POLICY ANALYSIS SERIES

ISSUES RELATED TO WELSCH v. LEVINE / NO. 22

IMPROVING THE QUALITY OF LIFE FOR PEOPLE WITH DISABILITIES:
POTENTIAL USES OF TECHNOLOGY

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I. INTRODUCTION

Modern technology has been a major force in improving the quality of life for disabled persons. In programs throughout the United States, technological devices have been developed and adapted to assist disabled people, especially severely disabled people, in many activities. Technology provides disabled people with improved means of communication, mobility, and control over their environment. It also provides access to a range of educational and vocational opportunities previously unavailable to persons with disabilities. However, in spite of numerous innovative programs, resources and expertise available in the area, many disabled people still do not have access to technology that could improve their quality of life.

The purpose of this paper is to describe the current use of technology by persons with disabilities, with particular emphasis on developmental disabilities; to outline the barriers which prevent greater use; and to discuss ways to increase the use of technology by disabled persons. This paper will be the first step in the development and implementation of a state policy agenda for use of technology by disabled people in Minnesota.

The primary definition of technology used in this report is the one developed by the Office of Technology Assessment (OTA) for its comprehensive study on technology and disability. The OTA definition covered technology "designed for and used by individuals with the intent of eliminating, ameliorating, or compensating for (bypassing) one or more functional limitations of individuals..." (OTA, 1983, p. 51).

Technology for disabled persons must be an interdisciplinary effort by virtue of the nature of technology and the range of functional limitations it seeks to minimize or eliminate. Some of the technology which is described in this paper is the result of work in rehabilitation engineering, a relatively new field which has been defined by the Rehabilitation Engineering Society of North America (RESNA) as the "application of science and technology to improve the quality of life of persons with disabilities" (U.S. Department of Education, 1980). Additional disciplines which contribute to the development and application of technology for disabled people include speech and communication, special education, rehabilitation medicine, computer science, occupational therapy, and others.

The lifecycle of technology for disabled people includes the typical stages of research, development, evaluation, diffusion, marketing, delivery, and use. The OTA report traced this lifecycle, analyzed the problems associated with each step, and suggested policy options to address them. The study also described the role of the federal government and the private sector in carrying out technology activities for persons with disabilities. The reader who is interested in an in-depth examination of the technology issue from this perspective is referred to the OTA report.

II. CURRENT USE OF TECHNOLOGY BY PERSONS WITH DISABILITIES

There are countless examples of how technology has changed and continues to change the ways in which persons with disabilities live, learn, and work.

A comprehensive description of all the activities which are currently taking place in the area of technology and disabilities is beyond the scope of this paper. Rather, this paper will present several major areas in which the current appplication of technology is significantly affecting the lives of disabled persons.

The recent development of relatively small, inexpensive, and powerful microcomputers ranks as one of the most important events in the history of technological applications for people with disabilities. Additional technological developments which merit discussion include the use of new designs and more lightweight, durable, and flexible materials in mechanical, electrical, and other types of equipment and devices. There are five major areas in which technology has significantly affected the lives of disabled people: (1) communication, (2) mobility and positioning, (3) independent living, (4) education, and (5) employment.

Communication

The development of microprocessor[1] based communication devices and the adaptation of microcomputers for communication purposes have greatly improved communication for individuals who are non-vocal, or have visual or hearing impairments, or other sensory disabilities. A recent article on computerized communication aids described the importance of this technology:

> The significance of tnis technological breakthrough can hardly be understated. As social beings, communication is our most important faculty. Without it, individual potential is severely restricted. Computerized communication devices represent a giant step forward for millions of neurologically and neuromuscularly impaired people. (U.S. Department of Education, 1982, p.9)

As a result of research at such places as the Trace Center at the University of Wisconsin-Madison, the Artificial Language Laboratory at Michigan State University, and the Biomedical Engineering Center at Tufts-New England Medical Center, and the efforts of a number of manufacturers, there are a wide range of communication systems currently available for non-vocal persons (Rosen & Goodenough-Trepanier, 1982; Kraat & Sitver, 1983; Vanderheiden & Krause,1983).

The electronic communication devices currently available vary in three major ways: the vocabulary content, the way the user chooses vocabulary items, and the way these choices are communicated to other people.

For young children who can not read and people with mental disabilities, there are communication devices with pictures or symbols. The appropriate content depends on the user's need and abilities; there are more complex devices which contain the alphabet, numbers, words, phrases, and whole sentences.

Most individuals who are nonvocal have severe physical disabilities which limit their movement and muscular control; some also have mental disabilities. Assessment is needed to determine the individual's most consistent physical response appropriate for using a communication device: hand, foot, head,

[1] The microprocessor is the central processing unit, i.e. the "brain" of the microcomputer.

mouth, or eye movement. With the help of modified keyboards, keyguards, headsticks,[1] and various types of adaptive switches, disabled individuals can choose vocabulary items. Some communication devices display the user's choices on a screen, while others print it out on paper, or speak it using a voice synthesizer; some devices offer more than one option.

