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ABSTRACT

This study, which was mandated in Title II of the Technology-Related Assistance for Individuals with Disabilities Act, explores issues surrounding the financing of assistive technology and examines questions of accessibility, availability, affordability, and cost-effectiveness. The study offers a paradigm of disability focusing on how specific disabilities change the manner in which the activities of life are performed. It outlines the demographics of disability, defines the problem of access to assistive technology, and presents 12 major findings. Findings focus on: information awareness and coordination, inconsistent standard of need to justify funding across public programs, awareness and enforcement of existing rights and entitlements, health care funding of assistive technology, coordination of services and funding, monitoring the use of assistive technology, consumer choice and control, funding for support services, gaps in access for specific populations, availability of funding resources, impact and benefits of assistive technology, and funding solutions. In general, findings indicate that assistive technology makes education in regular school settings possible, reduces dependence on family members, saves money, enables individuals to sustain and improve their employment, and generally improves quality of life for individuals with disabilities. Sixteen recommendations for policy adaptation and legislative action are provided. An appendix examines recent public policy experience in the area of assistive technology. (Contains 26 references.) (PB)

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Study on the Financing of Assistive Technology Devices and Services for Individuals with Disabilities

A Report to the
President and the Congress
of the United States

March 4, 1993

National Council on Disability

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ED 355 696



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An Independent
Federal Agency

Letter of Transmittal

March 4, 1993

The President
The White House
Washington, DC 20500

Dear Mr. President:

On behalf of all members of the National Council on Disability, we submit to you a special report, *Study on the Financing of Assistive Technology Devices and Services for Individuals With Disabilities*.

This report is in accordance with the statutory mandate of Title II of The Technology-related Assistance for Individuals With Disabilities Act, P.L. 100-407. The National Council developed this report in consultation with an Advisory Committee on the Financing of Assistive Technology, numerous persons with disabilities and their families, experts on disability and assistive technology throughout the country, federal and state agency directors, providers, manufacturers, and representatives from a sample of third-party payers. This report summarizes the National Council's findings and presents our recommendations for improving access to the financing of assistive technology devices and related services for all individuals with disabilities. Nine work products of the study are available in the form of supplementary readings.

In analyzing federal programs that finance assistive technology for individuals with disabilities and in formulating legislative recommendations, the National Council has been deeply cognizant of the financial implications of its proposals and has consistently sought to develop practical, fiscally responsible approaches. Indeed, one of the National Council's key objectives has been to suggest ways in which existing federal expenditures related to the financing of assistive technology can be more carefully directed. The National Council is confident that the recommendations in this report will prompt an approach to the financing of assistive technology devices and related services that is better coordinated

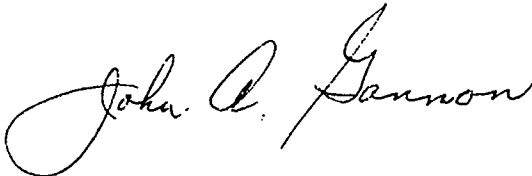
The President

Page 2

and more consistent across all programs serving individuals with disabilities and their families.

It is our belief that while significant gains have been made in recent years since the passage of The Technology-related Assistance for Individuals With Disabilities Act of 1988, much remains to be done to ensure that all individuals with disabilities have access to appropriate assistive technology devices and related services. The National Council on Disability looks forward to your leadership on behalf of Americans with disabilities. We are eager to work with you as we seek solutions to the problems faced by individuals with disabilities and their families in their efforts to finance assistive technology devices and related services in order to achieve full independence and integration.

Sincerely,



John A. Gannon
Acting Chairperson
February 1993-present



Sandra Swift Parrino
Chairperson
October 1983-January 1993

(This same letter of transmittal was sent to the President Pro Tempore of the Senate and the Speaker of the House of Representatives.)

ACKNOWLEDGMENT

The Council wishes to acknowledge and convey its sincere appreciation to the many individuals who contributed to this report. Members of the Advisory Committee, numerous people with disabilities and their families, Title I (P.L. 100-407) state funding directors, service providers, federal agencies, state agencies, advocates, and other experts from across the country contributed to this effort by participating in public forums, attending advisory meetings, researching state programs, completing studies, and otherwise providing input and assistance to the Council in the process of developing the ideas and recommendations contained in this report. A special thanks to Patricia A. Morrissey, Ph.D., for her support of this project.

STUDY ON THE FINANCING OF ASSISTIVE TECHNOLOGY DEVICES AND SERVICES FOR INDIVIDUALS WITH DISABILITIES

Publication date: March 4, 1993

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The views contained in this report do not necessarily represent those of the administration, as this document has not been subjected to the A-19 Executive Branch review process.

TABLE OF CONTENTS

	Page
MISSION OF THE NATIONAL COUNCIL ON DISABILITY	vii
NATIONAL COUNCIL ON DISABILITY, MEMBERS AND STAFF	ix
MEMBERS OF THE ADVISORY COMMITTEE	x
PROJECT STAFF	xi
EXECUTIVE SUMMARY	1
INTRODUCTION	14
DEFINITION OF ASSISTIVE TECHNOLOGY DEVICES AND SERVICES	18
A NEW DEFINITION OF DISABILITY	19
DEFINING THE PROBLEM	24
STATEMENT OF FINDINGS	26
RESEARCH FINDINGS	28
STATEMENT OF RESEARCH FINDINGS	31
POLICY RECOMMENDATIONS	62
TOPICS FOR FURTHER RESEARCH	105
CONCLUSION	108
REFERENCES	110

APPENDICES

A. Biographical Information: Members and Staff
of the National Council on Disability 114

B. List of Participants at Three Regional Public Forums 125

C. Recent Public Policy Experience in the Area
of Assistive Technology 135

TABLES

Table	Page
1. Assistive Technology Financing Options	30
2. Recent Public Policy Developments	37
3. Public Programs with a Potential to Fund Technology Access	42
4. Equipment Identified as Making a Significant Difference	53
5. Assistive Technology Funding Access: System Reform Options	65
6. Federal Income Tax Recommendations for Assistive Technology	97

SUPPLEMENTARY READING

Reports Available from the National Council on Disability

- Report 1. Literature Review
- Report 2. Review and Analysis of Federal Laws, Regulations, Policy, and Practice
- Report 3. Collection and Analysis of Information from a Nine-State Sample
- Report 4. Analysis of Policies and Practice of Private Health Insurers' Coverage of Assistive Technology
- Report 5. Alternative Funding Programs for Assistive Technology
- Report 6. Lending Practices of Financial Institutions Toward Individuals with Disabilities
- Report 7. Cost-Benefit Study of the Provision of Assistive Technology Devices and Services
- Report 8. Directory of Consultants on the Financing of Assistive Technology Devices and Services
- Report 9. Summary of Recommendations from Three Regional Public Forums

MISSION OF THE NATIONAL COUNCIL ON DISABILITY

The National Council on Disability is an independent federal agency composed of 15 members appointed by the President of the United States and confirmed by the U.S. Senate. The National Council was established in 1978 as an advisory board within the Department of Education (P.L. 95-602). The Rehabilitation Act Amendments of 1984 (P.L. 98-221) transformed the National Council into an independent agency. The statutory mandate of the National Council at the time of this study assigned the Council the following duties:

- Establishing general policies for reviewing the operation of the National Institute on Disability and Rehabilitation Research (NIDRR);
- Providing advice to the Commissioner of the Rehabilitation Services Administration (RSA) on policies and conduct;
- Providing ongoing advice to the President, the Congress, the RSA Commissioner, the Assistant Secretary of the Office of Special Education and Rehabilitative Services (OSERS), and the Director of NIDRR on programs authorized in the Rehabilitation Act;
- Reviewing and evaluating on a continuous basis the effectiveness of all policies, programs, and activities concerning individuals with disabilities conducted or assisted by federal departments or agencies and all statutes pertaining to federal programs, and assessing the extent to which these provide incentives to community-based services for, promote full integration of, and contribute to the independence and dignity of individuals with disabilities;
- Making recommendations of ways to improve research; the collection, dissemination, and implementation of research findings; service; and administration affecting persons with disabilities;
- Reviewing and approving standards for independent living programs;
- Submitting an annual report with appropriate recommendations to the Congress and the President regarding the status of research affecting persons with disabilities and the activities of RSA and NIDRR;
- Reviewing and approving standards for Projects with Industry programs;

- Providing to the Congress, on a continuous basis, advice, recommendations, and any additional information that the National Council or the Congress considers appropriate;
- Providing guidance to the President's Committee on the Employment of People with Disabilities; and
- Issuing an annual report to the President and the Congress on the progress that has been made in implementing the recommendations contained in the National Council's January 30, 1986 report, *Toward Independence*.

While many government agencies deal with issues and programs affecting people with disabilities, the National Council is the only federal agency charged with addressing, analyzing, and making recommendations on issues of public policy that affect people with disabilities regardless of age, disability type, perceived employment potential, economic need, specific functional ability, status as a veteran, or other individual circumstance. The National Council recognizes its unique opportunity to facilitate independent living, community integration, and employment opportunities for people with disabilities by ensuring an informed and coordinated approach to addressing their concerns and eliminating barriers to their active participation in community and family life.

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EXECUTIVE SUMMARY

The Vision

*For Americans without disabilities, technology makes things easier.
For Americans with disabilities, technology makes things possible.*
(Radabaugh, 1988)

The National Council on Disability (NCD) is proud to release this landmark study entitled *The Financing of Assistive Technology Devices and Services for Individuals With Disabilities*. As early as 1986, with the issuance of *Toward Independence*, the National Council recognized the important role that assistive technology can have in the lives of individuals with disabilities. As originator and developer of the Americans with Disabilities Act (ADA) (P.L. 101-336), the National Council believes that access to assistive devices and services is necessary to realization of the goals of the ADA.

This report is the culmination of 19 months of research by the NCD. The study was funded under Title II of the Technology-related Assistance for Individuals with Disabilities Act of 1988 (P.L. 100-407), referred to as the Tech Act. Under the Tech Act the Congress directed the National Council to conduct a study on the financing of assistive technology that will produce recommendations to the President and to Congress on improving access to the financing of assistive technology devices and services for individuals with disabilities.

Highlights

People with disabilities and their families have been involved in every step of the study. Individuals who are users of assistive technology have helped to demonstrate the benefits and costs of assistive technology. Indeed, an important objective of the research was to test something individuals with disabilities have long recognized—that assistive technology is as cost-effective as it is necessary in their lives. As a result, the study documents both the benefits and the costs of different kinds of technology-related assistance. The following are some highlights of responses from assistive technology users (Supplementary Reading, Report 7):

- Almost three-quarters of school-age children were able to remain in a regular classroom, and 45 percent were able to reduce school-related services.
- Sixty-two percent of working-age persons were able to reduce dependence on family members, 58 percent were able to reduce

dependence on paid assistance, and 37 percent were able to increase earnings.

- Eighty percent of elderly persons studied were able to reduce dependence on others, half were able to reduce dependence on paid persons, and half were able to avoid entering a nursing home.
- Almost one-third of assistive technology users indicated that their family saved money, averaging around \$1,110 per month, with assistive technology. At the same time, one-quarter of the users indicated that they experienced additional equipment-related expenses that averaged approximately \$287 per month.
- Of the 42 users of assistive technology who reported having paid jobs, 92 percent reported that the assistive technology enabled them to work faster or better, 83 percent indicated that they earned more money, 81 percent reported working more hours, and 67 percent reported that the equipment had enabled them to obtain employment. Fifteen percent indicated that the equipment enabled them to keep their jobs, 38 percent reported that the equipment allowed them to pursue advanced degrees, 23 percent reported taking a larger academic load, and 12 percent reported increasing training.
- When asked to estimate the impact of equipment on their quality of life, assistive technology users reported that without the equipment, their quality of life on a scale from 1 to 10 was around 3; as a result of the equipment, it jumped to approximately 8.4 points.

The Promise of Assistive Technology

Assistive technology is redefining what is possible for children and adults with disabilities. In the home, the classroom, the workplace, and the community, assistive technology is providing creative solutions that enable individuals with disabilities to be more independent, productive, and integrated into the mainstream of society and community life. Assistive technology can be simple or complex. It includes velcro, adapted clothing and toys, computers, seating systems, powered mobility, augmentative communication devices, special switches, and thousands of other commercially available or adapted items. These technology solutions improve an individual's ability to learn, compete, work, and interact with family and friends (Enders, 1990).

In every state, children and adults with disabilities and their families, friends, and advocates are searching for assistive technology solutions that will respond to individual needs and enhance independence. Testimony from

across the country reminds us that the major problem we face today is not the research and development of new technologies, but the delivery of existing assistive technology solutions to the people who need them.

Public Policy

Since 1986, the President and the Congress have adopted a series of laws that acknowledge the importance of assistive technology in the lives of individuals with disabilities (see Table 2, "Recent Public Policy Developments," p. 37). Perhaps the most significant of these is the Tech Act, which received overwhelming support in both the U.S. House and Senate. The legislative history surrounding its enactment includes testimony of dozens of witnesses providing firsthand information on the importance of assistive technology in people's lives, as well as the difficulties often encountered in gaining access to needed technology.

Title I of the Tech Act provides assistance to states for the development of consumer-responsive statewide programs of assistive technology services. Since 1988, 42 states have received funding to develop their statewide programs. Under Title II of the Act, the Congress mandated this study in recognition of the major problems faced by individuals with disabilities and their families with the financing of assistive technology devices and related services. Congress directed the National Council to conduct a study and to make recommendations concerning the following:

- Federal laws, regulations, procedures, and practices that facilitate or impede the ability of the states to develop and implement consumer-responsive statewide programs of technology-related assistance for individuals with disabilities;
- Federal and state laws, regulations, procedures, and practices that facilitate or impede the acquisition of, financing of, or payment for assistive technology devices and assistive technology services for individuals with disabilities;
- Policies, practices, and procedures of private entities (including insurers) that facilitate or impede the acquisition and financing of, or payment for, assistive technology devices and assistive technology services for individuals with disabilities; and
- Alternative strategies for acquiring or paying for assistive technology devices and assistive technology services [29 USC 2231].

The Scope of the Study

The National Council, in consultation with a distinguished Advisory Committee, engaged in a variety of efforts to collect pertinent information and viewpoints regarding the financing of assistive technology devices and services for all individuals with disabilities. This report summarizes the National Council's findings and presents recommendations for improving access to the financing of assistive technology devices and related services for all individuals with disabilities. The 12 work products of the study are available in the form of Supplementary Readings, which present in detail a range of issues related to the financing of assistive technology. Supplementary Readings include the following:

1. Literature Review

The *Literature Review on the Financing of Assistive Technology* is a comprehensive review of resources currently available on the financing of assistive technology. The National Council reviewed and summarized more than 100 documents related to financing; reviewed key public policy developments; outlined key findings from the literature; identified major barriers to the financing of assistive technology as indicated in the existing literature; and suggested options, based on the literature, for policy approaches to change (see Supplementary Reading, Report 1).

2. Review and Analysis of Federal Laws, Regulations, Policy, and Practice

The National Council analyzed policies and practices of 26 federal laws on the financing of assistive technology. The report identifies barriers and facilitators to financing assistive technology and offers suggestions to improve access to financing through various federal- and state-level initiatives (see Supplementary Reading, Report 2).

3. Collection and Analysis of Information from a Nine-State Sample

Nine states currently receiving funding under the Tech Act were selected by the National Council to participate in an analysis of state policies and practices on the financing of assistive technology: Arkansas, Illinois, Maine, Maryland, Minnesota, New Mexico, North Carolina, Oregon, and Utah. The report describes the effectiveness of various funding streams within each state in paying for assistive technology devices and related services for children and adults with disabilities (see Supplementary Reading, Report 3).

4. Analysis of Policies and Practice of Private Health Insurers' Coverage of Assistive Technology

Since private health insurance already covers many types of assistive technology under certain conditions, this study sought to analyze the determinants of private health insurance coverage for assistive technology. Four types of private health insurers were identified: Blue Cross-Blue Shield, commercial or for-profit health insurers, health maintenance organizations (HMOs), and self-insured employer plans. The benefits provided by these types of health insurance were compared with the medical benefits in workers compensation insurance plans.

In comparing these five types of insurers, the National Council worked with financing specialists in the Tech Act programs in nine states to learn which types of assistive technology were most likely and least likely to be covered. Written descriptions of each type of health insurance plan were examined to ascertain specific conditions under which covered services would be paid. In addition, the National Council gathered information about private insurance from different types of insurers, Durable Medical Equipment (DME) vendors and manufacturers, rehabilitation professionals, and consumers at the three regional forums and through selective interviews (see Supplementary Reading, Report 4).

5. Alternative Funding Programs for Assistive Technology

Assistive financing or loan guarantees, credit financing, revolving loan funds, and/or subsidy programs are sound alternatives to financing assistive technology. In this report, the National Council profiles 16 alternative strategies for acquiring and financing assistive technology. The report describes a variety of programs available for the purchase of assistive technology devices and contains information on each program's funding source, eligibility requirements, and strengths and weaknesses (see Supplementary Reading, Report 5).

