it should be recognized that more money will not in itself solve all problems.

There are a number of reasons for the above conclusions. As the White House Study has pointed out (226):

The development of new technology and the adaptation of existing technology for the handicapped have been hampered in the past by inattention to the definition of discrete, project-oriented tasks, by the lack of a suitable basic science to support the managerial decision processes required, by a scarcity of people trained and educated in the application of engineering principles to the handicapped, and by the high cost of technical failures induced by non-perception of real needs.

Obviously, few, if any, of the above problems would be totally remedied by the application of increased funds to the existing system. The non-perception of real needs is a reflection both of low levels of funds available and of a lack of perspective and sensitivity. In fact, the concept of need could be expanded to a blend of needs, desires, and capabilities. The user, the disabled individual, must be more involved in the defining of those characteristics. Even when addressing only the needs aspect of the three, the “real” needs of users must be distinguished from needs as perceived by researchers or others. The identification of needs, desires, and capabilities has to be strengthened both conceptually and methodologically, as discussed in chapter 5. When identification and assessment of disabilities and handicaps are performed with the user as a full participant and with the goal of developing effective plans for applying technologies appropriately, one byproduct will be the creation of data that can and should be used in directing future research—especially applied R&D.

Increasingly, the public is expressing disappointment and dissatisfaction with the rate of application of research results. OTA researchers were frequently told that the capability and resources to develop technologies that will benefit disabled people do exist, and further, that there are existing technologies that could be made much more widely available. Yet, currently only a fraction of disabled individuals are adequately benefiting from this capability (123). Much of this capability is in, or has come out of, the federally sponsored disability-related research system. The rapid pace at which the private sector is producing innovations is also adding to the list of technologies that could have significant benefits.

The public, especially those members with disabilities, has been witness to significant accomplishments of the government-private sector relationship, specifically in those instances when public policy has complemented private sector incentives and when actions at each step of the technology’s lifecycle have been consistent with actions at the other steps. These have been exceptions. In general, public and private policies are not established with lifecycle consistency in mind.

OTA believes that there has not been a full-scale attempt to address the range of lifecycle issues through an explicit consistency of policy. Certainly, other observers have noted the importance of considering the effects of R&D on marketing or of reimbursement on diffusion. And yet there are only beginning efforts to modify policies in line with a comprehensive perspective. Such efforts do not have to cost large amounts of additional funds. In this area, foresight is more important than finances.

There are a number of other issues that need to be resolved concerning Federal agencies’ approach to the lifecycle of technologies, especially at the R&D and diffusion stages. There appears to be a historical imbalance between, on the one hand, the emphasis on basic and applied research and, on the other, on the diffusion or marketing of technologies and the dissemination of information. Both the National Institute of Handicapped Research (NIHR) and the Veterans Administration (VA) are moving toward (on paper at least) a greater emphasis on these latter activities. The generation of research reports and the development of prototypes are unacceptable end-points for the federally supported disability-related R&D process. However, efforts to support more infor-
information dissemination activities have been slow to catch on and are underfunded. The efforts to enlist more private sector involvement in the transfer of research results into marketable devices have also been sporadic and of mixed results.

There is a need for a strengthened public-private sector partnership in marketing new technologies for disabled people. Companies that are interested in marketing such technologies should be encouraged and assisted to do so. Small private firms often have the capacity for developing innovative technologies yet lack the means to identify and reach those people who might benefit from their products. The cost of performing marketing surveys is usually large when the potential market is small, as it is with many segments of the population of disabled individuals. More importantly, the state-of-the-art of identifying (for marketing purposes or for public policy purposes) disabled individuals and populations is not advanced enough to consistently or even frequently provide valid and usable data.

Another marketing need is research on how technologies for disabled people can assist non-disabled people. Examples of such technologies often cited include ramps and curb cuts designed for wheelchairs that assist senior citizens, bicyclists, and people with baby carriages, and computer-assisted communications devices that may be applied to computer systems used by non-disabled people. A large-scale demonstration program, or even better a series of small-scale programs, on multiple uses of technological developments might help in fulfilling this need.

Public and private agencies involved in the disability-related R&D process have devoted a very small portion of their resources to any type of evaluation or monitoring of research programs or resulting technologies. Performance testing or evaluation is not pursued to any significant degree.

The disability-related R&D system has a tendency to focus its energies and attention on the “gee whiz” technologies. The “sophisticated,” and usually very expensive, approaches seem to consume a major portion of both the public and private sectors’ efforts. In a recent article announcing the opening of the new VA Rehabilitation Engineering and Development Center at the Palo Alto VA Medical Center, the world was served notice that: “The new center will put ‘Star Wars’ technology directly into helping the human being” (158). One needs only to open a current periodical or science magazine to discover accounts of “high-technology” innovation related to disabilities. However, when workshops or surveys of disabled consumers are conducted, a very common and important suggestion is that more emphasis should be put on the development of less sophisticated, more easily repairable, easier to use, cheaper technologies or approaches. As one professional has commented (147):

You wouldn't want to spend $1,000 on a piece of equipment that would be used on only 5 percent of the job tasks . . . It would be more practical to see if you could restructure the job tasks.

The same questions need to be raised in other situations. Is it feasible or desirable to spend a certain amount of dollars to achieve 95- to 100-percent efficiency when half or less of that amount would produce 60- to 80-percent efficiency; enough to handle most of a person’s needs in a given situation? All too often it appears that the research system becomes infatuated with the most technically sophisticated approach to attaining 100-percent efficiency. Alternative research strategies and goals need to be seriously considered and supported.