> For me rehabilitation is a struggle to express myself and to have others understand me... Both in infancy and childhood I used my eyes to communicate my wants and needs by staring at what I wanted... During pre-adolescence two things happened that changed my life and my rehabilitation. First, my teachers and therapists discovered the headstick. Secondly, I learned how to use the electric typewriter and spelling board... After eleven years of occupational therapy, I couldn't use my hands. After eleven years of physical therapy, I couldn't walk. After eleven years of speech therapy, which included blowing feathers off a plate and sucking water through a straw, I still couldn't talk. But with a headstick, if I wanted water, I could spell I WANT A DRINK... My new adventure was exciting, but my victory was only partial. Although I now have some self-expression, I still couldn't talk on the telephone. That problem was solved in 1979, when a computer science major built a computerized voice synthesizer. The voice synthesizer added a new dimension to my communication. For the first time in my life, I could talk on the phone. (Rush, 1983)

Mobility and Positioning

Potential for independent mobility has been greatly increased for severely disabled people as a result of microcomputer applications for powered wheelchairs. Flanigan (1981) and Aylors, Johnson, and Ramey (1981) described how microprocesser control systems can be activated by a variety of joysticks, and switches controlled by head or chin movement, sipping and puffing, humming, or voice commands. The flexibility provided by these input options and features such as automatic speed limiting, obstacle avoidance, and programmed acceleration and deceleration allow the wheelchair system to be adapted to the individual needs of the user.

The standard, non-powered wheelchair has also benefited from technological changes. Durability and maneuverability have been greatly increased by changes in design and construction materials (Massey, 1983).

Both powered and manual wheelchairs are now available which allow the user to assume a reclining or standing position. Adaptations for powered and manual

[1] Keyboard modifications include large keys, large spaces between keys, and membrane switch keys which are pressure sensitive; keyguards are covers with recessed holes which prevent inadvertent striking of keys; a headstick is a stick which is attached to the user's head, allowing him or her to use head movements to select keys.

wheelchairs as well as special purpose recreational vehicles make it possible for more disabled people to take part in outdoor activities and sports (Klein, 1983; Schwandt, 1983; Shapcott & Heinrich, 1983).

Advancements have also been made in orthotics (braces of various types, and standing frames), and prosthetics (artificial limbs), including the development of myoelectric limbs (electro-mechanical limbs controlled through use of existing nerve ends at the place of attachment, usually the upper arm or shoulder). For non-ambulatory, severely disabled people who have difficulty holding their bodies erect or maintaining correct seating posture, seated positioning systems are available. The insertion of a seated positioning system into a wheelchair can increase both an individual's comfort and ability to perform a variety of tasks, including communication, eating, educational and vocational activities (Holte, 1983; O'Rourke, 1983; Siekman & Flaningan, 1983).

> Joe is a nineteen year old young man with cerebral palsy. He is unable to communicate with his own voice and his physical limitations are severe enough that he has reasonably good control of only the index finger on his right hand... We acquired an Apple II computer and began developing modifications and programs to allow Joe to work effectively with it...The system served his needs quite well for about a year. During that year, Joe was presented with an electric wheelchair by the local St. Vincent de Paul Society. This made a tremendous difference for him as he was able to be much more mobile and independent than he had ever been before in his life. It created a communication problem however... He needed a system in which the computer communication system could be as mobile as he himself now was with his new wheelchair... We determined that the Atari 400 would best meet Joe's specific needs ... The software includes a collection of commercial and custom written programs which allow the system to be used as a versatile communication device, and at the same time, retain all of the variety of other functions of the computer system... The "Talking Wheelchair" has proved very effective in meeting the communication needs of one handicapped young man. (Bennin, 1983)

Independent Living

Within the category of aids for independent living, there are several types of devices which assist disabled people in performing everyday tasks. Many of these devices were either developed or greatly improved as a result of microcomputer technology. Others are simple mechanical or electrical devices which have either been developed or adapted for disability-related uses.

Security, monitoring, and environmental control systems address the needs of disabled people to control access to their homes, to call for assistance, and to turn appliances on and off. Both commercially available home security systems with adaptations and units which are specifically built for disabled people allow users to open, close, and lock doors and windows and to

operate radios, televisions, lamps, and other equipment with a minimum of physical effort (Flanigan, 1981; Vanderheiden, 1982; "Severely disabled can now run a variety of electric appliances," 1983; Klein, 1983).

A recently developed telecommunications device for people with many different kinds of disabilities has more than forty features, including emergency dialing (the device will dial up to six predetermined phone numbers in sequence when the user presses a "Help" key), monitoring (the device will check if the user is all right at predetermined times, and will call for help if the user does not respond in a few minutes), and automatic phone answering (Rush, 1982).

Robotic arms mounted on worktables or wheelchairs have proven useful for a range of tasks which require the disabled person to manipulate objects (Aylor, Johnson, & Ramey, 1981; Schneider, Schmiesser, & Seamone, 1981; Flanigan, 1981). These tasks include eating, managing reading materials, retrieving objects, setting up typewriters and personal computers for use, and using standard phones.

Anderson (1983), Heyer (1983), and Laenger and Brinnon (1983) described several examples of simple, inexpensive devices to assist disabled people with activities of daily living.

Many inventions in this area have come about as a result of research and development at the rehabilitation engineering centers and rehabilitation and research training centers located throughout the United States which are funded by the National Institute of Handicapped Research (NIHR); many have also resulted from the efforts of professionals from many disciplines working in various settings and "amateurs" -- individuals, both disabled and nondisabled, with interest in solving a particular adaptive equipment problem.