6. Lending Practices of Financial Institutions Toward Individuals With Disabilities

The National Council examined a broad spectrum of financial institutions nationwide to develop a preliminary understanding of current lending practices to individuals with disabilities. Analysis of study results led to the development of several important options to be considered for both private and public initiatives (see Supplementary Reading, Report 6).

7. Cost-Benefit Study of the Provision of Assistive Technology Devices and Services

This study is the first to examine whether the provision of assistive technology is cost-effective for both individuals and programs. The National Council studied the costs and benefits of providing assistive technology devices and related services for a random sample of more than 130 individuals with physical, sensory, or multiple disabilities in nine selected Title I states (see Supplementary Reading, Report 7).

8. Directory of Consultants on the Financing of Assistive Technology Devices and Services

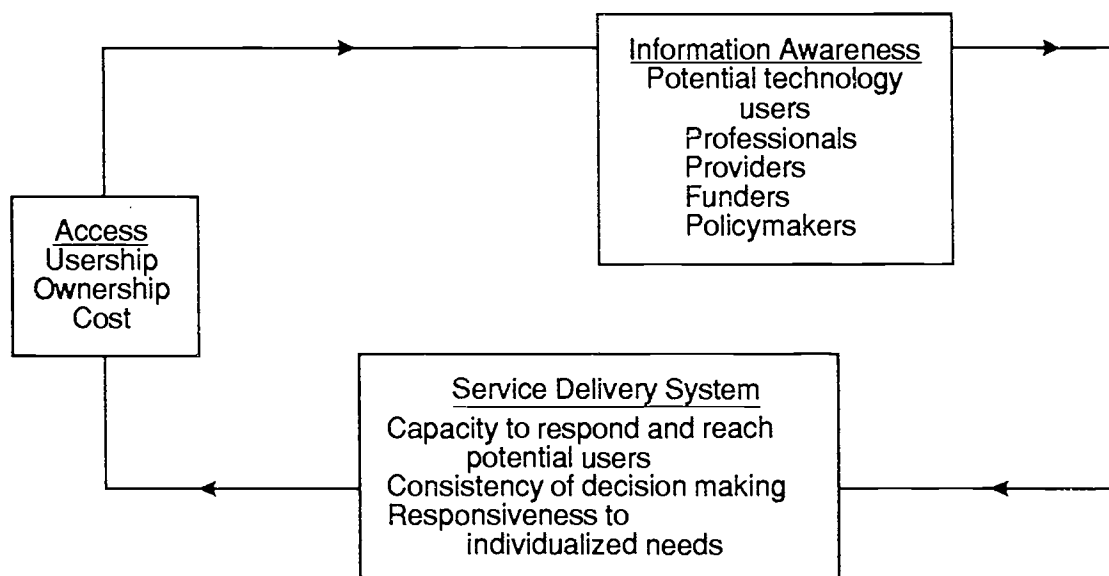
The National Council developed a directory that lists more than 60 knowledgeable consultants throughout the nation on the financing and acquisition of assistive technology devices and related services. The directory also provides sources for a range of assistance in all regions of the country (see Supplementary Reading, Report 8).

9. Summary of Recommendations from Three Regional Public Forums

The National Council conducted three regional public forums in Los Angeles, California; Portland, Maine; and Minneapolis, Minnesota. More than 100 witnesses from across the country representing a range of disabilities and perspectives participated in the forums (see Appendix B for a list of all forum participants). Witnesses included individuals with cognitive, physical, and sensory disabilities; parents; federal and state agency staff; providers and manufacturers of technology; insurers; Tech Act state directors; employers; and experts in the field of financing assistive technology (see Supplementary Reading, Report 9).

Issues and Problems

Several overarching issues were identified and affirmed across the body of research undertaken, as the following diagram illustrates. All decisions about access to assistive technology for a child or adult with a disability involve more than funding. Although ultimately all decisions are about resource allocation, there is an interdependence among user and provider information awareness, the capacity of the service delivery system to respond in a timely way to individual needs, and access to appropriate assistive technology.



There are costs associated with a national system of information awareness to reach all potential users of assistive technology. There are costs associated with the development of a consumer-responsive service delivery system with the capacity to reach all potential users of assistive technology. And there are obvious costs of purchasing assistive technology devices and support services in response to individual needs that continue to change over time. There are also significant costs to individuals and society of not making technology available to individuals with disabilities. At issue is the question of how to allocate resources in the most cost-effective and equitable manner to ensure access to assistive technology for all who need it.

Who should bear the costs of assistive technology services and devices? There is no single response that will prove to be effective for all circumstances. There are instead a combination of strategies or approaches that build on the success of current public policy, public-private sector partnerships, selected state experience, and legal precedents to create a vision of an accessible America, with technology playing a critical role in changing the ways individuals with disabilities interact with their social and physical environments. The research of the National Council has been reviewed, analyzed, and synthesized into a set of the 12 major findings summarized below:

Findings

Finding 1: Information Awareness and Coordination

Information on assistive technology devices and services is difficult to find and often inconsistent from source to source. Information dissemination is fragmented and uncoordinated. The barrier of awareness precedes questions of technology funding and thus denies individuals with disabilities an effective means to improved independence, productivity, and integration.

Finding 2: Inconsistent Standard of Need To Justify Funding Across Public Programs

There is no consistent standard of need to justify funding for assistive technology services and devices across public programs.

Finding 3: Awareness and Enforcement of Existing Rights and Entitlements

There is a paucity of expertise in applying rights' protections to secure individuals' right to assistive technology. Parents, providers, and individuals with disabilities are uninformed about their rights under the law. There has been only a limited effort at the state and federal levels to monitor and enforce the right to, or requirements for, expanding assistive technology access for children and adults with disabilities.

Finding 4: Health Care Funding of Assistive Technology

Typically, reimbursement for assistive technology devices and services in the health care system conforms to the requirements of the funding source, not to the functional needs of individuals with disabilities.

Finding 5: Coordination of Services and Funding

Information presented to the National Council strongly indicates a continued and widespread lack of cooperation and coordination between and within various funding agencies.

Finding 6: Monitoring the Use of Assistive Technology

There is no national database or legislative mandate that calls for the routine collection of data regarding the use of assistive technology or the collection of data regarding methods of financing through federal programs for assistive technology available to individuals with disabilities. There is no agreed-upon classification system at the federal or state level to distinguish different types of technology-related assistance for the collection and analysis of data on service delivery and funding patterns and trends.

Finding 7: Consumer Choice and Control

Emphasis on individual choice and control of assistive technology services and funding is conspicuously lacking in most programs.

Finding 8: Funding for Support Services

Once individuals with disabilities obtain needed technology, little attention and funding support are given to the training and ongoing assistance and maintenance needed to maximize benefits to the user.

Finding 9: Gaps in Access for Specific Populations

There are significant groups of individuals with disabilities who remain unserved or underserved by existing public and private programs that have financing available for assistive technology.

Finding 10: Availability of Funding Resources

There is no system, public or private, uniquely devoted to the funding and financing of assistive technology to respond to the full range of unmet needs. At best, assistive technology and related services funding is part of a menu of choices that must be made in the allocation of limited resources in multiple public and private service delivery systems.

Finding 11: Impact and Benefits of Assistive Technology

Preliminary study results from a sample of persons with disabilities in seven states from four age groups document the benefits compared to the costs of different kinds of technology-related assistance. Expanded documentation of the benefits of use of assistive technology should favorably influence resource allocation decisions at the national, state, and local levels.

Finding 12: Funding Solutions

There is no one answer to the complex problem of assistive technology funding for persons with disabilities of all ages nationwide. The National Council has identified seven successful approaches that can be refined and expanded to continue to enhance funding access to assistive technology for Americans with disabilities. These financing options are discussed extensively in individual topic papers presented in the form of supplementary reading to this report. These reports will provide readers with a better understanding of how identified programs contribute to the financing and acquisition of appropriate assistive technology devices and related services for individuals with disabilities. Each of these identified approaches is discussed in detail in the report. These seven approaches are:

1. Refining, refocusing, and expanding public programs;
2. Creating incentives for the development and replication of alternative financing mechanisms with public and private partnerships;
3. Refining and refocusing the health care system, including public and private insurance;
4. Creating tax incentives for improved technology access;
5. Refining and expanding the nexus of civil rights and technology access;
6. Mandating the concepts of universal design; and
7. Capitalizing on the important innovations in telecommunications and changing public policy.

Recommendations

The research conducted by the National Council, including three regional public forums, generated more than 200 suggestions to improve funding access for assistive technology devices and services. The National Council has thoroughly reviewed these suggestions as well as the research data generated from selected states and a random sampling of technology users with disabilities. A concise list of 16 recommendations has been refined from the larger list of suggestions by reviewing them according to the following criteria:

- Magnitude of the problem addressed;
- Potential scope of impact of the proposed solution on identified barriers;
- Potential for implementation;
- Consistency with the principles of ADA to promote full citizenship for persons with disabilities; and
- Potential to achieve cost-benefit results in quality of life for persons with disabilities and their families.

The policy recommendations are summarized as follows:

Recommendation 1

Mandate by statute the development of a national classification system for assistive technology devices and services and establish and collect uniform data sets across public programs.

Recommendation 2

Authorize the National Institute on Disability and Rehabilitation Research (NIDRR) to publish by the end of each calendar year an Annual Report to the Congress on the status of funding of assistive technology devices and services for Americans with disabilities.

Recommendation 3

Establish the statutory authority for a federal Assistive Technology Interagency Coordination Council to meet quarterly and be responsible for improved coordination of services and funding for assistive technology for Americans with disabilities.

Recommendation 4

Amend the state plan requirements in multiple statutes to require assurances and a planning process with timelines for expanding funding access to assistive technology for children and adults with disabilities.

Recommendation 5

Amend the individual program planning requirements in multiple statutes to provide notice to individuals with disabilities and their families of the right to assistive technology devices and services in response to individualized needs in a timely manner.

Recommendation 6

Add the complete definition of assistive technology devices and services adopted in the Technology-related Assistance Act (P.L. 100-407) to the following programs of the Social Security Act: Title II, Social Security Disability Insurance; Title V, Maternal and Child Health Block Grant; Title XVI, Supplemental Security Income; Title XVIII, Medicare; and Title XIX, Medicaid.

Recommendation 7

Reauthorize the Technology-related Assistance Act (P.L. 100-407) for an additional three years and strengthen opportunities for interagency coordination, systems change, and consumer choice and control.

Recommendation 8

Establish Assistive Technology Demonstration and Recycling Centers nationwide in an appropriate city of each state and in the top 50 Standard Metropolitan Statistical Areas to be operated by existing Centers For Independent Living or other community-based organizations that are consumer controlled and directed to enhance consumer choice in and control of assistive technology services and funding.

Recommendation 9

Authorize the use of the Social Security Trust Fund as a financing source for purchasing assistive technology that enhances the capacity to work through an Individualized Employment Account (IEA).

Recommendation 10

Establish a Technology Watch program patterned after the NCD's current ADA Watch activities to monitor compliance with enforcement of federal rights to or requirements for expanding technology access for children and adults with disabilities.

Recommendation 11

Authorize by statute the establishment of a National Center on Assistive Technology Legal Advocacy to specialize in funding issues.

Recommendation 12

Develop statutory authority that requires private health insurers to apply medical necessity standards to durable medical equipment, prostheses, and orthotics that enhance function in activities related to health, safety, and Activities of Daily Living (ADLs).

Recommendation 13

Create a comprehensive set of fiscal incentives encouraging private industry to invest in the production, marketing, and distribution of assistive technology to benefit Americans with disabilities.

Recommendation 14

Amend Section 162 of the Internal Revenue Code to allow taxpayers with disabilities who do not itemize the option of claiming assistive technology expenses as above-the-line adjustments to income. Request the Department of the Treasury to develop a cohesive set of tax policies on assistive technology for persons with disabilities that clarifies national values and goals as articulated in the Americans with Disabilities Act and the Technology-related Assistance Act.

Recommendation 15

Authorize by statute universal product design guidelines for application in the manufacture of electronic equipment and other products to enhance accessibility by individuals with disabilities.

Recommendation 16

Amend the Communications Act of 1934 to establish and implement a national policy of available, affordable, and accessible telecommunication services to Americans with disabilities.

Conclusion

These recommendations represent the urgent voices of people with disabilities and their families and the cogent statements of professionals. The NCD looks forward to the adoption and the implementation of these recommendations for the empowerment of people with disabilities and their families.

INTRODUCTION

Technology is a lot like freedom... Once it's uncorked, there's no putting it back. Its fruits are there for everyone's enjoyment and benefit. It is often said that assistive technology is liberating [for the individual with a disability] and that is certainly the case. But it is time to be clear that assistive technology is liberating not just for the individual with a disability but indeed for America as a whole.
(Williams, 1991)

Assistive technology is redefining what is possible for children and adults with a wide range of disabilities. In the home, the classroom, the workplace, and the community, assistive technology is providing creative solutions that enable individuals with disabilities to be more independent, self-confident, productive, and integrated into the mainstream of society. Assistive technology includes adapted toys, computers, seating systems, powered mobility, augmentative communication devices, special switches, and thousands of commercially available or adapted solutions. These technology solutions improve an individual's ability to learn, compete, work, and interact with family and friends (Enders, 1990).

At the public forum held by the Council in Portland, Maine, Elaine Clemm of Warwick, Rhode Island, shared a story about her seven-year-old son Christopher, who has severe cognitive and physical disabilities. Her story shows the role assistive technology can play in the lives of individuals with disabilities and their families:

One day when I happened to be at the [Child Development] Center, someone came looking for me and told me they wanted to show me something in my child's classroom. I went and what I saw I never in my wildest dreams expected.

My son Christopher was sitting in front of a computer. The screen had a touch plate on it, and when it was touched new colors would show up on the screen as well as a sound. But Christopher was not using his hand, he was using his nose! When I leaned over to speak to him, he looked up and gave me the biggest smile (which he very seldom did). I couldn't help but cry. It took six years for a response like this. Before this we were not even sure he had vision or adequate hearing. Thanks to the use of technology and the dedicated people who worked with him, this was the beginning of many new things for Chris. He now uses a computer on a routine basis and he also continues to use switches to operate toys, appliances for cooking and musical items.

In every state, children, youth, and adults with disabilities and their families, friends, and advocates are searching for assistive technology solutions that will respond to diverse individualized needs and enhance independence. Testimony from parents, individuals with disabilities, and professionals across the country remind us that the major problem we face today is not the research and development of new technologies, but instead the linking of already existing assistive technology solutions to the problems confronted by persons with disabilities as they learn, work, and engage in daily living activities. In the last 10 years there have been significant public policy developments that have improved access to assistive technology. These approaches to change have been as varied as new legislation focusing on access to assistive technology and amendments to a wide range of existing laws, to very specific agency policy directives clarifying the right to assistive technology in a major public program (see Appendix C, "Recent Public Policy Experience in the Area of Assistive Technology").

Perhaps the most significant public policy influence was enactment of the Tech Act, which received overwhelming support in both the U.S. House and Senate. The legislative history surrounding its enactment includes testimony of dozens of witnesses providing firsthand information on the importance of assistive technology in people's lives as well as the difficulties often encountered in gaining access to needed technology. Congressional findings are summarized in Section 2 of the legislation and include the following statement:

For some individuals with disabilities, assistive technology is a necessity that enables them to engage in or perform many tasks. The provision of assistive technology devices and assistive technology services enables some individuals with disabilities to— (A) have greater control over their own lives; (B) participate in and contribute more fully to activities in their home, school, and work environments, and in their communities; (C) interact to a greater extent with nondisabled individuals; and (D) otherwise benefit from opportunities that are taken for granted by individuals who do not have disabilities [29 USC 2201].

Congress found that resources are lacking that would help people with disabilities obtain and use assistive technology devices and related services. For example, these resources are lacking:

- Sources of payment for assistive devices and services;
- Trained personnel to provide assistive devices and services and to help individuals with disabilities use assistive technology effectively;

- Information about assistive technology for individuals, family members, and professionals working with individuals with disabilities;
- Coordination among public programs and between public and private sector programs; and
- Capacity of both public and private sector programs to provide necessary technology-related assistance [29 USC 2201].

The objectives of the Tech Act were designed to respond to these findings. The primary objective includes the provision of federal assistance to the states for the development of a consumer-responsive statewide program of assistive technology services. Since 1988, 42 states have received funding to develop their statewide programs.

Scope of the Study

This study was conducted in response to the congressional mandate in Title II of the Tech Act. Title II mandated a study on the financing of assistive technology to be conducted by the NCD that will produce recommendations to the Congress and the President concerning the following:

- Federal laws, regulations, procedures, and practices that facilitate or impede the ability of the states to develop and implement consumer-responsive statewide programs of technology-related assistance for individuals with disabilities;
- Federal and state laws, regulations, procedures, and practices that facilitate or impede the acquisition of, financing of, or payment for assistive technology devices and assistive technology services for individuals with disabilities;
- Policies, practices, and procedures of private entities (including insurers) that facilitate or impede the acquisition and financing of or payment for assistive technology devices and assistive technology services for individuals with disabilities; and,
- Alternative strategies for acquiring or paying for assistive technology devices and assistive technology services [29 USC 2231].