The need for information dissemination is just as great at the delivery and use stages of the technology lifecycle as it is at the R&D, evaluation, and marketing stages. Only with the best possible information can an individual’s needs, desires, and capabilities be appropriately matched with available technologies. Perhaps more important is that only with complete information on what technologies are available (on the market), how they perform, how they may be obtained, and how they may be funded can the best use be made of limited resources. Yet many of the numerous parties-at-interest, such as users, providers, and third-party payers, who need such information have only small parts of it available. Thus, the decisions made that result in an individual’s use or disuse of a particular technology are often desirable only on a short-term basis,
Much of the dissemination of information on available technologies currently occurs through publicly financed or publicly operated programs for disabled people. One result of this is often that individuals outside of the public service delivery systems, by virtue of their independence or their noneligibility for service programs, lack access to necessary information. A mechanism is needed whereby individuals who are capable of applying their own resources to purchasing technologies can find and use the information that is available. One mechanism is the use of an entry point into service delivery such as the State vocational rehabilitation agency.

Another result of the current method of information dissemination is that the systems for information dissemination that exist are confined to discrete subject areas. This is in part because of the multitude of uncoordinated and overlapping public and private programs. The average consumers and providers of technologies need information in many related subject areas. Currently, either this information is not obtained or substantial resources must be expended to obtain it. OTA believes that strategies for coordinating information on the delivery and use of technologies for disabled people should be supported. It is imperative that new policies in this area reflect a coordinated information dissemination effort, regardless of the (often low) degree of coordination in the legislated service programs.

Because most technologies used by disabled people are either paid for, directly provided by, or learned about through public and nonpublic programs and services, those who are eligible for the programs and services are generally those who have access to the technologies. Thus, decisions regarding who should be eligible and how eligibility should be determined are major determinants of the use of technologies. Boundaries to eligibility and methods for its determination in individual cases differ from program to program. Eligibility is most often determined by establishing the presence of an etiology-specific category of impairment, by finding a mental or physical impairment that results in a functional limitation, or by a combination of both methods. A common result of having a variety of methods is that individuals in similar situations receive different amounts and types of services. Services that are necessary may not be received, and those that are received are likely to lack continuity. Increasingly, public programs are moving toward determining eligibility on the basis of evidence of functional manifestations of physical or mental impairments, so that those who most need services may receive them and so that the services they receive are appropriate and provided in a coordinated fashion. Advocates for disabled people with specific categorical impairments who are served well by the earlier type of definition, however, are reluctant for changes to be made. It is unclear which type of definition, if any, can guarantee the most appropriate use of technologies, although ideally one based on function should be preferable.

Providing individuals with technologies requires the resolution of several policy issues. One issue concerns the type of provider needed to match the technology with the user. Traditionally, physicians have done most of the prescribing of device technologies, partly because disabled individuals most often receive their first services through the medical system and partly because the major third-party funding programs often will only pay for items that carry a physician's prescription. It is clear that physicians are best qualified to prescribe certain technologies, particularly many of those that are for medical purposes. Many technologies, however, are applied for purposes other than strictly “medical” ones, and there are other providers who are equally or better qualified than physicians to select the best technology, for their client. Yet these providers, including rehabilitation engineers, occupational therapists, and special education teachers, as well as users themselves, usually cannot obtain public funding for the technologies. For example, the NIHR-funded rehabilitation research and training centers (RTCs) are designed to develop innovative technological solutions to problems of disabled people. But even if RTCs are able to disseminate this information, those who receive it may be unable to apply it to their clients. Therefore, strategies for encouraging the use of various types of providers could be developed. These may include changing reimbursement policies as well as changing licensing laws or physician education curricula. It is important, however, that any provider
prescribing technologies have specific training in the relevant disciplines.

Another issue concerns the criteria for selecting a particular technology once the type of technology and its purpose have been decided. Effectiveness and cost have typically been the criteria used in the past. Certainly, they are the ones cited formally most frequently. These criteria are indeed important, yet they are insufficient for selecting technologies for people who will likely need assistance for most of their lives. OTA believes that users and providers alike must consider obsolescence, maintenance, and actual procurement of devices to be important criteria. With the rapidly advancing technological capabilities of our society, most technologies developed today will necessarily become obsolete sometime in the future. Providers must assess the predictable rate at which obsolescence will occur and use that information in making their selection. For maintenance, the frequency, the time taken, and the cost must be considered. For actual procurement, the location of the manufacturer in relation to the location of the client must be considered. Federal policies do not encourage the formal consideration of these criteria. Even though decisions utilizing these criteria may be based on individual preferences (e.g., for easy maintenance over distant obsolescence), there are few mechanisms for allowing individual users’ desires to be taken into account.

A third issue concerns the structure of the systems under which individuals receive technologies. A common problem, discussed in several sections of this report, is that services and funding for disabled people come from so many different, often uncoordinated sources that both providers and users often are unable to take advantage of available technologies. Reasons for the lack of coordination include the methods by which existing legislation was developed, the definitions used in determining eligibility, and the fact that disabled people need assistance in so many different areas of their lives—areas that have entire social systems designed specifically for them.

As noted earlier, money is a problem in the technology lifecycle, particularly in the areas of delivery and use. Simply put, there is not enough to provide all technologies to all people who need them, even if need is defined very narrowly. Thus, the way in which money is applied has important consequences for the use of technologies—what is used, how long it is used, where it is used, and for what purpose it is used. Money applied in one area of technologies usually means that less is available for other areas. Decisions on resource allocation are thus perhaps the most important ones that need to be made by society’s policy makers. These will be discussed in Part Three. However, decisions on how to allocate resources among programs for disabled people and between programs for disabled people and programs for nondisabled people cannot be made without an explicit understanding of the effect that funding decisions have on individuals. These effects must be clearly described when new programs are developed.