> By puffing and sipping on a straw, I can adjust the light in my living room to suit my own convenience. I can tune in a concert on the radio or dial a TV special. I am able to summon assistance, when I feel that it is needed, by means of an emergency signal light. I can involve myself in typing projects. I can answer incoming calls, and make outgoing calls with the help of the operator. Most important of all, I can engage in my chosen activity whenever I wish and without having someone present to help me.
>
> (Pfrommer, 1975)

Education

Foulds (1982) stated: "The recent explosion in the availability of personal microcomputers has perhaps no more important benefit than in special education and rehabilitation" (p. 155). A review of the extensive literature on microcomputer applications in special education supports Foulds' view. Numerous articles detail the efforts of parents, special education personnel, and other professionals to provide disabled children and adults with access to computers for educational purposes (Goldenberg, 1979; Bennett, 1982; Budoff & Hutton, 1982; Fay, Okamoto, Brebner & Winter, 1982; Sicoli, 1982; Weir,

Russell & Valente, 1982; Beckerman, 1983; Davis, 1983; Messinger, 1983; Merton, 1983, Blackhurst & Hofmeister, 1980; Uslan,1982; "Computer-Assisted Instruction for Handicapped Individuals," 1982; Papert, 1981; Loebl & Kantrov, 1984).

Individuals with a range of disabilities, including many types of physical impairments, learning disablities, mental retardation, and autism can use microcomputers with adapted hardware and/or software. (See Vanderheiden and Walstead,1983, for comprehensive and up-to-date information on adapted hardware and software, and issues of Closing the Gap for descriptions and evaluations of current microcomputer applications in special education.)

Microcomputers are being used in special education primarily in two ways: computer assisted instruction (CAI) and educational management. There are several methods of providing computer assisted instruction, including: (1) drill and practice, which is designed to provide practice of previously learned material; (2) tutorial programs, which assume the role of teacher and present material in a programmed learning format; (3) educational games, which are designed to develop general problem-solving methods and strategies while maintaining motivation; (4) simulations, which model the characteristics of a real phenomenon so that its properties can be studied; and (5) problem-solving in which the computer is used to develop problem-solving skills and help students apply them (Budoff & Hutton, 1982). While the majority of the CAI programs have been drill and practice or tutorial, efforts have increased recently to develop CAI programs which require more active participation by the student (Browning and Nave, 1982).

Hannaford (1983) described three advantages of CAI for special education students. The first is individualization of learning: the learning sequence and the level of instruction can be tailored to individual need; learning can be self paced; and reinforcement can be individualized. The second advantage is the ability of CAI to motivate students, including those who have been very frustrated by more traditional learning methods. Finally, CAI is an interactive medium which provides students with immediate feedback regarding their performance.

Computer assisted instruction has not, however, been without problems. In particular, the quality of software has been an ongoing concern of special educators. Hannaford and Taber (1982), Hofmeister (1982), and others have stressed the importance of tempering enthusiasm over CAI with caution and paying special attention to the following factors: educational compatibility, instructional design, and technical adequacy of the software. In terms of educational compatibility, the use of the computer must be appropriate, and the software must be compatible with learners' needs (reading and cognitive skills), the curriculum, and the teacher's instructional style.

Hannaford (1983) listed several prerequisites for good instructional design: software is developed with specific objectives and audiences in mind; it is accurate in terms of content, organization, and language; the material is presented properly; and the manner of student response and computer handling of responses is considered. His list of technical adequacy considerations includes: use of color, graphics, sound, and peripheral devices (such as printers, light pens, etc.), and flexibility, integrity, and durability of the software (pp. 16-17).

> Stefanie Head is fifteen years old. She has never walked or talked. Because she has cerebral palsy, she has poor muscle control. Sometimes her head is upright and under control as she sits in her wheelchair, sometimes not. One hand is immobile. The other often takes detours en route to its destination. She can not use a pencil. Tongue thrusts give her a limited ability to control swallowing so drooling is frequent. Yet a year ago September, Stefanie enrolled in four regular seventh grade classes in King Junior High School in Berkeley, California, thanks to her determined parents and to the miracle of the microcomputer... For the first time Stefanie could do all her homework, neatly and at an ever-increasing level of achievement... A side benefit was that the computer brought neighborhood children to Stefanie's house. They wanted to see and use Stefanie's computer and to communicate on the screen, like Stefanie. For the first time, Stefanie was "mainstreamed" into her community. (Messinger, 1983)

Microcomputers have been used for educational purposes with infants as young as three months old (Behrmann & Lahm, 1983). Infants and young children have also had opportunities to experience the beneficial results of technology as a result of the development of adapted toys. Adaptive switches and other controls make it possible for even the most severely disabled children to control mechanical and electrical toys. Adapted toys allow children with disabilities to learn about cause-effect relationships and how to manipulate controls, which are important prerequisites to using other technology such as communication and mobility devices. In many areas of the country, toy libraries have been set up which loan adapted toys to families of disabled children. Guides to toy adaptation have been published, and some assistive device manufacturers offer switches to be used in toy adaptation as well as modification services and already modified toys (Wethered, 1979; Romich, 1979; Shane, 1981; Kanor, undated).

In the area of educational management, special education teachers and administrators are using microcomputers for a number of tasks, including assessment, prescription of learning activities, and maintenance of information for monitoring and documentation of P.L. 94-142 (the Education for All Handicapped Children Act) compliance activities. Software has been developed for the specific purpose of creating and updating individual educational plans (IEPs) for disabled students (Hofmeister, 1982; Browning & Nave, 1983; Hannaford, 1982; Ragghianti & Miller, 1982; "A Sampling of IEP Software Packages," 1984).