This report is the outcome of 19 months of research. It consists of a review of the literature on the financing of assistive technology, six days of public forums with more than 100 witnesses from across the nation providing testimony, a review of policy and practice for 26 federal laws affecting

individuals with disabilities, an analysis of state-level policies affecting financing of assistive technology, an examination of the benefits and costs of assistive technology with the assistance of individuals with disabilities who are users of technology, a review of alternative funding practices, and an analysis of private insurance and the financing of assistive technology (see Appendix B for a list of all forum witnesses).

DEFINITION OF ASSISTIVE TECHNOLOGY DEVICES AND SERVICES

For the purpose of this study, the definition of assistive technology devices and services is the definition incorporated in the Tech Act.

Assistive technology device: Any item, piece of equipment, or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities.

Assistive technology service: any service that directly assists an individual with a disability in the selection, acquisition, or use of an assistive technology device. Such term includes:

- (A) the evaluation of the needs of an individual with a disability, including a functional evaluation of the individual in the individual's customary environment;*
- (B) purchasing, leasing, or otherwise providing for the acquisition of assistive technology devices by individuals with disabilities;*
- (C) selecting, designing, fitting, customizing, adapting, applying, maintaining, repairing, or replacing of assistive technology devices;*
- (D) coordinating and using other therapies, interventions, or services with assistive technology devices, such as those associated with existing education and rehabilitation plans and programs;*
- (E) training or technical assistance for an individual with disabilities, or, where appropriate, the family of an individual with disabilities; and*
- (F) training or technical assistance for professionals (including individuals providing education and rehabilitation services), employers, or other individuals who provide services to, employ, or are otherwise substantially involved in the major life functions of individuals with disabilities.*

A NEW DEFINITION OF DISABILITY

A New Paradigm

Historically, public policy has defined disability largely from a medical and clinical perspective, focusing on the causes and effects of congenital conditions, disease, and injury. Today the focus is instead on function: how specific disabilities change the manner in which the activities of life are performed.

A noted disability demographer, Mitchell P. LaPlante, describes disability as a limitation, caused by one or more chronic, physical, or mental health conditions, in performing activities that people of a particular age are generally expected to be able to perform. Disability in basic life activities, while highly associated with aging, begins at birth and occurs throughout the life span. LaPlante describes the various tools used to measure functioning:

Measures of functioning in basic life activities include ability to eat, control excretory function, transfer, toilet, dress, and bathe—the well-known activities of daily living (ADLs) and may also include ambulation and the ability to walk or go outside. The Index of Activities of Daily Living has been demonstrated a valid and reliable assessment tool for elderly and nonelderly persons with chronic conditions and for institutionalized as well as noninstitutionalized persons. Measures of functioning in activities instrumental to independent living include ability to use the telephone, shop for groceries, prepare meals, do household chores, do laundry, use transportation, take medications, and handle money matters.
(LaPlante, 1991a)

Traditionally, "major life activities" are defined as social roles such as going to school, working, or performing instrumental activities of daily living such as household chores or shopping. However, for the purposes of this study, traditional performance-based definitions of disability simply do not offer enough detail to answer important questions about effective functioning within these life areas. A better understanding of the functional needs of the individual with a disability may be achieved through questions such as the following:

- What barriers are there in the environments of school, work, recreation, home, community, travel, or daily life that prevent an individual from full participation?

- Can these barriers be ameliorated, bypassed or eliminated by assistive technology devices and related services?

Barriers to performing actions exist everywhere. Understanding barriers is the last step in defining whether a disability exists for a specific individual at a particular moment in time (World Institute on Disability, 1991). Indeed, an exact definition of disability is less important than acceptance of the principle that severity of disability is best understood within an environmental context. The Institute of Medicine endorses this approach, describing disability in the following manner:

...the expression of a physical or mental limitation in a social context— the gap between a person's capabilities and the demands of the environment. People with such functional limitations are not inherently disabled, that is, incapable of carrying out their personal, familial, and social responsibilities. It is this interaction of their physical or mental limitations with social and environmental factors that determines whether they have a disability. (Institute of Medicine, 1991)

As Susan Daniels, associate commissioner of the Administration on Developmental Disabilities, has discussed in "The Meaning of Disability: Evolving Concepts," the use of technology in the lives of persons with disabilities is bringing about a "paradigm shift" that is redefining the meaning of disability in our culture (Daniels, Fall 1990). The old perception of people with disabilities in society, which she refers to as the "individual defect" paradigm, is based upon the assumption that disability is a physical or mental difference that is not desirable. Under this individual deficit paradigm, people with disabilities are regarded as in need of special care or services that will cure them or else help them to adjust to their "affliction."

Daniels calls the new perspective the "technology/ecology" paradigm. Under this paradigm, disability is defined as a "lack of fit between a person's goals, his or her capabilities, and environmental resources." Pointing out that we all are dependent on technology, Daniels observes that a broken wheel has a similar effect on a nondisabled truck driver, a bus passenger who is blind, and an athlete who uses a wheelchair. Attention must not be placed to the "patient" or "client" who is disabled, but on improving "the fit" between the person and the environment.

Recent trends in disability public policy appear to support this transformed philosophy of disability. This is particularly evidenced in, among others, the ADA and the Tech Act. The language of the Tech Act acknowledges the value of technology for persons with disabilities, enabling them to:

- Have greater control of their lives;
- Participate in and contribute more fully to activities in their home, school, and work environments;
- Interact to a greater extent with nondisabled individuals; and
- Otherwise benefit from opportunities that are taken for granted by individuals who do not have disabilities (Section 2: Findings, 29 USC 2201).

The ADA focuses on eliminating barriers to full participation by persons with disabilities in American life. Its goal is not to "cure" the person with a disability but to cure the problems in the environment that serve as barriers to participation. It provides many of the same legal remedies that are available to traditional civil rights constituencies. For the goals of this law to be accomplished, many segments of American society will need to make changes, either in their policies or in their premises.

This clear trend in public policy as it affects persons with disabilities is the result of advocacy. People with disabilities and parents of children with disabilities are strong supporters of the use of technology because of the dramatic results it has made in their own lives. It is no great surprise that as people with disabilities have become more involved in public policy, either as advocates or as policymakers, access to technology has emerged as a high priority (World Institute on Disability, 1991).

Assistive technology devices and services are the keys to improving the fit between individuals and their environments. According to the World Institute on Disability, in discussing the assistive technology and related services needs of persons with disabilities, it is important to recognize the following basic principles:

The first is that people with disabilities are as diverse as the human population; thus, most generalizations based upon particular types of disabilities are accompanied by numerous exceptions. Within any particular type of disability there are many differences that affect an individual's ability to function and adapt: age at onset, severity, availability of training and rehabilitation, degree of support from family and friends, cultural attitudes toward disability, and other factors. There is no escape from the fact that people with disabilities are individuals who approach life with different histories, attitudes and resources. Two people can have the same functional limitation

and yet require completely different services or types of assistive technology.

A second important concept is that people with disabilities should be regarded as problem solvers. Unfortunately, the history of people with disabilities in the U.S. and elsewhere has been, in large part, one of paternalism. Entire professions of "experts" have emerged who have obtained degrees, and also taken control over basic life decisions away from their clients. However, recent trends have demonstrated that, given the proper tools, people with many different types of disabilities can devise creative approaches to eradicate barriers that had stumped the so-called experts. (World Institute on Disability, 1991)

Demographics of Disability

The promise of legislation such as the Tech Act and the ADA can be realized only when the public and private sectors have consistent and functional demographic data upon which to base policy and practical business decisions. The effective design, production, and distribution of products and services usable by individuals with functional limitations is currently restricted because specific data on how people use their physical, sensory, and cognitive capacities are not clearly understood and are largely undocumented. In addition, most researchers who focus on statistics relating to persons with disabilities generally utilize a medical or health care perspective.

The most widely quoted data on disability are those derived from the National Health Interview Surveys (NHIS) conducted by the National Center for Health Statistics (NCHS). Other sources, less frequently cited, include "The Survey of Income and Program Participation" (SIPP), documentation of children with disabilities emanating from the special education field, states' attempts to count individuals with particular "impairments" such as blindness and severe visual impairment, and the International Center on Disability Survey, conducted by Louis Harris and Associates, Inc., at the request of the NCD. As one might suspect, methodologies differ, data sets are dissimilar and results, predictably, are not comparable. However, there are some indicators that may help establish a baseline with which to work (World Institute on Disability, 1991).

In general, approximately 14 percent of the United States population report a limitation relative to one or more "major life activities" such as working or going to school. Rates are higher for families with lower annual incomes and for certain racial and ethnic groups such as African Americans, Latin Americans, and Native Americans. Prevalence varies little between male and

female, except in older age groups. Age, on the other hand, is strongly linked to functional limitations. Limitations in seeing and hearing show higher prevalence rates within older age groups. Certain limitations in moving also increase with age. Memory limitations are more apparent among elderly individuals (World Institute on Disability, 1991). In addition, the Institute of Medicine reports the following statistics:

- About 35 million people (one in every seven) have disabling conditions that interfere with their life activities.
- More than 9 million people have physical or mental conditions that keep them from being able to work, attend school, or maintain a household.
- More than half of the four-year increase in life expectancy between 1970 and 1987 is accounted for by time spent in activity limitations.
- Disabilities are disproportionately represented among minorities, the elderly, and lower socioeconomic populations.
- Of the current 75-year life expectancy, a newborn can be expected to experience an average of 13 years with an activity limitation.
- Annual disability-related costs to the nation total more than \$170 billion (Institute of Medicine, 1991).

The chance of having an activity limitation rises with increasing age. Among noninstitutionalized Americans 65 and over, 37 percent (10.6 million individuals) report some limitation in activity as compared to 11 percent of people under 65 (22.5 million) (LaPlante, 1991b). The incidence and severity of disability increases dramatically with age. Forty-five percent of people age 65-69 report functional limitations and 72.5 percent of people over age 75 have functional limitations (Kraus and Stoddard, 1989).

Having a disability is more frequently reported among low income groups. About 20 percent of people under 65 who earn less than \$10,000 annually report having disabilities as compared to only 7 to 8 percent of people earning at least \$30,000 per year (Robert Wood Johnson Foundation, 1991).

For the purposes of this study, individuals with disabilities of all ages, from infants through older Americans, may have an identified need for access to assistive technology devices and services. Their needs in terms of funding are common throughout their entire life span. The findings and recommendations of this report, therefore, transcend age and type of disability.

DEFINING THE PROBLEM

With the passage of the Tech Act, children, youth, and adults with disabilities and their families and advocates have an expanding set of expectations that assistive technology devices and services will be more available, accessible, and responsive to consumer needs. In every state, consumers, parents, and professionals are still learning about and refining "best practices" in the delivery of technology-related assistance. There is no single definitive model or exemplary program that can or should be replicated as states attempt to meet their new mandate requiring a statewide, consumer-responsive system of technology service delivery (U.S. Senate, 1988).

Increased awareness of what is possible and the delivery of services across disciplines will enable individuals with disabilities to be part of the decision-making team that identifies the most appropriate technology to make a difference in their lives. Assistive technology is a means to increased opportunity rather than an end in itself. An adaptive switch to activate a toy is a means to more independent play, to gaining an understanding of cause and effect, and to expanded social interaction with other children and family members (Winter, 1990). An adaptive keyboard, a computer, and an augmentative communication device are a means to compete in the work force, express one's thoughts and desires, or learn in school. Through experience we have learned that assistive technology is much more than an adaptive device or special equipment. Application of assistive technology involves awareness, assessment, identification of appropriate solutions, training, practice, skilled professionals from multiple disciplines, follow-up support over time, and maintenance. Only when each of these is applied successfully does assistive technology meet its full potential—the empowerment and increased independence of individuals with disabilities.

What makes assistive technology devices and services possible on an individual level, on a local service agency level, and on a systems-wide basis? The obvious answer is funding. All decisions about access to assistive technologies relate to resource allocation. What is not so obvious is where to go to secure funding and how to deal with the multiple options within public programs and the private sector.

There is no single solution to solving the assistive technology funding problems across all states and local communities. The challenge is to clearly identify the entry points for a particular funding source, bridges to other funding options, and ways to avoid detours and stop signs that delay or deny reimbursement of assistive technology. Unlike the typical road map, negotiating existing and emerging funding streams will require frequent updating as efforts are made collectively to change regulations, amend state

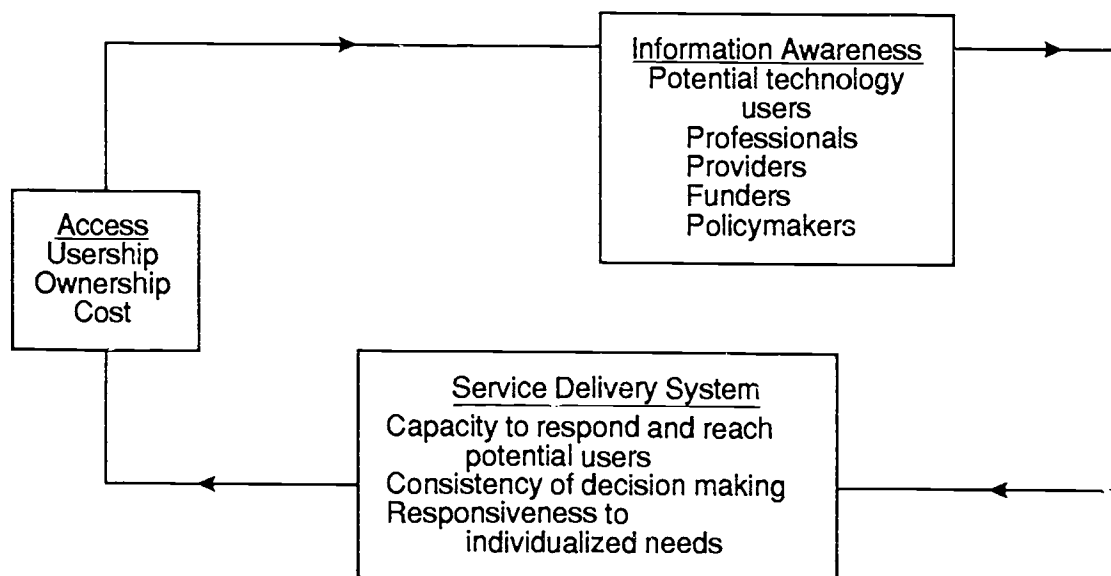
plans, refine interagency agreements, develop new policies and procedures, and revise day-to-day practices as they affect the individual technology user. To develop a comprehensive road map will require the involvement of all potential stakeholders, including individuals with disabilities, parents, providers, professionals, technology manufacturers and dealers, insurers, and federal and state agency officials.

The Council is committed to the challenge of ensuring that children, youth, and adults with disabilities, as well as their families and advocates, have information about, access to, and financing for the necessary assessment, choices, purchases, training, and long-term support across the full range of assistive technology devices and services. It is the Council's goal to move increasingly closer to full independence, productivity, and integration of people with disabilities into the mainstream of society and community life.

STATEMENT OF FINDINGS

The findings that follow are based on 19 months of research on the current state of funding of assistive technology to benefit persons with disabilities and their families nationwide. In developing these findings, the Council analyzed testimony presented by more than 100 witnesses in six days of public hearings, reviewed available literature on the financing of assistive technology, conducted an in-depth examination of funding practices at the federal and state level, and examined from a cost-benefit analysis the impact of technology on the lives of 130 children and adults with disabilities.

Several overarching issues were identified and validated across the body of research undertaken, as the diagram illustrates. All decisions about access to assistive technology for a child or adult with a disability involve more than funding. Although ultimately all decisions are about resource allocation, there is an interdependence between user and provider information awareness, the capacity of the service delivery system to respond in a timely way to individual needs, and access to appropriate assistive technology.



There are costs associated with a national system of information awareness to reach all potential users of assistive technology. There are costs associated with the development of a consumer-responsive service delivery system with the capacity to reach all potential users of assistive technology. There are also the obvious costs of purchasing assistive technology devices and support services in response to individual needs that continue to change over

time. However, there are also significant costs to individuals and society of not making technology available to individuals with disabilities.

Who should bear the costs of assistive technology services and devices? There is no single response that will prove to be effective for all circumstances. There are instead a combination of strategies or approaches that build on the success of current public policy, public-private sector partnerships, selected state experience, and legal precedents to create a vision of an accessible America. Technology plays a critical role in these approaches by changing the way individuals with disabilities interact with their social and physical environments.

The research of the Council has been reviewed, analyzed, and synthesized into a set of 12 major findings. The next section of this report describes and reviews these key findings.