Employment

The availability of microprocessor based devices for communication, mobility, and independent living purposes has enhanced the general employability of many disabled people. In addition, computer access has opened up specific job opportunities for disabled people. The initial emphasis in this area was on

computer programming jobs, and a number of programs were set up around the U.S. to train disabled people as computer programmers (Koleski, 1983; Schmidt, 1983; Warren & Stone, 1983). While these programs continue to provide important job opportunities for physically disabled people with aptitude for programming, both the number of individuals in this category and the number of positions in this area in the job market are limited. Recently, there has been a growing emphasis on employment of disabled people as "computer users" in a wide variety of job fields (Apple Computer, 1984). Saddler (1983) noted:

> Access to computers is crucial for the disabled because the machines can greatly expand their job opportunities. That access would make many offices and some factory jobs possible as well as let some disabled people join the growing number of people who work by "telecommuting," or transfering their work product electronically from their homes to an office across town or across the country. (p.1)

Job site modifications by rehabilitation engineers and others have made it possible for disabled people to perform a variety of jobs (Sixth Institute on Rehabilitation Issues, 1979). While the adaptation of work sites for disabled workers is not a new activity, technology has improved the resources available for this purpose, and thus expanded the range of modifications that can be made.

> To begin his workday, Thomas Shworles maneuvers his electric wheelchair over to his computer, braces his right hand on a special metal keyboard overlay and begins working.
>
> Mr. Shworles suffers from a muscle disorder that has incapacitated his left arm and both legs and left him with only partial control of his right hand and forearm. He runs his computer's word processing program with the aid of the special keyboard overlay, a cover with holes above each key that helps prevent accidental key depression; the cover also has mechanical levers that help him hold down more than one key at a time.
>
> (Saddler, 1984)

Benefits of Technology

For people with disabilities, there are specific benefits to be obtained through use of technology in each of the five areas discussed in this section Access to appropriate technology can make the difference in a disabled person's ability to communicate, to be mobile, to live more independently, to receive an education in the "least restrictive environment," and to work.

In addition to these specific benefits, technological applications have certain general beneficial results in common. Technology can allow children and adults with disabilities to experience a sense of independence and control over their environment. It can allow them to have many experiences which are

similar to those of nondisabled people. By increasing the ability of people with disabilities to function as more independent individuals, and to interact with other people and with their environment, technology can facilitate the integration of many disabled people into community settings.

III. ACHIEVING GREATER USE OF TECHNOLOGY: MAJOR BARRIERS AND POSSIBLE SOLUTIONS

The Overall Scene

As awareness of technology's potential for improving the quality of life for disabled people grows, disabled persons and their advocates increasingly question why many disabled people lack access to technology which could increase their wellbeing and productivity. This question was addressed extensively by the Office of Technology Assessment study and a number of previous reports, including Urban Institute (1975), the White House Conference on Handicapped Individuals (1977), La Rocca and Turem (1978), and Brown and Redden (1979).

These studies described problems with various aspects of the technology delivery system for people with disabilities, and reached similar conclusions about the reasons for the system's problems in developing new technology and making existing technology more widely available. The OTA report summarized a number of reasons why marketing and diffusion are difficult:

> The disability market population is ill-defined, the economic status of users if often far below the median; disability-related technologies often do not appear viable from a strictly "market" perspective, resulting in a lack of interest in their production; product liability is often perceived by manufacturers to be a problem; and especially, the systems of reimbursement of devices sometimes provide disincentives to the marketing of certain types of technologies. (p.111)

Other difficulties cited by OTA and others include the fact that technology is rapidly changing; that users, providers, and third-party payers lack information on what technologies are available, how they perform, and how they may be obtained; that there is a scarcity of rehabilitation engineers and other professionals with training in disability-related technology; and that geographical access still plays a major role in determining access to technology-related services, with many of the programs located in large urban areas.

Some of these problems are particularly important at one stage in the technology life cycle, whereas others create barriers throughout the process; many of the problems are interrelated. Reimbursement mechanisms, for example, affect not only the ability of the disabled individual to purchase a needed device but also are critical determinants of whether that device gets

developed or marketed in the first place. Brown and Redden's comparison of the utilization levels for internal and external prostheses illustrated this point well. They indicate that most health insurance plans routinely cover internal prostheses, such as pacemakers, to a much greater extent than external prostheses, such as artificial limbs, and that the result has been a much greater investment of money in research and development of internal devices as well as wider utilization (Brown & Redden, 1979, pp. 36-37).

The federal government is the major force in setting research priorities for disability-related research, and is a major funding source for research and development activities in the disability area. While the problems associated with these early stages of the technology lifecycle are critical, the emphasis in this policy paper will be on problems and solutions related to the delivery and use of technology which already exists. The main reason for this focus is that, although federal action is certainly needed, problems related to the delivery and use of technology are more amenable to action on the state and local levels than problems in the early stages of the technology lifecycle.

> 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. (Office of Technology Assessment, 1982)

There are three major categories of problems related to the use of existing technology: problems resulting from lack of knowledge and training regarding technology, those relating from lack of access to technology-related services, and funding problems. Depending on the individual's need and circumstances and the type of technology, some or all of the above problems may limit technology use.

The need for increased awareness of technology and knowledge of specific devices among professionals, people with disabilities, parents, and advocates has been well documented. The OTA report described the situation:

> Information on available technologies is currently disseminated through publicly financed or publicly operated programs for disabled people. Information is often fragmented, since many of the programs cover discrete subject areas and are uncoordinated. Strengthened information dissemination in a coordinated fashion is urgently needed. (OTA, 1982, p. 13)

The problems resulting from lack of access to technology-related services have also been well documented (La Rocca & Turem, 1978). There are gaps in the delivery of technology-related services because of program eligibility problems, and lack of geographical access to services. A limited number of centers provide technology-related services, and many severely disabled individuals experience difficulty in traveling long distances.

Funding issues have been addressed by rehabilitation engineers and other professionals, advocacy groups, device manufacturers, and the press (Ris, 1980; Enders, 1983; Enders, Blote, & Reed-Heumann, 1983; Holte, 1983; DePape & Krause, 1980; Ruggles, undated; "Communication devices available but are out of reach to many," 1981; Hoffman, 1982; Laenger, 1982; United Cerebral Palsy Association of California, 1982; Thomas, 1981).

These articles stress the importance of funding in determining access to services. Enders, Blote, and Neumann make this point clear. They cited a study done by the Children's Hospital at Stanford which found that, based on data from 1974-1978, "lack of funding accounted for 46% of people who did not receive a device after an initial evaluation for a seating or positioning device" (p.403).

> Funding issues are generally the bottom line in actual provision of technology for disabled people. We can research, develop, transfer to private sector, utilize, build, and adapt, but if payment is unavailable, the device--be it simple or sophisticated--will not reach the intended user, the disabled individual.
>
> (Enders, Blote, & Neumann, 1983)

Certain characteristics of the public and private programs which provide disabled people with technology, and of the service system as a whole, are largely responsible for these problems. In order to develop programmatic and policy responses to these problems, it is necessary to first understand how individuals currently obtain technological devices and services through these programs.

Problems in Current Programs and the Service System

As the OTA report noted, the use of technology by disabled people depends primarily on public (federal, state, and local government) and private (non-profit and for profit sectors) programs which provide information, funds, and devices. There are five major categories of programs which affect the use of technology: income maintenance, health and medical care, social services, educational services, and vocational rehabilitation and independent living services. The nonprofit and for profit sectors are the actual service providers under many publicly funded programs; they also provide services not covered by public programs, additional funding, and coordination of various public programs. Private insurance companies provide income maintenance benefits to certain disabled workers as well as disability-related health and medical care coverage (OTA, 1982, pp. 101-102, 119).

The major income maintenance programs for people with disabilities, Social Security Disability Insurance (SSDI), Supplemental Security Income (SSI), and Veteran's Administration (VA) benefits, provide disabled people with income which can be used to purchase technology. They also provide supplemental benefits, such as Medicare and Medicaid, which sometimes cover such purchases. The extent to which SSDI and SSI can be used to increase technology use by disabled people depends on program eligibility and benefit levels. As the OTA report observed, program eligibility is a problematic area because of lack of uniformity in the eligibility determination process (p.105).

The primary federal social services program, Title XX, can be used to fund the delivery and use of technology for eligible disabled people; however, as OTA cautions, Title XX's closed-end budget realistically places considerable limitations on the use of the program for this purpose.

Educational programs, including those authorized under P.L. 94-142 and the Vocational Education Act, provide some funding for technological devices; they also prepare disabled people to use technologies and provide information on available technology. P.L. 94-142 mandates the provision of "related services" which would allow a child to be served in the "least restrictive environment," but as OTA observed,

> Determining what may be included as "related services" and who is responsible financially have been very difficult issues and certainly a source of confusion and long debate for policymakers, providers, and consumers. One reason for this difficulty is that the law and subsequent regulations suggest some examples of related services but the list is intentionally not exhaustive...A second reason...is that education agencies now have the responsibility for providing services that have historically been the domain of the medical community. (p.115)

While the mandate of P.L. 94-142 clearly has an impact on the delivery and use of technology by disabled children, the extent of its implementation varies according to a school district's budget and resources. Consequently, many disabled children are denied essential "related services" (OTA, p.116).

The federal-state vocational rehabilitation programs provide disabled people with goods and services, including technological aids and devices, which may reasonably be expected to assist in their employment. The OTA report declared that the range of technologies available to and funded for disabled clients is "clearly extensive and varied"; the key issue in this program, as with the income maintenance programs, is eligibility. For vocational rehabilitation agencies, the mandate to serve severely disabled people and the requirement of a "reasonable expectation that rehabilitation service will result in gainful employment" have lead to conflict over eligibility determinations (OTA, p. 118). The Rehabilitation Act does authorize state vocational rehabilitation agencies to provide independent living services to disabled individuals who do not have present potential for employment. Technological devices are among the allowable independent living services which can be provided, but the level of funding appropriated under the independent living authority has not allowed payment for these services (OTA, pp. 118-119).

The two major publicly financed health care programs, Medicaid and Medicare, have a significant effect on the use of technology by disabled people as a result of the amount of funds they provide, their payment authorization methods, and their impact on the organization of service provision. The OTA report summarized Medicare and Medicaid policy issues with respect to disability-related technology:

> Policy issues that affect eligible Medicare and Medicaid recipients include: what technologies are covered and how are those decisions made, what types of professions and institutions are recognized as providers, what amount is reimbursed for the cost of covered services, what technologies are considered medically necessary, and what effects the Medicare and Medicaid programs have on the type and location of services to disabled beneficiaries. (p. 12)

Under Medicaid and Medicare, coverage for certain technologies is mandated by statute or regulation, but many individual technologies are not specifically covered on such lists. In that case, coverage will depend on a determination by the contractor (the intermediary who reimburses providers with federal funds) (OTA, p. 109). According to the OTA report, coverage decisions are "rarely made on the basis of a consistent national policy, and vary widely from contractor to contractor." Once a technology is approved for coverage, it must then be declared "medically necessary" for individual users. This process can present real problems for disabled people because many needed devices are not curative in nature (p. 110).