RESEARCH FINDINGS

This study resulted in 12 distinct findings. These findings are summarized below. Following the summary, a discussion of each finding is provided.

Finding 1: Information Awareness and Coordination

Information on assistive technology devices and services is difficult to find and often inconsistent from source to source. Information dissemination is fragmented and uncoordinated. The barrier of awareness precedes questions of technology funding and thus denies individuals with disabilities an effective means to improved independence, productivity, and integration.

Finding 2: Inconsistent Standard of Need to Justify Funding Across Public Programs

There is no consistent standard of need to justify funding for assistive technology services and devices across public programs.

Finding 3: Awareness and Enforcement of Existing Rights and Entitlements

There is a paucity of expertise in applying rights' protections to secure individuals' entitlements to assistive technology. Parents, providers, and individuals with disabilities are uninformed about their rights under the law. There has been only a limited effort at the state and federal levels to monitor and enforce the right to, or requirements for, expanding assistive technology access for children and adults with disabilities.

Finding 4: Health Care Funding of Assistive Technology

Typically, reimbursement for assistive technology devices and services in the health care system conforms to the requirements of the funding source, not to the functional needs of individuals with disabilities.

Finding 5: Coordination of Services and Funding

Information presented to the Council strongly indicates a continued and widespread lack of cooperation and coordination between and within various funding agencies.

Finding 6: Monitoring the Use of Assistive Technology

There is no national database or legislative mandate that calls for the routine collection of data regarding the use of assistive technology or the collection of data regarding financing methods through federal programs for assistive technology available to individuals with disabilities. There is no agreed-upon classification system at the federal or state level to

distinguish different types of technology-related assistance for the collection and analysis of data on service delivery and funding patterns and trends.

Finding 7: Consumer Choice and Control

Emphasis on individual choice in, and control of, assistive technology services and funding is conspicuously lacking in most programs.

Finding 8: Funding for Support Services

Once individuals with disabilities obtain needed technology, little attention and funding support are given to training and ongoing assistance and maintenance needed to maximize benefits to the user.

Finding 9: Gaps in Access for Specific Populations

There are significant groups of individuals with disabilities who remain unserved or underserved by existing public and private programs that have financing available for assistive technology.

Finding 10: Availability of Funding Resources

There is no system, public or private, uniquely devoted to the funding and financing of assistive technology to respond to the full range of unmet needs. At best, assistive technology and related services funding are part of a menu of choices that must be made in the allocation of limited resources in multiple public and private service delivery systems. (See Table 1, "Assistive Technology Financing Options.")

Finding 11: Impact and Benefits of Assistive Technology

Preliminary study results from a sample of persons with disabilities in seven states from four age groups document the impact and benefits as compared to costs of different kinds of technology-related assistance. Expanded documentation of the benefits of use of assistive technology should favorably influence resource allocation decisions at the national, state, and local levels.

Finding 12: Funding Solutions

There is no one answer to the complex problem of assistive technology funding for persons with disabilities of all ages nationwide. The Council has identified seven distinct successful approaches or strategies that can be refined and expanded to continue to enhance funding access to assistive technology for Americans with disabilities.

Table 1

ASSISTIVE TECHNOLOGY FINANCING OPTIONS

PUBLIC PROGRAMS

Medicare

Medicaid

- Required and Optional Services
- Intermediate Care Facilities for Persons Who Are Mentally Retarded (ICFs/MR)
- Early and Periodic Screening, Diagnosis and Treatment (EPSDT)
- Section 2176 Home and Community Based (HCB) Waivers
- Community-supported Living Arrangements

Maternal and Child Health

- Maternal and Child Health Block Grant
- Children with Special Health Care Needs
- Special Projects of Regional and National Significance (SPRANS)

Education

- Individuals with Disabilities Education Act (IDEA) State Grants (Part B)
- IDEA: Programs for Infants and Toddlers with Disabilities and Their Families (Part H)
- State-operated Programs (89-313)
- Vocational Education
- Head Start

Vocational Rehabilitation

- State Grants
- Supported Employment
- Independent Living Parts A, B, and C

Social Security Benefits

- Title II: Social Security Disability Insurance (SSDI)
- Title XVI: Supplemental Security Income (SSI)
- Work Incentive Programs

Developmental Disability Programs

Department of Veterans Affairs Programs

Older Americans Act Programs

ALTERNATIVE FINANCING

- Revolving Loan Fund
- Lending Library
- Discount Program
- Low-interest Loans
- Private Foundations
- Service Clubs
- Special State Appropriations
- State Bond Issues
- Employee Accommodations Program
- Equipment Loan Program
- Corporate-sponsored Loans
- Charitable Organizations

U.S. TAX CODE

- Medical Care Expense Deduction
- Business Deductions
- Employee Business Deductions
- ADA Credit for Small Business
- Credit for Architectural and Transportation Barrier Removal
- Targeted Jobs Tax Credit
- Charitable Contributions Deduction

PRIVATE HEALTH INSURANCE

- Health Insurance
- Worker's Compensation
- Casualty Insurance
- Disability Insurance

CIVIL RIGHTS

The Americans with Disabilities Act
Rehabilitation Act

- Section 504

UNIVERSAL ACCESS

Rehabilitation Act, Section 508
Decoder Circuitry Act

TELECOMMUNICATIONS

Telecommunications for the Disabled Act of 1982

Telecommunications Accessibility
Enhancement Act of 1988

STATEMENT OF RESEARCH FINDINGS

Finding 1: Information Awareness and Coordination

Information on assistive technology devices and services is difficult to find and often inconsistent from source to source. Information dissemination is fragmented and uncoordinated. The barrier of awareness precedes questions of technology funding and thus denies individuals with disabilities an effective means to increase independence, productivity, and integration.

Current, reliable, and easy-to-understand information remains out of reach for many persons with disabilities and their family members. The information needs of current and potential technology users are multiple in scope. They include the following:

1. Information about the full range of assistive technology devices and related services and their potential in different environments to respond to the functional needs of varied users;
2. Information that compares and contrasts device effectiveness, affordability, operability, and dependability;
3. Information on reachable distribution points to access identified assistive technology devices and related services (vendors, nonprofit services providers, state and local public agencies);
4. Information on training support options;
5. Information on appropriate assessment approaches and the availability of qualified individuals or teams in a potential user's local area or state;
6. Information on available maintenance and repair points in a potential user's local area or state;
7. Information on funding options available through public or private sources; and
8. Information about guaranteed rights to assistive technology through public (federal or state) entitlements.

These awareness and specific information areas must also be targeted to respond to the needs of other important audiences such as teachers,

therapists, administrators, funding/claim agents and decision makers, employers, medical and rehabilitation professionals, and the general public.

Tom Owens of Portsmouth, New Hampshire, in his testimony before the Council, illustrated the need to increase the assistive technology knowledge base of all service providers when he stated,

Many physicians don't know what is available for me, "the consumer." There have been several occasions where I have found it myself and requested of the physician certain adaptations necessary for my wheelchair. He had no idea these were available and needed assistance in how to write up the prescription. The potential is limitless as to what adaptive equipment could be made available but educating the insurance companies and the physicians is necessary to get the full potential.

The experience of a southern Maine school-age child with cerebral palsy demonstrates the lengths families must go to justify the need and increase the awareness among providers of the benefits of assistive technology:

This junior high boy's family and teacher believed that the child can benefit from a power chair. The family's primary care physician has repeatedly refused to prescribe a power chair. So the teacher videotaped a field trip to a local art museum. In one segment, the child was "pushed" through the museum by an aide; in the other, the young boy "toured" the museum solo, in a borrowed chair. The dramatic difference portrayed in the videotape convinced the child's physician to order the power chair.

The problem of inadequate knowledge of appropriate technology solutions to respond to individualized needs is compounded by the rapidity with which the assistive technology field is growing. There is nowhere a family can go to try out different assistive technology devices before purchasing begins. A frustrated young father, Martin Sweeney of Los Angeles, California, painfully explained this point to the Council:

Assistive technology represented hope, opportunity, communication, and who knew what else [for daughter Eva]. I started asking questions. I asked the staff at UCLA and got some information. Then I went to my local computer store and got next to none. When I tried to explain my situation, the poor salesman looked at me like I was from another planet. It was then that I realized that there was nobody out there—at least no one I know—who could help answer the kind of questions I needed answered.

I bought a few devices and programs only to discover at home with Eva the "bug" or "glitch" that put it just beyond her reach. Some of the possibilities were too expensive to risk a trial run. This trial-and-error approach lasted the better part of a year.

Batavia and Hammer have identified criteria used by individuals with disabilities to evaluate their satisfaction with assistive devices (1989). Although the relative ranking of 17 criteria depended on the user's disability and the type of technology under evaluation, overall the 4 most important criteria across all disabilities were effectiveness, affordability, operability, and dependability. Unfortunately, there is no system that exists on a national level to enable potential technology users to gain information about expressed satisfaction with particular technology.

Most individuals with disabilities and families with children with disabilities cannot afford to purchase the assistive technology devices and services they need. The potential user is dependent on third-party funding support, both public and private. The availability of, and access to, information that is reliable, easy to understand, and responsive to the needs of users does not guarantee funding and access. But clearly information awareness is an important foundation for the creation of a seamless system of technology assistance for persons with disabilities.

The passage of the Tech Act and the funding of 42 states under the Act has resulted in improved awareness of, and access to, information. However, information management, especially in awareness and dissemination activities, remains fragmented and uncoordinated.

There are a number of electronic databases that are publicly and privately funded (such as Apple Link and Hyper-ABLEDATA). Many of the Tech Act states have established toll-free lines to respond to information requests and to make information on electronic databases more accessible to potential technology users. However, there are no minimum performance measures to evaluate and guide information dissemination efforts in the 42 states funded under the Act.

There are more than a dozen federal programs that authorize funding for assistive technology devices and services at the discretion of the state administering agency. There is a critical need to provide information and training to individuals with disabilities and their families on how to successfully influence resource allocation decisions by public programs. There is a similarly critical need to provide information and training on how to successfully influence the reimbursement or prior approval decisions of private health insurers to increase access to assistive technology.

Finding 2: Inconsistent Standard of Need To Justify Funding Across Public Programs

There is no consistent standard of need to justify funding for assistive technology services and devices across public programs.

Congressional mandates over the last 25 years have consistently expanded coverage, benefits, and rights for persons with disabilities. Each federal mandate has responded to a particular area of need: medical assistance, early intervention, education, rehabilitation, civil rights. Some of the policy goals of the programs authorized by Congress include the following:

- To assure that all children with disabilities have available a free appropriate public education (IDEA).
- To develop and implement a comprehensive program of rehabilitation and independent living for individuals with disabilities to maximize their employability, independence, and integration into the workplace and the community (Rehabilitation Act).
- To provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities (ADA).

Assistive technology is proving to be a powerful means for individuals with disabilities to achieve the outcomes of these and other policy goals from more than 20 programs authorized by Congress (see Supplementary Reading, Report 2).

Unfortunately, a clear concept of entitlement to assistive technology is missing from this patchwork of funding streams. Instead, coverage is left to the authority of individual programs such as education, employment, independent living, and health care. Disability as a functional issue and the importance of technology in addressing functional needs have not been addressed in a comprehensive manner.

Witnesses at each of the public forums explained how the same device or piece of equipment would be defined in very different ways to meet varying standards of needs required to justify funding by different programs. The different rules for payment are made more difficult by differences in interpretation of funding justification from the same public agency in different parts of a state and from state to state.

On a more positive note, the existence of more than 20 defined categorical public programs for individuals with disabilities helps expand the range of funding options that may respond to individuals' technology needs. Whether the public program has a distinct orientation to education, employment, independent living, or income maintenance, the need for assistive technology can be shaped to justify funding.

There are choices, but no guarantees. The choices, as described by multiple witnesses at public forums held by the Council, are real only for those individuals who are more aware, more educated, and more informed about how to document and justify the need for technology. Mary Ann Glicksman of Santa Monica, California, described the anxiety that she and so many families experience in their effort to find funding for much-needed technology:

Funding probably could be found for everything, but it requires a lot of knowledge of many systems: social service, medical, government, community. It also requires time, and most of all a tenacity and almost a girding for battle to face all the agencies and programs requiring information and justification from you. My heart pounds before I make the initial phone call, whether it be for an IEP [individualized education program] addendum, an assessment appointment, a doctor's appointment, or to the insurance company.

Despite recent efforts to amend and improve selected public program requirements to fund assistive technology, the varying standards of need remain a significant barrier for potential and current technology users with disabilities (see Appendix C, "Recent Public Policy Experience in the Area of Assistive Technology").

Finding 3: Awareness and Enforcement of Existing Rights and Entitlements

There is a paucity of expertise in applying civil and constitutional rights protections to secure individuals' entitlements to assistive technology. Parents, providers, and individuals with disabilities are uninformed about their rights under the law. There has been only a limited effort at the state and federal levels to monitor and enforce the right to, or requirements for, expanding assistive technology access for children and adults with disabilities.

In recent years, Congress and the Executive Branch of the federal government have clarified or expanded the rights of individuals with disabilities to access assistive technology. Table 2, on page 37, summarizes 17 such changes in public policy that have occurred since 1986. Unfortunately, most

parents, providers, and individuals with disabilities remain unaware of many of these expanded benefits and rights.

This general lack of awareness and understanding of existing potential benefits and rights extends to federally funded advocacy agencies such as Client Assistance Programs (CAPs) authorized under the Rehabilitation Act and Protection and Advocacy Agencies (P&As) authorized under the Developmental Disabilities Assistance and Bill of Rights Act. The body of case law involving the protection of a right to assistive technology as authorized by IDEA, the Rehabilitation Act, or by Sections of the Social Security Act (Medicaid or Medicare) is almost nonexistent. As the Council heard from witnesses at all three public forums, there are numerous potential cases involving children and adults with disabilities being denied access to assistive technology. Yet there is a paucity of expertise among advocates, attorneys, persons with disabilities and their families, and professionals across disciplines who can effectively weave their way through the complex web of federal regulations regarding eligibility and reimbursement for technology funding. Indeed, the Council was able to identify only 60 experts nationwide on the financing of assistive technology (see Supplementary Reading, Report 8).

In addition, to date there is no clearinghouse of information on a national, regional, or state level that is available to assist individuals with disabilities and their families in effectively navigating public funding streams to gain access to assistive technology. As a result, children with varying disabilities and their families and advocates frequently remain unaware of the right to assistive technology as part of a free appropriate education. Work incentive provisions through the Social Security Program remain underutilized as an assistive technology financing option. These deductions and credits are not well understood by persons with disabilities and their families or by service providers as a benefit that will cover a wide array of assistive technology devices and services.

Criteria on payment decision making are frequently not well defined. There is no system operating on an national basis to transfer precedent-setting decisions within the various public programs in a timely way to other individuals, organizations, and agencies having an interest in protecting the right to assistive technology.

Despite oversight requirements, there has been only a limited effort at the federal and state levels to monitor and enforce the right to, or requirements for, expanding assistive technology access for children and adults with disabilities. The result is weak and variable state implementation of federal policies and requirements.

Table 2

RECENT PUBLIC POLICY DEVELOPMENTS

Year	Action	Approach
1986	Amendments to Rehabilitation Act: added definition, expanded program requirements	Clarified and expanded program benefit of major public program
1986	Amendment to Rehabilitation Act, Section 508: new guidelines for federal procurement of computers	Changed procurement practices; impacted manufacturers' expectation of accessible design standards at lower cost
1986	Early intervention: created new entitlement, expanded program benefits	Established major public program
1986	Social Security Amendments	Tax sheltering of income to purchase technology
1987	Amendments to Developmental Disabilities Act: expanded program requirements	New priority within existing public program
1987	Older Americans Act Amendments: created new provision of assistive technology within existing program; defined assistive technology	Expanded program benefit
1988	Medicaid Amendments: clarified funding options and mandates	Clarified and expanded existing program benefit
1988	Tech Act: created statewide systems of technology assistance	Created new funding, new public program

Table 2

RECENT PUBLIC POLICY DEVELOPMENTS
(continued)

Year	Action	Approach
1988	New Telecommunications Access	Established new Telecommunications Law Device for individuals who are Deaf (TDD) access requirement within federal agencies
1990	ADA: employment, transportation, public accommodations, telecommunications	New access requirements of private sector; access technology by expanding concept of civil rights
1990	ADA Tax Credit for Small Businesses	Created tax incentives to expand access to assistive technology
1990	Decoder Circuitry Act: designed standard for televisions	Required new manufacturer standard for access
1990	Policy Letter Special Education	Clarified rights under existing major public program
1990	Policy Memo Rehabilitation	Clarified rights under existing major public program
1990	Amendment to IDEA: added definitions of assistive technology devices and services	Clarified rights under existing public program
1991	Amendment to Part H of IDEA: added definitions of assistive technology services and devices	Clarified rights under existing public program
1991	Policy Letter Special Education	Clarified right to take technology home from school

With passage of the ADA, there are now affirmative obligations on business and public entities to provide access to persons with disabilities. The Act defines requirements of reasonable accommodation to include the purchase or adaptation of aids and equipment. However, the nexus between civil rights coverage and access to assistive technology as an affirmative obligation on government contractors, business and industry, and the providers of public services has been a subject of limited inquiry.