The OTA report further stated that because a technology is covered does not mean that it will be fully reimbursed:

> The amount authorized for Medicare or Medicaid reimbursement may be such that indigent clients needing expensive equipment (and, by definition, Medicaid recipients are indigent) may effectively be denied access to it. (p.111)

The private and nonprofit insurance companies present many of the same problems for disabled people seeking coverage of technological devices. Many companies avoid or limit coverage of preventable or remedial rehabilitation services under their policies (OTA, p. 119).

In addition to the problems of specific public and private programs, the structure of the entire service delivery system also creates barriers to greater use of technology by disabled people. These system problems include a lack of coordination among sources of services and funding, primarily caused by the existence of categorical legislation, and a lack of consistency in the amounts and types of assistance provided to people with similar needs. Because funding for the same or similar technologies is often available under various programs with different rules of payment, potential users and advocates often spend considerable time locating funding (OTA, pp. 120-121).

> What distresses me is that although technology has advanced, it is not benefiting the people who need it so desperately in order to lead equal lives. We are not asking for luxuries. Technology has allowed many Americans to live more luxurious lives. We are asking for basics: To go to the bathroom by ourselves, to go down a street by ourselves, to get on and off a bus by ourselves, to be able to obtain a job, to be able to live lives free from fear of whether we will have to live in a nursing home, to live free of fear about how we will pay for our next wheelchair, to live free of fear that we have to institutionalize a loved one because we can longer physically take care of that individual. (Testimony of Judy Heumann at the Joint Congressional Hearing on Technology and Handicapped People, September 29, 1982)

Possible Solutions

Efforts are currently being made to solve the three major types of problems related to the use of existing technology: problems resulting from lack of knowledge and training regarding technology, those resulting from lack of access to technology-related services, and funding problems. Each of these areas will be discussed below.

In the first category, efforts have been focused on increasing awareness of technology and knowledge of specific devices among relevant parties, including professionals, disabled consumers, parents, and advocates. Information dissemination, training, and technical assistance activities are being conducted by federal programs, national and local consumer advocacy groups, universities, device manufacturers, and professional associations. Specific activities include the publication of articles in professional journals and "popular" periodicals, conference proceedings, informational materials, and newsletters, sponsorship of training workshops, inservices, conferences, and display fairs on disability-related technology; the set up of resource centers and libraries of devices and resource materials; and the development and maintenance of data bases and computer networks on technology.

There have been an increasingly large number of articles on technology and disabled people in professional journals in fields such as education, rehabilitation, and speech, as well as in magazines and newspapers for computer users, parents, and the general public. Special issues devoted to computer usage by disabled people have been published by Byte (September 1982), The Exceptional Parent (June 1983), and Computer (January 1981). Several comprehensive bibliographies have been published on disability-related technology, including Nave, Browning, and Carter (1983) (on computer technology in special education and rehabilitation), the Edu-Tech Series (1983) (on various technologies in special education), and Rabush, Lloyd, and Gerdes (1983) (on aided non-speech communication).

In dissemination of informational materials on technology, three centers' efforts are particularly noteworthy. The Reprint Service at the Trace Center, Madison, WI, makes available several publications on communication and computer access for severely disabled people. The International Software/ Hardware Registry, which contains information on software written or adapted for disabled people, and on special hardware modules and adaptors; the Non-Vocal Communication Resource Book, which provides descriptions of over 90 commercially available aids, and Comparison of Apple, Epson, IBM,... Microcomputers for Applications in Rehabilitation of Persons with Physical Handicaps, a comparative guide to several major microcomputer systems and their applications for disabled people, are among the resources available through this service. The Assistive Device Center, Sacramento, CA, publishes a series of device evaluations as well as articles on assessment, delivery of services, the Center's Assistive Device Database System, and related topics. The Rehabilitation Engineering Center, Children's Hospital at Stanford, publishes a guide to controls for devices, as well as reports on seating systems and other topics.

Newsletters and newspapers specializing in disability-related technology include: Link and Go, which is published by COPH-2 (The Committee on Personal Computers and the Handicapped) in Chicago, covers the use of personal computers by disabled people; Closing the Gap, which is published by Dolores and Budd Hagen of Henderson, MN, focuses on computer usage in special education; Communication Outlook, which is published by the Artificial Language Laboratory at Michigan State University, covers developments in augmentative communication; and Bulletins on Science and Technology for the Handicapped, which are published by the American Association for the Advancement of Science - Project on the Handicapped in Science, cover disability-related technology.

Numerous organizations currently provide workshops, inservice training, conferences, and display fairs on various aspects of disability-related technology. The Johns Hopkins National Search for Applications of Personal Computing to Aid the Handicapped was one very innovative effort in this area (Proceedings, 1981; Hazan, 1982). An additional useful source of information on disability-related technology is the annual conference of the Rehabilitation Engineering Society of North America which covers technological advancements in seating and positioning, prosthetics, orthotics, communication, wheelchairs and other mobility devices, devices for daily living, and workplace adaptations (Proceedings, 1981, 1982, 1983).

Recently developed resource centers and libraries which contain informational materials, and in many cases, displays of assistive devices, are additional resources for information dissemination and technical assistance on existing technology. The PAM Assistance Centre in Lansing, MI, functions as an information clearinghouse and referral service, with three rooms of hands-on display items and files of product information. The Northeast Communication Enhancement Group has organized several regional resource centers in the Northeastern United States which disseminate information on non-speech communication, including device information and referrals from local resource lists of non-vocal people and their families. As part of its Bio-Engineering program, the Association of Retarded Citizens (ARC) of the United States has

begun consolidating information on the use of technological aids into a technology resource library.

The PAM Assistance Centre and the Rehabilitation Engineering Center, Children's Hospital at Stanford are among several centers which serve as local brokers for a national data base on commercially available assistive devices. The database, called Abledata, is a service of the National Rehabilitation Information Center (NARIC). It includes physical descriptions, and cost, manufacturing, distributing, and evaluatory information on over 6000 products in thirteen different categories: personal care, home management, mobility, vocational/educational management, seating, transportation, ambulation, communication, recreation, orthotics, prosthetics, sensory aids, and therapeutic aids.

While progress has been made in increasing awareness of technology and knowledge of specific devices, more effort is needed in this area. As microcomputer usage becomes more widespread, the role of microcomputers in facilitating the exchange of information about technology may prove to be as important as the role they play as part of the technology.

> 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.
>
> (Office of Technology Assessment, 1982)

Various innovative approaches have been taken to address the second category of problems, those resulting from a lack of access to technology-related services. Some programs have chosen to make extensive outreach efforts. For example, the Rehabilitation Engineering Outreach Program at the University of Wisconsin Hospital in Madison sends specialists to agencies throughout the state to evaluate disabled children for seated positioning systems, powered mobility aids, and other specialized assistive equipment. Some programs have targeted specific settings, such as public schools or state institutions, for service provision. The Artificial Language Laboratory has worked for several years with Michigan schools to bring communication systems and microcomputer technology to severely disabled students. The Trace Center has cooperative service delivery programs with the University of Wisconsin Hospital and the county surrounding Madison.

Some programs have increased access to technology-related services by utilizing volunteers to make simple adaptive equipment with professional guidance from a rehabilitation engineer or other professional. In some cases, these volunteers are retired engineers or handypersons who receive training in the adaptive equipment needs of disabled persons.

Costigan and Littleman (1983) described one such successful effort using

engineers from a local business. Tufts University and the Rehabilitation Engineering Center, Tufts-New England Medical Center present short-term, intensive, "hands-on" courses in adaptive design for people from a variety of backgrounds to learn basics of equipment adaptation.

While many programs have made commendable efforts in outreach and service provision, a high level of need for services remains. More effort is needed to provide all disabled people with access to adequate assessment, prescription, and follow-up services within a reasonable distance from their homes.

In the third category, funding problems, efforts have been focused on seeking funding from public and private sources to cover the costs of devices and related services for individuals, and on seeking legislative and regulatory changes in funding programs.

Several authors have described ways to deal with problems in the funding process; Enders, Blote, and Neumann (1983) and Holte (1983) addressed rehabilitation engineering services and devices, while Hoffman (1982), DePape and Krause (1980), and Ruggles (undated) focused on communication devices. They listed potential funding sources, described case histories, and suggested strategies for successful applications and appeals of funding decisions.

A number of authors raised the question of problems inherent in a case-by-case approach to obtaining funds, including time delays, additional expenses, and the inequitable outcomes which often result. Laenger (1982), for example, was critical of reliance on private fundraising for devices. After reviewing several case histories, he concluded:

> Fundraising for rehabilitation of severely disabled clients has been suggested as a means of acquiring community support. Fundraising for cute, pitiful, and popular clients can work. But if we examine the true costs of multiple fund-raisings and delays imposed on the rehabilitation process, we may decide that we cannot afford this prejudicial and 'apanaceic' activity. (p.38)

Many authors emphasized the need for policy changes in public and private funding mechanisms. Holte suggested three courses of action for rehabilitation engineers: promoting rehabilitation engineering as cost effective to funders, controlling costs by making careful choices about durability and suitability of devices, and providing clients with information so they can influence the legislative process (1983, pp. 401-402). In addition to suggesting a number of ways in which local fundraising could be more effective, the summary of the RESNA advanced topical discussion on "Funding strategies for the 1980's" also addressed the importance of advocacy for funding on a national level. The RESNA report suggested tax credits for equipment as an option that should be considered, a possibility that was also suggested by the OTA report (Enders, 1983).

There has been considerable interest in obtaining Medicaid coverage for communication devices. Justice and Vogel (1981) and others addressed the issue of legal action to achieve Medicaid coverage for these devices. A bill, (S. 115), was introduced in Congress in 1983 which would amend

Titles XVIII and XIX of the Social Security Act (Medicare and Medicaid) "to treat certain sensory and communication aids as medical and other health services." In describing this proposed legislation, Hoffman (1983) noted, "Although payment for such aids, equipment, and devices is not expressly prohibited by statutes authorizing Federal health insurance programs, regulations of both Federal and State agencies result in widespread denial of such payments."

There are some hopeful signs on the funding scene. The costs of certain technologies, especially those involving microcomputers, have decreased as production has increased. At the same time, the capabilities and flexibility of many devices have increased. Many individuals have been successful in obtaining funding from a range of public and private sources. However, many more still are in need of funding. Given the economic status of most disabled people and the problems in the current funding system, funding issues must be a top priority in any policy agenda focused on increasing use of technology by disabled people.