Finding 4: Health Care Funding of Assistive Technology

Typically, reimbursement for assistive technology devices and services in the health care system conforms to the requirements of the funding source, not to the functional needs of individuals with disabilities.

Health care coverage for assistive technology devices and services remains unpredictable. Success depends greatly on one's ability to document medical necessity, indicating how functional limitation is attributable to an injury or illness, describing the assistive technology as a prosthesis that replaces the function of a body part, and demonstrating the cost-effectiveness of the assistive technology to the insurer by reducing future health care costs. By the time funders decide who pays for the device, it may no longer be appropriate to meet the need of the individual.

Most private insurance plans do not explicitly include or exclude coverage of assistive technology in their benefits; therefore, consumers do not know to what they are entitled. Health insurance has traditionally financed assistive devices that were medically necessary. These criteria, however, do not provide an adequate basis for determining the type of assistive technology that is appropriate.

Payment decision-making criteria are not well defined at policy levels, making it more difficult for clinical and claims' representatives at the case level to judge with confidence the appropriateness of given alternatives. In the absence of criteria for appropriate assistive technology, insurers have relied on arbitrarily excluding major categories of assistive technology (such as augmentative communication devices) to achieve cost-containment goals. Dr. Judy Montgomery of the Fountain Valley School District in California describes the magnitude of this problem:

Schools cannot carry the full responsibility for assistive technology, as a child's world is much larger than his or her school hours five days a week. This is where health insurance, both public and private, has failed to take responsibility. We have been unable to get assistance in purchasing needed technology for children in over

95 percent of our attempts in my local school district. The response is always the same—the device is not keeping the child alive, therefore it is not a medical necessity. What about quality of life, freedom of speech, freedom to worship, the exercise of political debate and access to one's elected representative? These rights are all denied the person who cannot receive assistive technology in any place other than the school building. It is vitally important for learning, we would all agree, but it is just as vital in the rest of the child's life. A recent denial of a device from a private insurance company declared the communication unit a "convenience." How many of us consider our ability to talk as a convenience?

The medical necessity requirement for funding by both private and public insurers of assistive technology must be altered to a standard that responds to the need to improve function for enhanced productivity and independence. Kristin Siegesmund, an attorney with Legal Advocacy for Persons with Developmental Disabilities in Minneapolis, Minnesota, explained the futility of consumer attempts to resolve the disputes that arise:

State Medical Assistance Programs or Medicaid have no specific guidelines for the type or amount of documentation needed for any of their criteria except the criteria of medical necessity. This allows the state to keep asking for additional information. The (person's) right to appeal a denial of service is not activated as there has been no denial. The communication has all been between the professionals, the supplier, and the medical assistance program. The (person) is often left in the dark during the prior authorization process. The vast majority of controversies involve disputes over whether a "life skill" is really a medical necessity.

The Council's analysis of nine states confirms the significance of this restrictive eligibility problem. This analysis found that all states identified a restrictive definition of the "medical" necessity as a barrier to the financing of assistive technology by all the leading technology funding sources, including Early and Periodic Screening, Diagnosis and Treatment (EPSDT), Medicaid, and Medicare. Funding agency personnel need to be educated on the benefits of assistive technology, both functionally and fiscally.

Finding 5: Coordination of Services and Funding

Information presented to the Council strongly indicates a continued and widespread lack of cooperation and coordination between and within various funding agencies.

During the life span of an individual with severe disabilities, he or she may be considered eligible for, and benefit from, more than 20 federal programs (see Table 3). Each public program has congressionally authorized eligibility and scope of service requirements. The level of funding varies from hundreds of thousands to hundreds of millions of dollars to be expended on a range of services for eligible populations. No public program guarantees an absolute right to assistive technology. Qualifiers include limitations on eligibility, availability of resources, status as payers of last resort, and agreement that the standard of need has been met.

A prime example of arbitrary limitations was substantiated by the Council's analysis of Medicaid as a financing source for assistive technology devices and related services in nine states. A majority of states reported that funding caps were imposed on the amount of coverage for assistive technology devices and related services. As one witness at the Los Angeles, California, public forum testified,

There is an abundance of inconsistencies between and within various agencies, leading to an extraordinary amount of confusion and frustration for individuals with disabilities and their families.

The passage of the Tech Act was a response by Congress to the widespread lack of cooperation and coordination between and within various funding agencies. The Tech Act seeks to stimulate interagency cooperation between funding agencies with grants to states "to develop consumer-responsive statewide systems of technology-related assistance."

Despite funding under the Tech Act, study responses from selected states document the continuing problems associated with improving interagency cooperation in the funding of assistive technology for children and adults with disabilities (see Supplementary Reading, Report 3).

There are no incentives in current federal policy either to encourage the pooling of resources from multiple public agencies or to stimulate interagency agreements to improve and increase coordination between agencies. For the potential technology user with a disability, there is no single point of contact to help navigate the funding maze.

Table 3

PUBLIC PROGRAMS WITH A POTENTIAL TO FUND TECHNOLOGY ACCESS

- Early Intervention – IDEA (Part H)
 - Special Education – IDEA (Part B)
 - Medicaid – Mandated and Optional Services
 - Early and Periodic Screening Diagnosis and Treatment
 - Intermediate Care Facilities for Persons with Mental Retardation and Related Conditions
 - Medicaid 2176 Home and Community Based Waivers
 - "Katie Beckett" Eligibility (TEFRA 134 Option)
 - Community Supported Living Arrangements
 - Vocational Rehabilitation – State Grants
 - Independent Living Services
 - Supported Employment
 - Social Security – Supplemental Security Income
 - Social Security – Social Security Disability Insurance
 - Work Incentive Provision of Social Security
 - Developmental Disabilities Programs
 - Vocational Education
 - State Operated Programs (89-313)
 - Child Care Development Block Grant
 - Older Americans Act
 - Medicare
 - Maternal and Child Health Block Grant – Title V
 - Veterans Administration programs
 - Technology Act
-

From the perspective of a potential user, there is a compelling need for clear application and documentation guidelines, requirements and criteria for eligibility, coordination of benefits, and appeals procedures. Each of these key points in the process of access to public funds for assistive technology needs to be expressly defined with clear timelines. Without such guidelines and timelines, funding decisions remain unnecessarily arbitrary, inconsistent, and slow. Witnesses from all three public forums shared their frustration that even after favorable funding decisions in public programs (education, vocational rehabilitation, and Medicaid) are made, there are long delays as a result of cumbersome procurement practices before they actually gain access to appropriate assistive technology devices.

Finding 6: Monitoring the Use of Assistive Technology

There is no national database or legislative mandate that calls for the routine collection of data regarding the use of financing of assistive technology through federal programs available to individuals with disabilities. There is no agreed-upon classification system at the federal or state level to distinguish different types of technology-related assistance for the collection and analysis of data on service delivery and funding patterns and trends.

Any monitoring of the use of assistive technology or the financing of assistive technology through federal agencies is currently nonexistent. With the exception of the Prosthetic and Sensory Aids Program of the Department of Veterans Affairs, there is a marked lack of information on the magnitude of federal programs that finance assistive technology, including the extent to which federal programs are currently financing assistive technology, the number of dollars being spent, and the quantities and costs of the various assistive technology devices and services. A concerted effort is needed to improve data collection methods and systems.

If such a concerted effort is made, a classification system must be established at the federal and state levels to distinguish different types of technology-related assistance for a collection and analysis of data on service delivery and funding patterns and trends. Without the acceptance of such a classification system across public funding streams, it will be impossible to analyze the impact of current expenditures from a cost-benefit perspective and to compare individual state experiences in implementing federal requirements.

Finding 7: Consumer Choice and Control

Emphasis on individual choice and control of assistive technology services and funding is conspicuously lacking in most programs.

Meaningful participation by people with disabilities regarding the identification of appropriate technology and individualized program planning is a concept in its infancy. There are few mechanisms in public and private programs for allowing individual users' desires to be taken into account at all points in the life span, from infancy to maturity.

Individuals with disabilities and, when appropriate, their families and advocates, would like to play a more pivotal role in decision making about technology choices responding to individualized needs. Funding of technology is most often based on needs of persons with disabilities as perceived by professionals or program administrators. Many witnesses at all three public

forums testified about the reluctance to allow consumers an opportunity to be partners.

The Tech Act mandates the implementation of consumer-responsive systems of service delivery. Several states funded under the Act are supporting efforts at peer mentoring to improve potential technology users' knowledge and understanding of assistive technology access and funding.

There is a critical need to expand education and training opportunities for persons with disabilities as well as for professionals (teachers, therapists, rehabilitation counselors, etc.) on how to translate the usefulness of appropriate technology to individual learning goals and objectives.

In the Council's nine-state analysis, it became evident that the problem of uninformed professionals is nationwide in scope and extends to all major funding sources. All states indicated that "lack of informed professionals" was a significant barrier to effective financing of assistive technology.

Because the ultimate users of technology typically are dependent on others to purchase appropriate devices and services, the issue of individual choice and control of assistive technology access and funding is one of the most critical to the Council. Over and over, witnesses shared their frustration about lack of choice as a result of exclusive public funding contracts with vendors who failed to offer or lacked knowledge of the full range of equipment options.

The problems associated with limited choice are further compounded by the lack of equipment available for rent, loan, or trial through public agencies. Potential users of assistive technology and their families would like the opportunity to try out devices to determine usefulness before an item is purchased. Katherine Huggins of Pepperell, Massachusetts, stressed the importance of having choices and the critical role that time plays, especially in the lives of developing children:

The issue of allowing Matt the opportunity to communicate has been an enormous challenge. As a parent and consumer, I was unable to find a place where we could do some comparison shopping. I wanted desperately to communicate with my son. I was aware of different devices on the market. We never had the opportunity to try different devices. Our experience was that each clinic had its own bias toward a particular device or had knowledge limited to a single device. The insurance route was started but I quickly became discouraged. I was unwilling to let what I felt was critical time pass in my son's development. My son needed to communicate. Three

years is a long time in a child's development to go without being able to meaningfully communicate his wants, needs, and feelings.

Finding 8: Funding for Support Services

Once individuals with disabilities obtain needed technology, little attention and funding support are given to training and ongoing assistance and maintenance needed to maximize benefits to the user.

With the passage of the Tech Act, Congress recognized the distinction between access to assistive devices and assistive technology services. Individuals with disabilities may need assistance in the selection, acquisition, or use of an assistive technology device. The definition for assistive technology services incorporated in the Tech Act includes the following:

- selecting, designing, fitting, customizing, adapting, maintaining, repairing, or replacing assistive technology devices;
- coordinating and using other therapies, interventions, or services with assistive technology devices, such as those associated with existing education and rehabilitation plans and programs; and
- training and technical assistance for an individual with disabilities.

Although this definition of assistive technology services has now been added to the IDEA and the Developmental Disabilities Act and is being considered for amendment as part of the reauthorization of the Rehabilitation Act, funding availability for this broader concept of technology access and support remains limited and is inconsistent from most public agencies and the health care system.

A parallel concern to lack of funding of support services voiced by witnesses at all three public forums is the continued practice of funding only one-time technology needs of an individual with disabilities. As stated by Alexandra Enders,

Little recognition has been given to the ongoing nature of a disabled person's need for technological support. Assistive technology services frequently do not fit well into our traditional delivery systems geared to cure, closure, aging out, or some other fixed end point. Significant problems, particularly related to funding, occur for example when transitioning between systems such as special education vocational rehabilitation, or when the need for ongoing

maintenance and replacement of the equipment occurs. Equipment was, and still is, often viewed as a one-shot event, an attitude that is reflected in the policies of many of the sources for funding assistive technology. (Enders, 1990)

Analysis of information from the nine-state sample and the public forum records also indicates that maintenance and repair services can be a serious problem (see Supplementary Reading, Report 3, "Selected State Perspectives"). Technology users must be able to obtain parts for their device(s), locate skilled repair workers, devise a way to function while the device is being repaired, and search for others to assist the financing of these activities. Functioning without a particular device or piece of equipment while it is being repaired may leave an individual with disabilities without mobility or a means of communication. Yet public agencies and the health care system have not responded to this critical problem.

Finding 9: Gaps in Access for Specific Populations

Significant groups of individuals with disabilities remain unserved or underserved by existing public and private programs that have financing available for assistive technology.

Assistive technology devices and services are not readily available to culturally diverse populations, families in rural areas, older Americans, and individuals in long-term care facilities.

For minorities and culturally diverse populations, the absence of culturally relevant information about assistive technology devices and services is an additional obstacle to obtaining any information or financing for assistive technology. Language barriers, lack of informed medical advisors, and little exposure to other individuals using assistive technology are some of the contributing factors. For individuals living in rural areas, the problem is compounded by inadequate service delivery systems, lack of public transportation, and the limited reach of vendors who are often located in metropolitan areas.

Many devices that are taken for granted by the general public are unavailable to individuals of cultural diversity. Consider the statement by Jean Wright from St. Paul, Minnesota, who testified before the Council:

As a child I attended regular public schools, although I was legally blind. My education during those early years was a struggle. I could not read, I could not see blackboards unless I was very close, and my handwriting speed was slow so I could not take notes.

Despite these barriers in grade school and in college, I managed to graduate with a C+ average. When I was accepted at Western Michigan University to do my graduate work in Rehabilitation Teaching for the Adult Blind, I graduated in 18 months with a B+ average. The difference in my grade point average was due to my discovery that you could use a tape recorder to take notes, hand-held telescopic aids could help you see blackboards, and a skilled optometrist could prescribe glasses that would clear up blurred vision when studying print materials. These options were not available to me sooner because (1) I lived in the South, (2) I was black, and (3) I was poor.

While the direction of national policy is away from placement and retention of persons with disabilities in institutions and other long-term care facilities, it is the case that many Americans with disabilities continue to be housed in such facilities. Information presented to the Council confirms that persons with multiple and severe disabilities in long-term care facilities are also among those who do not benefit from assistive technology. These individuals are least frequently targeted for movement from inappropriate nursing facility placements into community settings. Several witnesses concurred on the following observations:

1. The equipment being used in facilities is often in extremely poor condition.
2. There are significant disparities in the use of assistive technology in small versus large institutional settings.
3. The lack of understanding of the difference that assistive technology devices can make and lack of knowledge of the many options that are readily available to individuals with disabilities are serious problems in the existing service delivery systems for individuals residing in state facilities.
4. There is a lack of clarity under state Medicaid plans defining who is responsible for payment for assistive technology—the facility through its daily rate or the state Medicaid agency as an extraordinary expense.

The Council had the privilege of meeting and speaking with Anna Clark from Springfield, Illinois. Anna was born with cerebral palsy. When she was nine years old, she took a ride with her dad. He dropped her off at a large brick building and said he would pick her up later. But he never did. The little girl never again saw her family or experienced home life. For most of her life,

Anna lived in state institutions or nursing homes. She never received an education, and she never had a place to call her own. In the summer of 1989, United Cerebral Palsy of Land of Lincoln rented a house for Anna and hired a skills trainer to assist her and her housemate in learning to live independently. Now, with the assistance of her power wheelchair, her augmentative communication device, and numerous environmental controls, Anna is employed and paying taxes. She also keeps a busy schedule of ice cream socials, baseball games, church meetings, and Bible study classes, and manages her own house.

This dramatic change in Anna's life was made possible through an innovative project of the Illinois Planning Council on Developmental Disabilities called SPICE (Supported Placement in Integrated Community Environments). A statewide study identified Anna as among the thousands of adults with developmental disabilities who were confined to nursing homes when they could actually be living a "normal" life in their own homes with supports that would include the use of assistive technology. There are tens of thousands of individuals living in state facilities, like Anna, who could greatly benefit from assistive technology, given the opportunity.

The Council had the opportunity to hear from several experts on issues related to aging. More than 80 federal and many state and local programs offer some level of assistance for long-term care and rehabilitation needs (U.S. House of Representatives, 1986; U.S. Government Accounting Office, 1989; Price and O'Shaughnessy, 1990). However, program objectives, definitions of disability, eligibility criteria, and reimbursement schemes vary widely and interact unevenly across programs. Here again, existing public policies provide limited incentives for a coordinated continuum of services. The experts acknowledged that for older Americans with disabilities living at home, assistive technology represents an untapped resource. The Council's nine-state analysis conclusively supports this finding. Despite the availability of many programs for older Americans, 87 percent of these programs were described by states as somewhat effective or ineffective in the financing of assistive technology devices and related services.

Finding 10: Availability of Funding Resources

There is no system, public or private, uniquely devoted to the funding and financing of assistive technology to respond to the full range of unmet needs. At best, assistive technology and related services funding are part of a menu of choices that must be made in the allocation of limited resources in multiple public and private service delivery systems.

Alexandra Enders explains why it is so difficult to integrate technology into human services:

If services to people with disabilities can be viewed as a patchwork quilt of woven cloth, it becomes easier to see why it is so difficult to integrate technology into human services. A service like early intervention or supported employment can be viewed as a square of the quilt, one that had been overlooked and now is being tacked on. The challenge is how to stitch the piece into the quilt, and much emphasis was placed on the joining "needlework." Technology is, however, not just another square that needs to be stitched in (nor are the other support services). To be effective, technology must be viewed as a thread that needs to be woven throughout the entire patchwork quilt; it needs to be integrated. (Enders, 1990)

Nonetheless, the chronic federal underfunding of public programs that serve individuals with disabilities is an additional significant barrier to securing financing for assistive technology devices and related services. The problem of inadequate federal funding includes several levels—poor predictability, inefficient use of available funding, and inadequate dollar allocations.

As a witness at the public forum in Los Angeles stated,

There is a lack of funds across all funding sources, public and private. Even those systems that work better than others are subject to the limits of their funding supply, and claims that may otherwise be eligible for funding are often rejected because of a lack of funds. Access to assistive technology should not be determined by the availability of resources.

A parallel problem identified is that assistive technology is widely perceived by the general public as expensive. Resource concerns are a key factor in the reluctance of many federal and state level programs to purchase customized technology. A lack of knowledge about the benefits of assistive technology by individuals with disabilities and their families diminishes their ability to challenge these decisions. Witnesses at all three public forums voiced concerns that arbitrary limits on funding are imposed in the name of cost-containment. Limitations include dollar caps, "last payer" requirements, limitations in amount, scope, duration, location, and purpose, and lack of coverage of customization of a device to meet an individual's specific needs.

The allocation of a limited resource base in multiple public and private service delivery systems is a barrier to access of assistive technology that is further compounded by inconsistent decision making, as described earlier in

Finding 2. The research of the Council documents that access to appropriate assistive technology funded by public programs will depend on nine significant factors:

1. the degree to which services and funding are coordinated between programs and are consistent from locality to locality and from state to state;
2. the degree of consistency in determining eligibility;
3. the extent of gaps in eligibility for services under public and nonpublic programs;
4. the degree to which maintenance and repair of devices are difficult or costly;
5. the degree to which consumers are sufficiently informed about their funding options and aware of the latest technology innovations;
6. the degree to which consumers are effectively involved in service delivery;
7. the extent of available and adequately trained therapists and rehabilitation providers;
8. the extent of available funds, even in entitlement programs; and
9. the degree to which persons with disabilities and their families are supported in pursuing their legal rights and entitlements.

Finding 11: Impact and Benefits of Assistive Technology

Preliminary study results from a sample of persons with disabilities in seven states from four age groups document the impact and benefits as compared to costs of different kinds of technology-related assistance. Expanded documentation of the benefits of use of assistive technology should favorably influence resource allocation decisions at the national, state, and local levels.

Other than anecdotal information, there has not been available research data to substantiate the impact and benefits of use of assistive technology by children and adults with disabilities. As part of this study, the Council, with the assistance of seven states funded under the Tech Act, studied 106 individuals with disabilities to evaluate the costs and benefits associated with

the use of different kinds of technology-related assistance. The individuals were asked to complete a written questionnaire and then participate in a telephone interview. They were from four age groups: infants and toddlers; school-age children; working-age individuals; and senior citizens. The questions were structured to gather information about the impact and benefits to the individual of assistive technology in terms of health status, independence, productivity, integration, and prevention of secondary disabilities.

The majority of infants with disabilities benefited by having fewer health problems because of assistive technology. In addition, 44 percent of the families were able to use child care or decrease the amount of parental care because of assistive technology.

Almost three-quarters of school-age children were able to remain in a regular classroom, and 45 percent were able to reduce their use of school-related services.

Sixty-two percent of working-age persons were able to reduce dependence on family members, 58 percent were able to reduce dependence on paid assistance, and 37 percent were able to increase earnings.

Among elderly persons, 80 percent were able to reduce dependence on others, half were able to reduce dependence on paid persons, and half were able to avoid entering a nursing home.

Ninety-six respondents identified specific types of assistive technology that would make a difference in their lives (see Table 4, "Equipment Identified as Making a Significant Difference"). The average cost of this equipment was \$5,645; respondents indicated that they would be willing to pay an average of \$1,421 for this equipment.

Among the benefits attributable to assistive technology were time savings in activities of daily living (ADLs) and household chores; time savings in reading, writing, and studying; more time spent on community participation; and monetary savings. Sixty-four percent of those reporting time savings reported reduction in ADL time; 48 percent reported less time reading, writing, studying, or learning; and 43 percent reported less time on household chores. The average time saved in a week was 19.8 hours for ADLs, 16 hours for reading, writing, studying, or learning; and 15 hours for household chores. This time saving allowed persons with disabilities to engage in an average of 15 extra hours of recreation and more than 10 hours of extra time with the family. Sixty-six percent of respondents reported that they were able to visit family and

friends an additional 10 visits per month, and everyone reported making new friends and participating more in community activities.

Almost one-third of the respondents indicated that their family saved money, averaging \$1,110 in the previous month. At the same time, one-quarter of the respondents indicated that they experienced additional equipment-related expenses, averaging approximately \$287 per month. Nevertheless, almost one-quarter of the respondents reported that their family members could work an average of an additional 25 hours each week, although only 5 percent reported that they earned more money. For those reporting additional earnings, the average was approximately \$249 each week.

Of the 42 respondents who reported having paid jobs, 92 percent reported that the assistive technology enabled them to work faster or better, 83 percent indicated that they earned more money, 81 percent reported working more hours, and 67 percent reported that the equipment has enabled them to obtain employment. Fifteen percent indicated that the equipment has enabled them to keep their jobs. Equipment also enabled 38 percent to pursue additional schooling.

From a societal point of view, equipment was reported to have enabled 6 out of 36 Social Security Disability Insurance (SSDI) beneficiaries to reduce their SSDI payments an average of \$572 per month, while 5 out of 31 Supplemental Security Insurance (SSI) recipients reported a reduction in SSI payments, averaging \$261 per month because of the use of assistive technology. Of the 16 persons who reported reductions in public transfer payments, the total was \$5,240 per month or an average of \$327 per person. A smaller number reported a reduction in public expenses for social services as a result of their use of assistive technology.

When asked to estimate the impact of equipment on their quality of life on a scale from 1 to 10, respondents reported that without the equipment their quality of life was around 3, while their quality of life jumped to approximately 8.4 points with the equipment.

For a discussion of the benefit-cost study design and results, see Supplementary Reading, Report 7. These preliminary results substantiate the need to expand our knowledge about the impact and benefits of assistive technology in the lives of people with disabilities. Policymakers, funding decision makers, and individuals with disabilities and their families at national, state, and local levels need this kind of research data to justify and increase the allocation of limited resources for the purchase of assistive technology devices and services.

Table 4

EQUIPMENT IDENTIFIED AS MAKING A SIGNIFICANT DIFFERENCE

	Frequency	Cost		
		Average	Minimum	Maximum
Is there equipment to make a difference?	96			
Cost of such equipment	77	\$5,645	\$80	\$40,000
Willingness to pay for such equipment	60	\$1,421	\$0	\$15,000

Description of Other Equipment Identified as Making a Significant Difference

All-terrain Vehicle	Ball Bearing Feeder
Bathroom Modifications (5)	Bicycle
Button Hooker	Car Chair Carrier
Chair to Help Stand	Closed Caption Unit
Communication Board (2)	Communication Device (2)
Computer (8)	Computer Peripherals (5)
Computer Software (3)	Cushion and Manual Chair
Customized Walker (2)	Device to Open Jars
Document Scanner	Driver Equipment (3)
Easy Pivot	Transfer
Electric Wheelchair (4)	Environmental Control Device (2)
Feeding Machine	Filing System
Functional Electrical Stimulator	Hearing Device (2)
Home Modifications (9)	Home Office Work Station
Hydraulic Lift (4)	IBM Speech Program
Lift/Transfer Equipment	Page Turner
Power Wheelchair (5)	Public Accommodations
Robot	Shower Adaptor Equipment (4)
Sort Scooter	Speech Communication Board, Switch
Stair Climber	Talking Books Player (2)
Three-wheeler	Van – Modified (7)
Van Lift (6)	Universal Gym
Voice/Audio Outputs	Exercycle

Finding 12: Funding Solutions

There is no one answer to the complex problem of assistive technology funding for persons with disabilities of all ages nationwide. The Council has identified seven distinct, successful approaches or strategies that can be refined and expanded to enhance funding access to assistive technology for Americans with disabilities.

The Council's research has identified seven successful approaches to the financing of assistive technology devices and related services. These seven approaches are:

1. Refining, refocusing, and expanding public programs;
2. Creating incentives for the development and replication of alternative financing mechanisms with public and private partnerships;
3. Refining and refocusing the health-care system, including public and private insurance;
4. Creating tax incentives for improved technology access;
5. Refining and expanding the nexus of civil rights and technology access;
6. Mandating the concepts of universal design; and
7. Capitalizing on the important innovations in telecommunications and changing public policy.

Each of these approaches is discussed below.

1. Refining, Refocusing, and Expanding Public Programs

Federal assistance to persons with disabilities for the financing of assistive technology and related services is available through a range of federally funded programs. In the report, "Analysis of Policy and Practice In Federal Programs," the Council selected and analyzed 26 federal programs for promotion and identification of federal policies that facilitate payment for assistive technology, identification of policies or practices that impede assistive technology financing, and discovery of ways to eliminate barriers to financing (see Supplementary Reading, Report 2). The programs described in this report reflect a broad spectrum of public policy goals, magnitude, target populations, eligibility requirements, mechanisms for financing, and state flexibility. This

report is not intended to be a complete compendium of federal assistance programs for individuals with disabilities. However, it provides the following useful information:

- An overview of (1) the ways federal programs finance assistive technology, (2) the flexibility states have in implementing programs, (3) features that act as facilitators in the financing of assistive technology, and (4) features that act as barriers;
- A descriptive profile of each covered program; and
- A discussion of the implications for federal action to eliminate inappropriate barriers and to enhance access to the financing of assistive technology for individuals with disabilities.

The Council also documented 17 recent changes in public policy that have resulted in improved access to assistive technology. Table 2 summarizes the range of approaches that have proved effective to change policy and enhance technology access.

2. Creating Incentives for the Development and Replication of Alternative Financing Mechanisms with Public and Private Partnerships

A variety of alternative funding programs exist for the purchase of assistive technology equipment and devices. These funding sources are "alternative" in that they are generally smaller, more targeted funding sources available to people with disabilities who typically are denied funding by the more traditional funding sources. Eligibility and program formats vary widely, but in most cases, these funding sources have less stringent eligibility requirements and certifications than the traditional funding sources.

The Council analyzed 18 alternative funding programs, representing a wide variety of policies and objectives (see Supplementary Reading, Report 5). Many are "payers of last resort" – places to turn when all other traditional private and public sources have been pursued and adequate funding has not been obtained for the desired piece of equipment. With almost every program, there are more applications received than there are funds available. Particularly for those programs with liberal eligibility requirements and the most flexible terms, the waiting lists of approved applications are long.

These alternative funding programs are operated and supported by state governments, local and national agencies that serve people with disabilities, manufacturers of assistive technology devices, manufacturers of equipment

that can be adapted for use by people with disabilities, and one federal government employer. They include a variety of loan programs, manufacturers' discounts, reimbursements for adaptations made to equipment, and outright grants for the purchase of assistive technology devices and accommodations. Some funds are available only for the purchase of specific types of equipment, while other programs will fund virtually any type of assistive technology.

These alternative programs receive funding from a variety of sources—state or federal government appropriations, federal grants, private corporate contributions, or manufacturer support. While their specific goals and target audiences may differ, each program has a desire to make assistive technology more available and accessible to people with disabilities. The majority of applications of these alternative funding sources are user-friendly, although many require an extensive credit evaluation. Most of the alternative funding sources offer a variety of support services in addition to funding, including information about assistive technology options, needs assessment, local resources, training, education, and information for a wide range of audiences, with and without disabilities (see Supplementary Reading, Report 5).

3. Refining and Refocusing the Health-Care System, Including Public and Private Insurance

Private health insurance is funded primarily through voluntary annual contracts, mostly with employers, to cover the health-related needs of employees and their dependents. This fact, and the fact that private insurance historically has been developed by hospitals to finance the care they can provide, has tended to reinforce an acute care orientation to health insurance in the United States. This acute care orientation, which has been institutionalized through the role of physicians as gatekeepers in the health care system, has tended to slight prevention and rehabilitation, even though almost half of the U.S. population has chronic health conditions. One consequence of the acute care orientation of health insurance is the restrictive funding for assistive technology. Removing obstacles to financing assistive technology is part of the larger challenge of redefining health from the absence of disease and impairment to the management of chronic conditions in order to maximize functional capacity to participate as fully as possible in society.

In a voluntary health insurance marketplace, with few if any requirements on the employer or insurer to provide a comprehensive health insurance benefit package, it is difficult to expand private insurance coverage for assistive technology without public mandates. In this study, the National Council on Disability has explored various strategies for expanding coverage of assistive technology through private health insurance. In addition, the Council

has examined the funding barriers and facilitators in the public health insurance programs to see how they can be utilized to promote access to assistive technology.

The major focus of this analysis has been on the concept of medical necessity which the NCD believes should be broadened to include durable medical equipment, prostheses, and orthotic devices that can promote health, safety, and activities of daily living (ADLs) (see Supplementary Reading, Report 4).

4. Creating Tax Incentives for Improved Technology Access

No study of financing options for assistive technology devices and services would be complete without an examination of the subsidies offered by the tax system to individual purchasers of technology and their families. The notion that tax benefits, such as deductibility, represent a government subsidy may seem novel at first. Yet for those individuals who can reduce their out-of-pocket costs through effective use of the tax law, the end result is similar to what would be achieved with a government check for the same amount as the savings.

In the analysis, "Federal Income Tax Law and Assistive Technology Financing," the Council focuses on selected tax law provisions bearing upon assistive technology. This section discusses the legal and factual issues surrounding successful utilization of these provisions. Finally, it suggests reforms that could either materially enhance the ability of many persons to secure the technology they need or provide incentives to business to accomplish similar objectives.

As a source of subsidization for the self-funding of technology, the tax system offers opportunities of great magnitude to individuals with disabilities who can personally finance the up-front costs. Unfortunately, this potential for reducing the cost of technology for the consumer remains surprisingly unknown to assistive technology providers, advocates, and users.

5. Refining and Expanding the Nexus of Civil Rights and Technology Access

The Americans with Disabilities Act (ADA) is the most expansive civil rights legislation enacted into law in the past 25 years. It originated in recommendations made by the Council. Patterned after the 1964 Civil Rights Act, the ADA will have many similar historic effects. First and foremost, it will confer upon a full 43 million Americans with physical, sensory, or cognitive

disabilities what is their birthright: all of the rights, privileges, and responsibilities that go along with being first-class citizens of our nation.

For the ADA to be truly effective in striking such a powerful blow for increased freedom and independence for all Americans with disabilities, assistive technology must become a major force behind its full implementation. Now that it is enacted, the ADA will extend full civil rights and equal opportunities to people with disabilities in both the public and private sectors. Specifically, it will prohibit discrimination on the basis of a disability in employment, transportation access, all state and local government services, public accommodations, and telecommunications.

The link between equal opportunity and access to assistive technology is strong. The benefits of access to a sip-'n'-puff electric wheelchair, an augmentative communication device, or an Optacon can make dramatic changes in the individual lives of people with disabilities. In order for the promise of the ADA to become reality, assistive technology must be better understood as a means to achieve reasonable accommodation as a part of civil rights protections for Americans with disabilities.

Indeed, access to assistive technology must be seen as a fundamental right in itself. This second-generation paradigm shift will occur as people with disabilities seek the information, tools, and responsibility needed to better define what assistive technology is and how best it can facilitate equal opportunity and access. As with ADA and civil rights, people with disabilities and parents of children with disabilities must become much more insistent on what they expect from assistive technology as a means to achieve fundamental rights (Williams, 1990).

6. Mandating the Concepts of Universal Design

The principal of "universal design" is better understood as accessible or inclusive design. The fundamental goal of this design principle is always to examine the broadest possible application of the design objective for the broadest range of individuals. Design concepts must be developed with an understanding of how individuals function in using a product, service, or physical environment. When ease of use and convenience for the broadest possible range of individuals is sought, the potential pool of users expands, marketability multiplies, and the cost is contained. Profitability can be maintained and public expenditures can be stabilized or diminished.