IV. SUMMARY

The major findings of this report on the use of technology by people with disabilities are as follows:

- Significant technological advancements have been made in the areas of communication, mobility, independent living, education, and employment;
- These advancements have potential for improving the quality of life for people with disabilities but many are not obtaining needed technology;
- Inability to obtain needed technology results largely from problems in programs which provide information, funds, and technological devices and services, and in the service delivery system as a whole;
- These problems include lack of knowledge and training regarding technology, lack of access to technology-related services, and funding problems;
- While efforts are currently being made to solve these problems, more action is needed;
- These actions should be taken to ensure that all persons with disabilities have access to technological applications which could improve their quality of life:
  - A state policy agenda for use of technology by disabled people in Minnesota should be developed and implemented;

- Awareness of technological advancements should be increased among disabled persons and their families, professionals, policymakers, and the general public.

- Professionals from a range of disciplines should receive up-to-date training on the uses of technology for disabled persons.

- Disabled individuals who need technological aids should have access to adequate assessment, prescription, and follow-up services within a reasonable distance from their homes.

- Funding mechanisms should be changed to cover the purchase and maintenance of technological aids as well as the support services necessary to fully utilize the aids.

V. POLICY IMPLICATIONS

In contrast to commonly held perceptions of technology as a "dehumanizing" force, many technological applications for people with disabilities can be characterized as "profoundly humanistic" (Moses, 1983, p. 16). That is why it is so important for people with disabilities to have access to needed technology.

> A national commitment is needed to assure that all disabled Americans regardless of the nature of their disabilities or their financial status, can secure and utilize proven technologies that will enable them to lead more productive, satisfying lives.
>
> (La Rocca & Turem, 1978)

In previous sections, this paper examined some of the reasons why disabled people are not receiving needed technolgy, and suggested possible ways to increase use. Throughout this analysis of technological applications for disabled people, one issue in particular has important policy implications. The Office of Technology Assessment articulated this issue well when it declared: "all decisions concerning the development or use of technologies for disabled persons are either directly or indirectly resource allocation decisions" (p.141). The resource allocation issue is one that policymakers will increasingly be called upon to address. A 1980 Congressional hearing on technological applications recognized this fact, framing the question as one of societal values:

> Is the cost of developing and applying technology for handicapped individuals worth it - in terms of the single person whose mobility, productivity, and communication is improved (the microperspective) and of society as a whole whose lost earning capacity and welfare payments may be decreased (the macroperspective)? (p.54)

De Jong and Lifchez (1983) went one step further by raising the question of society's obligation to provide new technologies and highly intensive services to disabled people. They said:

> These developments present important ethical and public policy issues that can not be ignored in any consideration of the demands of disabled people for fuller access to society and its institutions. Many questions have already been asked about the quality of life that can be expected for those whose existence appears marginal.
>
> These questions, however, implicitly place the onus on the disabled individual rather than on society, whose services can in many cases materially affect the quality of life. What about society's obligation to provide a minimum quality of life for those who survive as the result of medical research and technological advances that have been publicly demanded, publicly supported, and publicly financed? The financial consequences of these public decisions are so overwhelming that few individuals or families are capable of assuming the financial burden for services and environmental supports needed to provide a minimum quality of life. (p. 41)

Clearly, policymakers will need to consider many issues in attempting to resolve the policy debate over access to technology for people with disabilities. In the process, they would do well to keep in mind the challenge raised by Rahimi (1981), who said:

> In a world where human beings and the machines they command have the power to control the quality of life, handicapping conditions can only be the result of a failure to properly apply technology or the neglect of its development. (p. 22)

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VII. RESOURCES

Minnesota

Closing the Gap
P.O. Box 68
Henderson, MN 56044

Rehabilitation Engineering Program
Communication Resource Center
Courage Center
3915 Golden Valley Road
Golden Valley, MN 55422

Orthotics/Prosthetics Department
Gillette Children's Hospital
200 East University Avenue
St. Paul, MNM 55101

Sister Kenny Institute
Abbott Northwestern Hospital, Inc.
800 E. 28th Street at Chicago Ave.
Minneapolis, MN 55407

Minnesota Educational Computing Consortium (MECC)
2520 Broadway Drive
St. Paul, MN 55113

Department of Physical Medicine and Rehabilitation
University of Minnesota Hospitals
Minneapolis, MN 55455

Other States

Assistive Device Center
California State University
6000 J Street
Sacramento, CA 95819

Bioengineering Program
Association for Retarded Citizens (ARC) of the USA
2501 Avenue J
Arlington, TX 76011

Biomedical Engineering Center
Tufts-New England Medical Center
171 Harrison Avenue
Box 1014
Boston, MA 02111

Bulletins on Science and Technology for the Handicapped
American Association for the Advancement of Science
1515 Massachusetts Avenue
Washington, DC 20005

Communication Outlook
Artificial Language Laboratory
Computer Science Department
Michigan State University
East Lansing, MI 48824

Department of Rehabilitation Engineering
University Hospital
University of Wisconsin-Madison
600 Highland Avenue E3/211
Madison, WI 53792

Link and Go
Committee on Personal Computers and the Handicapped (COPH-2)
2030 Irving Park Road
Chicago, IL 60618

National Institute of Handicapped Research
Office of Special Education and Rehabilitation Service
U.S. Department of Education
Washington, DC 20202

National Rehabilitaiton Information Center (NARIC)
4407 Eighth Street N.E.
The Catholic University of America
Washington, DC 20017

PAM Assistance Centre
6011 W. Maple
Lansing, MI 48906

Rehabilitation Engineering Center
Children's Hospital at Stanford
520 Willow Road
Palo Alto, CA 94304

Rehabilitation Engineering Society of North America (RESNA)
4405 East-West Highway, Suite 210
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Trace Research and Development Center
314 Waisman Center
1500 Highland Avenue
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