Congress recognized the importance of the universal design principle as early as 1986, when Section 508 was added to the Rehabilitation Act Amendments (P.L. 99-506). Section 508, Electronic Equipment Accessibility,

mandates the adoption of guidelines for accessibility in federal and state procurement practices in terms of electronic office equipment. According to the U.S. General Services Administration (GSA), the intent of this provision is:

- To ensure that people with disabilities can access and use the same databases and application programs as other people.
- To ensure that people with disabilities shall be supported in manipulating data and related information resources to attain equivalent end results as other people.
- To ensure that when electronic office equipment is part of a telecommunications system, people with disability-related needs are provided the capacity to communicate with other users of the system (GSA, 1990).

Section 508 of the Rehabilitation Act has enormous potential to effect change in the marketplace. It has the potential to impact the design of equipment for a broad range of abilities. In addition, the federal government has new guidelines for functional performance to be accomplished by manufacturers. Because the government is the major purchaser of technology, the impact of this law has only begun to be realized. The federal government acts as a stimulus to industry, which must respond to its accessibility requirements. It is anticipated that as businesses and state governments implement accessible environments in response to the requirements of the ADA, efforts to develop accessible information systems will become even stronger (GSA, 1990).

The Council's report focuses on how design principles developed through an examination of the needs of individuals with functional limitations can increase accessibility and decrease the cost of financing specialized assistive technology. The report recognizes that a universal approach to technology cannot meet 100 percent of the needs of people with disabilities. Clearly, there will always be a need for a customized approach to satisfy particular technology needs. However, to the extent that accessibility to product, service, and environmental use can be incorporated in basic designs, there will be less need to dedicate additional funds for modifying or retrofitting goods and services. According to Sandra Parrino,

The Council sees many of the concepts and ideas as the next steps in addressing the civil rights of people with disabilities. In our global village, characterized by extraordinary diversity, it simply makes good sense to design our products, buildings, and communications

and information systems for a broad range of abilities. (Parrino, 1992)

7. Capitalizing on Important Innovations in Telecommunications and Changing Public Policy

Analysis of telecommunications access was not originally contemplated as a distinct aspect of this study on financing assistive technology for individuals with disabilities. However, as the study unfolded it became apparent that both technical and economic issues in this area must be addressed if assistive technology is to become an effective tool for information and network access and the integration of individuals with disabilities into educational environments, the workplace, and community life.

Telecommunications is the moving, storing, and manipulating of information by electronic means. It includes such items as telephones, telegraphs, radios, televisions, and cables as well as "enhanced services" such as electronic data exchanges, alarm and security systems, transaction and credit validation services, automated teller machines, data processing services, and audio and video text services, among many others. Telecommunication policy has become critically important to people with disabilities because of the changes in these areas that have propelled us as a society into an Information Age.

Individuals with disabilities are more at risk of social and physical isolation than most other groups. Telecommunication technologies are vehicles for preventing, reducing, or even eliminating that isolation. Additionally, telecommunications is becoming an essential component of how Americans work, do business, socialize, take care of basic needs, and engage in the political process. It is difficult to imagine how one might function in American society, or even survive, without telecommunications.

The explosion in the growth of telecommunications products and services offers opportunities as never before for all individuals. However, for many people with disabilities, access even to basic telephone service cannot be assumed. Many emerging telecommunications devices, products, and services are designed in a way that requires an ever greater number of functional abilities. Persons with disabilities will be excluded from access to the telecommunications infrastructure unless, through public policymaking and accommodation by the telecommunications industry, action is taken to build "electronic curb cuts" into the design of all products and services. It is essential that the needs of persons with disabilities be considered as these information age markets develop, to ensure that emerging systems are

accessible to, and usable and affordable by, persons with a full range of disabilities.

At issue is the potential for people with disabilities to take full advantage of emerging telecommunications technologies and products that would enable them to function and compete fully in society. Passage of the ADA was an important stride forward in this effort. However, with regard to telecommunications access by persons with disabilities, many fundamental issues remain to be addressed (World Institute on Disability, 1991).

The Council's analysis, "Equality of Access to Knowledge Through Telecommunications for All Individuals Including Those with Functional Limitations," provides background on the issue of telecommunications and people with disabilities, reviews the federal and state policies affecting telecommunications access, defines key terms, and discusses both federal and state level solutions for reform.

POLICY RECOMMENDATIONS

Passage of the Technology-related Assistance Act in 1988 (P.L. 100-407) has helped create a new set of expectations for individuals with disabilities. It is probable that in 1993, all 50 states will have begun to receive funding under this federal mandate for building capacity to respond to the diverse needs for assistive technology of children and adults with disabilities. The research conducted by the Council, including the three national public forums, generated more than 100 suggestions to improve funding access for assistive technology devices and services (see Supplementary Reading, Report 9).

The Council has thoroughly reviewed these suggestions as well as the research data generated from selected states and a random sampling of technology users with disabilities. A list of 16 recommendations has been refined from the larger list of suggestions by reviewing them according to the following criteria:

1. Magnitude of the problem addressed;
2. Potential scope of impact of proposed solution on identified barriers;
3. Potential for implementation;
4. Consistency with the principles of ADA to promote full citizenship for persons with disabilities; and
5. Potential to achieve cost-benefit results in quality of life for persons with disabilities and their families.

The policy recommendations are summarized as follows:

Recommendation 1

Mandate by statute the development of a national classification system for assistive technology devices and services and establish and collect uniform data sets across public programs.

Recommendation 2

Authorize the National Institute on Disability and Rehabilitation Research to publish by the end of each calendar year an Annual Report to the Congress on the status of funding of assistive technology devices and services for Americans with disabilities.

Recommendation 3

Establish the statutory authority for a federal Assistive Technology Interagency Coordination council to meet quarterly and be responsible for improved coordination of services and funding for assistive technology for Americans with disabilities.

Recommendation 4

Amend the state plan requirements in multiple statutes to require assurances and a planning process with timelines for expanding funding access to assistive technology for children and adults with disabilities.

Recommendation 5

Amend the individual program planning requirements in multiple statutes to provide notice to individuals with disabilities and their families of the right to assistive technology devices and services in response to individualized needs in a timely manner.

Recommendation 6

Add the complete definition of assistive technology devices and services adopted in the Tech Act to the following programs of the Social Security Act: Title II, Social Security Disability Insurance; Title V, Maternal and Child Health Block Grant; Title XVI, Supplemental Security Income; Title XVIII, Medicare; and Title XIX, Medicaid.

Recommendation 7

Reauthorize the Tech Act for an additional three years and strengthen opportunities for interagency coordination, systems change, and consumer choice and control.

Recommendation 8

Establish Assistive Technology Demonstration and Recycling Centers nationwide in the capital city of each state and in the top 50 Standard Metropolitan Statistical Areas to be operated by existing Centers For Independent Living or other community-based organizations that are consumer controlled and directed to enhance consumer choice and control of assistive technology services and funding.

Recommendation 9

Authorize the use of the Social Security Trust Fund as a financing source for purchasing assistive technology that enhances the capacity to work through an Individualized Employment Account (IEA).

Recommendation 10

Establish a Technology Watch program patterned after NCD's current ADA Watch activities to monitor compliance with enforcement of federal rights to or requirements for expanding technology access for children and adults with disabilities.

Recommendation 11

Authorize by statute the establishment of a National Center on Assistive Technology Legal Advocacy to specialize in funding issues.

Recommendation 12

Develop statutory authority that requires private health insurers to apply medical necessity standards to durable medical equipment, prostheses, and orthotics that enhance function in activities related to health, safety, and Activities of Daily Living (ADLs).

Recommendation 13

Create a comprehensive set of fiscal incentives encouraging private industry to invest in the production, marketing, and distribution of assistive technology to benefit Americans with disabilities.

Recommendation 14

Amend Section 162 of the Internal Revenue Code to allow taxpayers with disabilities who do not itemize the option of claiming assistive technology expenses as above-the-line adjustments to income. Request the Department of the Treasury to develop a cohesive set of tax policies on assistive technology for persons with disabilities that clarifies national values and goals as articulated in the ADA and the Tech Act.

Recommendation 15

Authorize by statute universal product design guidelines for application in the manufacture of electronic equipment and other products to enhance accessibility by individuals with disabilities.

Recommendation 16

Amend the Communications Act of 1934 to establish and implement a national policy of available, affordable, and accessible telecommunication services to Americans with disabilities.

Table 5, "Assistive Technology Funding Access: System Reform Options," on page 65 summarizes the Council's system reform options, which, when collectively implemented, will provide a new level of access to assistive technology for Americans with disabilities.

Table 5

**ASSISTIVE TECHNOLOGY FUNDING ACCESS:
SYSTEM REFORM OPTIONS**

I. Public Program Focus

- State Plan Requirements
- Individual Program Plan Requirements
- Reauthorize Tech Act
- Amend Multiple Statutes Definition of Assistive Technology

II. Interagency Coordination

- Annual Report to Congress
- Assistive Technology Interagency Coordination Council
- Uniform Classification System and Data Collection

III. Protection and Advocacy

- National Center on Assistive Technology Legal Advocacy

IV. Information Awareness

- Assistive Technology Watch

V. Service Capacity and Consumer Choice

- Establish Demonstration and Recycling Centers

VI. Alternative Financing Options

- Private Industry Research and Development Fiscal Incentives
- Social Security Trust Fund Loans
- Individual User Tax Incentives
- Health Care Reform
- State Low-interest Revolving Loan Funds

VII. Alternative Approaches

- Establish Universal Product Design Guidelines
 - Expand National Telecommunications Goals To Include Affordability, Accessibility, and Availability for Individuals with Disabilities
 - State Specialized Customer Premises Equipment Loan Program
-

Detailed discussion of each recommendation follows:

Recommendation 1

Mandate by statute the development of a national classification system for assistive technology devices and services and establish and collect uniform data sets across public programs.

The emergence of assistive technology as a major tool for the increased independence, productivity, and integration of children and adults with disabilities requires a means to ensure public accountability for the use of limited resources for these activities. The Council has determined that data sets are not in place in most federal programs to track expenditures for, and outcomes of, technology-related assistance. Far too little is known about the allocation of resources for assistive technology and its relationship to national trends and best practice in the lives of persons with disabilities. Yet everyday decisions on the allocation of public resources for technology-related assistance are made with limited knowledge of data and national trends.

To ensure the continuity of emerging data sets it is essential that a single taxonomy and agreed-upon nomenclature of different types of technology-related assistance be adopted for use by all publicly funded programs.

The classification system using this taxonomy will collect the following kinds of data across public programs:

1. Expenditures for the different types of technology-related assistance;
2. Environment(s) in which the assistive technology is used;
3. Type of disability;
4. Age of the person;
5. Gender of the person;
6. Ethnicity of the person;
7. Geographic residence of the person;
8. Cost-benefit(s) of the assistive technology;

9. Changes in the independence, productivity, and integration of the person with a disability; and
10. Degree of consumer choice, control, and satisfaction.

These data sets will have an impact similar to those developed on the "State of the States in Developmental Disabilities" by Braddock et al. (1990) and "Persons with Mental Retardation and Related Conditions in State-operated Residential Facilities" by White et al. (1992). These data sets and trend reports have assisted state and national policymakers in redirecting resources and reshaping public policy for the target populations.

The data sets will improve consistency between and among federal programs in the states and at the federal level. They also will assist in isolating problems and identifying state, regional, and national trends in the funding of technology-related assistance. Finally, the data can be used for education and training with varied audiences.

Statutory authority for these responsibilities should be placed within the Tech Act, which will be reauthorized during 1993. The responsibility for the data set will be entrusted to NIDRR and the Assistive Technology Interagency Coordination Council, which is described in Recommendation 3. Statutory authority would require the completion of the classification system and the development of the data system within 18 months of enactment. The Council recommends an authorized funding level of \$200,000 to develop the classification and data systems.

Response to: Findings 1, 5, 6, 8, 9, 10

Implementation strategy: Amend the Tech Act as part of the Reauthorization in 1993.

Jurisdiction: Senate Subcommittee on Disability Policy
House Subcommittee on Select Education

Recommendation 2

Authorize the National Institute on Disability and Rehabilitation Research (NIDRR) to publish by the end of each calendar year an Annual Report to the Congress on the status of funding of assistive technology devices and services for Americans with disabilities.

The report will include, but not be limited to, the following information:

1. Status report on funding made available per public program to purchase or loan assistive technology devices and services during the previous 12-month period. The report will distinguish funding levels for different types of technology-related assistance within each public program and indicate the number of individuals served.
2. Status report on demonstrated successes at federal and state levels to improve interagency coordination, streamline access to funding, and produce beneficial outcomes for users of technology with disabilities. Types of coordination should be reported across the following factors: age of individuals served, categorical programs, and varying types and levels of disabilities. Continuing barriers and policy and procedure problems should also be identified.
3. Status report on adoption of interagency and interdepartmental uniform data collection sets and classification systems.
4. Report on demonstration activities to promote funding access in existing public programs and establish new funding options.
5. Report on education and training activities to promote funding access in public programs and the health care system.
6. Report on research activities that improve our understanding of the cost-benefit results of access to assistive technology for individuals across the full age span and with varying disabilities.
7. Report on oversight activities by the public agencies listed below regarding state implementation of the right to expand assistive technology access for children and adults with disabilities. Specific enforcement or compliance actions should be detailed.

NIDRR would be charged with the responsibility of collecting and coordinating the information required to publish the Annual Report. At a minimum, cooperation and participation would be needed from the following agencies:

- Office of Special Education Programs
- Rehabilitation Services Administration
- Health Care Financing Administration
- Social Security Administration
- Office of Maternal and Child Health

- Office on Aging
- Department of Veterans Affairs

The report would begin to provide a baseline for policymakers, administrators, individuals with disabilities, and their families to identify funding trends and unresolved policy and procedural issues. The Annual Report should be the focus of oversight hearings by the Senate Subcommittee on Disability Policy and the House Subcommittee on Select Education.

The report would provide a new level of visibility for the problems of assistive technology access to policymakers and foster a new level of responsibility by federal agency administrators and by individuals with disabilities and their families, who would be a part of the data collection and reporting effort.

Response to: Findings 1, 3, 5, 6

Implementation strategy: Amend the Tech Act

Jurisdiction: Senate Subcommittee on Disability Policy

Recommendation 3

Establish the statutory authority for a federal Assistive Technology Interagency Coordination Council to meet quarterly and be responsible for improved coordination of services and funding for assistive technology for Americans with disabilities.

There are in existence several interagency coordination councils with varying missions (research, early intervention) authorized by statute. Such councils respond to a primary objective of improving communication between agencies that share a common mission, such as services to infants and young children with disabilities or technology-focused research. Such councils have been able to negotiate interagency agreements to resolve funding responsibilities, develop clarifying policy memoranda, and share funding for collaborative projects.

With a growing number of states now implementing the Tech Act, there is additional justification for a more formal process on a federal level to try to improve coordination between funding streams and provide guidelines to produce more consistent decision making in different states regarding the same federal funding criteria for assistive technology.

With the Tech Act reauthorization scheduled for 1993, statutory authority could be appropriately added to establish a Federal Assistive Technology Interagency Coordination Council with a focus of activities including, but not limited to:

1. The adoption and monitoring of formal interagency agreements to improve consistent decision making by states in meeting public funding objectives and coordination of services.
2. The joint funding of demonstration activities to improve access to, and the coordination of, resources at a state and local level for assistive technology for children and/or adults with disabilities.
3. The joint development of data sets for the collection of critical information about assistive technology funding and funding trends across federal agencies and state governments, including an agreed-upon classification system to distinguish different types of technology-related assistance as described in recommendation 1.
4. The joint development of competency-based education and training materials to improve funding decision making by agencies at the local and state levels with guidance from the newly formed Coordination Council.

The Council should include, at a minimum, representatives from the following agencies:

- Office of Special Education Programs
- Rehabilitation Services Administration
- National Institute on Disability and Rehabilitation Research
- Health Care Financing Administration
(including a Medicaid and Medicare Representative)
- Administration on Developmental Disabilities
- Department of Veterans Affairs
- Office on Aging
- Office of Maternal and Child Health Care

- Clearinghouse on Computer Accommodation – General Services Administration

The Council should meet quarterly and be chaired by the chairperson of NCD, with appropriate staff support. The unique status of the Council as an independent agency focused on policy oversight should help eliminate and mediate disputes of authority between agencies of parallel status in the same or different departments.

The expected outcomes from cooperative efforts of the Interagency Council should benefit both individuals with disabilities and states grappling with the problems of allocation of limited resources, multiple federal mandates, and inconsistent standards and procedures to justify the funding of assistive technology. The Annual Report to Congress on the status of funding assistive technology should also document the activities and impact of the Council's efforts. Although the creation of the Council will not create new funding, it will improve the utilization and coordination of existing funding sources in the public sector.

Response to: Findings 1, 2, 3, 5, 6, 9, 10

Implementation strategy: Amend the Tech Act as part of the Reauthorization in 1993

Jurisdiction: Senate Subcommittee on Disability Policy
House Subcommittee on Select Education

Recommendation 4

Amend the state plan requirements in multiple statutes to require assurances and a planning process with timelines for expanding funding access to assistive technology for children and adults with disabilities.

The flow of federal dollars to states in multiple statutes is conditioned upon receipt and approval of a state plan that spells out responsibilities and priorities according to those required by law. State planning requirements are often in three-year cycles and dictate a process of public participation that typically includes public hearings and comments on what is being proposed. In 1986, the Rehabilitation Act was amended to include a state plan requirement that focused on expanding access to rehabilitation technology for adults with disabilities. The receipt of federal dollars under Title I of the Act was conditioned upon receipt and approval by the Rehabilitation Services Administration of plans from each state that provided assurances that the

capacity to deliver rehabilitation technology services would be expanded during the next three-year cycle. In its plan, each state was required to describe how such expanded capacity would be developed, the approach or design to be followed, who would be responsible for such activities, and a timeline for accomplishment.

Recommendation 4 proposes the adoption of a similar requirement in other statutes that already have a focused set of responsibilities to meet the needs of persons with disabilities, but do not yet have to detail in a state planning document how access to assistive technology will be expanded to eligible populations. Most statutes that authorize federal funding to states must be reauthorized by Congress every three to five years. As part of the reauthorization process, the Council recommends the addition of a state planning requirement that mandates expanded access to assistive technology and requires a description of actions with a timeline including, but not limited to:

- Design or approach to expand access with measurable objectives;
- Identification of responsible parties for implementation;
- Design or approach to improve consumer choice and control;
- Method of evaluating progress according to timelines and consumer satisfaction;
- Approach to outreach and notice to eligible populations, including unserved and underserved groups, with special attention to the problems of rural service delivery and issues of cultural diversity; and
- Approach to education and training of staff to improve their knowledge and ability to provide expanded services.

The statutes with state planning requirements that should be amended are:

- Rehabilitation Act—Title VI—Supported Employment
- Rehabilitation Act—Title VII—Independent Living Services
- IDEA Part H—Early Intervention
- IDEA Part B—Special Education
- Social Security Act—Title XIX—Medicaid
- Maternal and Child Health Block Grant—Title V
- Developmental Disabilities Assistance and Bill of Rights of 1990
- Older Americans Act

To achieve the full impact of these state plan requirements, it is imperative that the responsible federal agency charged with oversight provide effective leadership to the states with clarifying guidelines, regulations, and technical assistance activities. Monitoring of state implementation efforts is essential to achieve the full impact of these amendments. Although these amendments do not require Congress to authorize and appropriate higher funding levels in the programs identified above, each state will need to allocate expanded resources to meet the intent of the state plan requirements.

The intent of the amendments is to establish a new set of conditions for receipt of federal financial assistance to the states that view assistive technology access as a critical means to meeting statutory goals and purposes on behalf of persons with disabilities.

Response to: Findings 1, 3, 7, 9, 10

Implementation strategy: Amend each of the above listed statutes over the next three years

Jurisdiction: Senate Committee on Finance
Senate Subcommittee on Disability Policy
House Subcommittee on Health and Environment
House Subcommittee on Select Education

Recommendation 5

Amend the individual program planning requirements in multiple statutes to provide notice to individuals with disabilities and their families of the right to assistive technology devices and services in a timely manner in response to individualized needs.

Several million children and adults with disabilities participate in, or are the subject of, the development of an individual program plan on an annual basis, or more frequently if the need arises. By statute, Part H of IDEA requires each state as a condition of receipt of federal funds to develop individual family services plans (IFSP) for all children with disabilities from birth through age two. By statute, Part B of IDEA requires an individualized education program (IEP) be developed for school-age children with disabilities each year. Title I of the Rehabilitation Act requires an individual written rehabilitation plan (IWRP) for adults with disabilities who meet the eligibility test required under the Act. And last, Title XIX of the Social Security Act requires individual habilitation plans (IHP) for mentally retarded or developmentally disabled persons who are served in intermediate care facilities.

With each of the four program plan requirements, there are different standards of need, descriptions of scope of services, and requirements of financial responsibility. However, all four plans establish a binding agreement in the nature of a contract between the public agency and the individual with a disability regarding services and equipment to be provided. Each of these plans must be prepared in writing and involve the individual with a disability and his or her parents as appropriate in the decision-making process. Each of these plans in statute addresses the issue of access to assistive technology and has specific requirements that must be met. The Council seeks to strengthen these requirements in two ways.

First, many individuals with disabilities and their families remain unaware of their right to assistive technology within the individual program planning requirements of these statutes (Findings 1 and 3). To improve awareness levels, the Council proposes a written notice requirement that would be a part of the individual program plan document. The written notice would explain to the intended beneficiary that the individual by law has a right to assistive technology services and devices to respond to individualized needs, explain the standard of need that must be met to justify funding, and alert the individual that he or she is a partner in the decision-making process. The notice would then explain the process of appeal and timelines if there is disagreement regarding type, scope, or amount of services and equipment, and whom the individual may consult for advice on these issues.

The notice takes the form of a consumer protection awareness and warning. It must be noticed to the party prior to the individual program planning meeting, and a copy of the notice must be provided again in writing at the meeting prior to commencement of discussions. The public agency must document that notice has been received.

The second part to this recommendation is that not only must assistive technology services and devices be written in and included as part of the individual program plan, but also that the equipment and/or services must begin in a timely manner. Timeliness is essential to meeting the needs documented in the plan document. No individual should be expected to wait longer than 30 days to receive assistive technology devices and services. Failure to meet these timelines should jeopardize the continued receipt of federal funds by the public agency.

This recommendation places an emphasis on consumer involvement and choice in determining appropriate technology to respond to individualized needs, with a sense of urgency about meeting public policy goals of these statutes. The notice requirement should make clear that the public agency is

obligated to fund not just a piece(s) of equipment, but also training and other ongoing assistance in order to maximize benefits to the user.

Response to: Findings 1, 2, 3, 7, 9

Implementation strategy: Amend the Individuals With Disabilities Education Act,
Parts B and H
Amend Rehabilitation Act
Amend Title XIX of the Social Security Act

Jurisdiction: Senate Subcommittee on Disability Policy
House Subcommittee on Select Education
Senate Committee on Finance
House Subcommittee on Health and the Environment

Recommendation 6

Add the complete definition of assistive technology devices and services adopted in the Tech Act to the following programs of the Social Security Act: Title II, Social Security Disability Insurance; Title V, Maternal and Child Health Block Grant; Title XVI, Supplemental Security Income; Title XVIII, Medicare; and Title XIX, Medicaid.

The federal entitlement and discretionary programs within Titles II, V, XVI, XVIII, and XIX of the Social Security Act impact millions of Americans with disabilities and represent billions of federal dollar expenditures per year. Most of these public policies were enacted prior to the national recognition of the role that technology-related assistance can have on the overall functioning as well as the health, education, employment, and competency of children and adults with a full range of disabilities. Consequently, within these federal programs there are no consistent definitions or criteria for payment/credits/allowances, a situation that works to the detriment of persons with disabilities who are beneficiaries under one or more of the programs.

In addition to adopting the statutory definition of assistive technology, the Council recommends that the following five principles be amended into the appropriate Titles of the Social Security Act:

Principle 1. A major purpose of assistive technology is to increase functional capacity, competency, and/or capability of people with disabilities to interact with the full range of social and physical environments of everyday life rather than simply to replace or substitute for a missing or malfunctioning body part.

- Principle 2. A major outcome of assistive technology is to increase the independence, productivity, and integration of the person with a disability, using the definition of these terms contained in the Developmental Disabilities Assistance and Bill of Rights Act of 1990 (P.L. 101-496) and to assure the equal opportunity outcomes stated in the ADA.
- Principle 3. A purpose of assistive technology is to prevent institutional or nursing home placement.
- Principle 4. Consumer input, choice, control, and satisfaction (effectiveness, affordability, operability, and dependability) must be assured in all aspects of the programs, including policy development (in areas such as screens being developed for Medicare), implementation (including assessment, purchasing, and training), monitoring, and evaluation.
- Principle 5. Consumer responsiveness demands a timely approval and purchase process that must be disengaged from cumbersome procurement policies often tied to exclusive vendor contracts.

Each of the Social Security Titles also shall be amended as follows:

A. Title II, SSDI—Income Replacement:

- Consistent with Recommendation 9, the Council recommends that the statute be amended to authorize the use of the Social Security Trust Fund as a no-interest loan fund for the full range of assistive technology that will enhance the person's ability to regain employment status.
- Principles 1, 2, 4, and 5 are to be included in these amendments.
- The Council also recommends that the statute be amended to allow access to Medicare prior to the two-year waiting period for those beneficiaries who are unable to take advantage of Consolidated Omnibus Budget Reconciliation Act (COBRA) continuation of private insurance coverage, including access to assistive technology.
- The Council recommends that the statute authorize a work incentive program similar to section 1619 under the SSI program so that SSDI recipients will be willing to purchase assistive

technology without any fear of benefit loss during the transition to work period.

B. Title V, Maternal and Child Health Services Block Grant and Children with Special Health Care Needs:

- Since this statute currently articulates the principles of "family-centered, community-based coordinated care for children with special health care needs," the Council recommends the addition of principles 1, 3, and 5 into the statute.
- Moreover, the statute should clarify the role of assistive technology in reducing the burden on the child's primary caregiver(s).

C. Title XVI, SSI Maintenance:

- The Council recommends that the statute be amended to clarify that any type of assistive technology devices and/or services are an appropriate component of a Plan for Achieving Self-Support (PASS), thus allowing persons with disabilities to purchase their assistive technology from earnings set aside for this purpose without counting these earnings in determining their SSI eligibility or benefit.
- The Council recommends the inclusion of Principles 1, 2, 4, and 5.

D. Titles XVIII, Medicare:

As the largest single payer for durable medical equipment (DME), Medicare sets the standards for health insurance coverage of assistive technology both in private health insurance and in the Medicare program, which is actually administered by private health insurers. The Health Care Financing Administration (HCFA) has developed regulations for DME that arbitrarily restrict coverage for certain categories of equipment that can vitally affect the health of persons with disabilities.

Reflecting the acute-care bias that existed at the time (1965) that the Medicare program was established, HCFA has defined medical purpose very narrowly. The Medicare statute prohibits payment for services "which are not reasonable and necessary for the diagnosis or treatment of illness or injury or to improve the functioning of a malformed body member."

Assistive technology that does not meet these definitions of durable medical equipment or the Medicare statutory definition of a prosthesis—which is to replace all or part of an "internal body organ"—is generally determined to be "comfort" or "convenience" items for which Medicare will not pay. HCFA regulations do not recognize that assistive technology that is a convenience item for persons without disabilities may be medically necessary for persons with disabilities.

The Council recommends that the statute be amended in the following ways:

- Expand the concept of medical necessity to include health and safety needs of the individual; this would include Activities of Daily Living (ADL) needs, environmental control devices, and safety needs. It would also cover communication needs to the extent that they affect communication with medical personnel, reaction to an emergency situation, and prevention of depression. Although the enhancement of function is not always medically necessary, medical necessity must take into account functional necessity as it affects health and safety needs of the individual in the home and the community.
- Eliminate home-based definitions of need. Locus can be a relevant factor in determining the purpose of assistive technology but it must not be determinative. If a device is used exclusively in the workplace, it is reasonable to consider that it has a vocational purpose that would not be covered by health insurance (e.g., oxygen tank for coal miner), but many devices like wheelchairs that are used in both the home and workplace are considered to have health-related purposes.
- Eliminate HCFA regulation that certain devices are nonmedical in nature; a device must be looked at in terms of the health and safety needs of the individual to determine whether it is medically necessary. Health is not limited to acute care; it must also take into account prevention, rehabilitation, and ongoing maintenance, especially for ADL needs.
- Expand the definition of prosthesis so that it not only replaces a missing body part but also enhances the functioning of a malfunctioning or nonfunctioning body part (whether or not removed from the body).
- Include Principles 1, 3, 4, and 5 above.

E. Title XIX, Medicaid:

The Medicaid program impacts millions of children and adults with disabilities in all states and currently provides authority for coverage for a full range of assistive technology. However, states have inconsistently recognized such authority. The Council recommends that the statute be amended to,

- Clarify that the primary purpose of Title XIX is to *habilitate* as well as rehabilitate individuals to maximum self-care, thus clarifying the definition of medical necessity as being long-term.
- Clarify that home health care and personal care can be provided in a variety of settings outside of the person's home.
- Include a secondary prevention component recognizing the importance of assistive technology in preventing secondary disability.
- Expand Medicaid Community-supported Living Arrangements as a state plan option for all states and expand eligibility for Medicaid from persons with developmental disabilities to all persons with disabilities.
- Expand the definition of prosthesis so that it not only replaces a missing body part but also enhances the functioning of a malfunctioning or nonfunctioning body part (whether or not removed from the body).
- Include Principles 1, 2, 3, 4, and 5 in the statute.

These statutory changes will establish a more uniform and consistent set of criteria for payment decision making to fund assistive technology within the scope of each program. They will create a framework to develop a uniform standard for need across all federally funded programs. These changes will also result in greater interagency cooperation within the Department of Health and Human Services and facilitate greater ease in developing the classification system and data sets in Recommendation 1 and the information for the Annual Report to Congress in Recommendation 2.

Response to: Findings 1, 2, 4, 5, 6, 7, 8, 10

Implementation strategy: Amend Titles II, V, XVI, XVIII, and XIX of the Social Security Act

Jurisdiction: Senate Committee on Finance
House Committee on Ways and Means
House Subcommittee on Health and the Environment

Recommendation 7

Reauthorize the Tech Act for an additional three years and strengthen opportunities for interagency coordination, systems change, and consumer choice and control.

In 1993, the Tech Act will be the focus of oversight by the Senate Subcommittee on Disability Policy and the House Subcommittee on Select Education. It is probable that by the spring of 1993, all 50 states will have received funds under the Act to develop a consumer responsive statewide system of technology-related assistance. Based on testimony at all three public forums and the study responses regarding funding barriers in nine selected states currently funded by the Tech Act, states are effectively working to leverage additional resources, expand the flow of information about technology services and funding, and encourage a dialogue between individuals with disabilities and public agencies about promising approaches to consumer responsiveness. However, the testimony and study responses indicated that critical issues of interagency coordination, system change, and consumer choice and control remain unresolved.

The Council recommends strongly that the Act be reauthorized for three years to maintain and expand the level of effort and to target and leverage resources to meet the technology-related assistance needs of children and adults with disabilities. As was stated in Finding 10, there is no system, public or private, uniquely devoted to the funding and financing of assistive technology to respond to the full range of unmet needs. As the next best alternative, the Tech Act is continuing to provide a focal point for critically required system change activities.

The Council recommends the following package of amendments to be considered as part of the reauthorization process:

1. With an expectation that currently unfunded states will be receiving funds in 1993, change the process of funding states from a competitive grant application process to a grant-in-aid program that guarantees funding to all states, conditioned upon receipt and approval of a state plan. Establish a level of minimum allotment of \$600,000 and consider adopting the grant-in-aid formula currently allocating funds in the Developmental Disabilities Act. Authorize

funding levels for the next three years for Title I state funding at \$45 million, \$50 million, and \$55 million, respectively.

2. Establish a series of state plan requirements that will promote interagency coordination and consumer responsiveness. In addition to describing a plan of operation, funding priorities, and an evaluation design that is impact and outcome oriented, the state plan would:
 - a. Require the establishment of a state interagency coordination council to meet, at a minimum, quarterly and agree to develop clear written funding policies on factors in decision making, scope of coverage, reimbursement, and appeal procedures; expected to participate would be identified lead staff who are experienced in their agency's assistive technology funding policies and practices.
 - b. Require an assurance that, at a minimum, the following agencies would participate on the council: special education, early intervention, vocational rehabilitation, independent living, aging, insurance, medical assistance, and developmental disabilities. The council would be chaired by an individual selected by the governor.
 - c. Require the above-mentioned agencies to provide assurance that within 12 months a uniform data collection system would be adopted to yield information about assistive technology funding and funding trends, including a classification system to distinguish different types of technology-related assistance for individuals with varying types of disabilities in specific or multiple environments prescribed by recommendation 1.
 - d. Describe and document successful approaches of interagency coordination in service delivery, funding, education, and training activities.
 - e. Provide a plan of operation for improving funding coordination in public schools and at the following key transition points: early intervention to preschool, aging out of special education, adult to senior status, and institution to community.
 - f. Provide a plan and dedicate resources to increase outreach to unserved and underserved populations.

- g. Describe the approach and resources dedicated to expand consumer choice and control of assistive technology services and funding.
 - h. Describe the approach to improve, across specific funding streams, the support for training and ongoing assistance needed to maximize benefits to the users of assistive technology devices.
3. Establish a new Title III under the Tech Act to authorize funding to states to create a low-interest revolving loan fund modeled after the success of the Maine fund that is consumer responsive. The Maine experience has demonstrated the effectiveness of this alternative financing mechanism. States would be asked to match federal funding on a dollar-for-dollar basis up to one million dollars. States would submit a proposal that would be reviewed on a competitive basis based on the following factors:
- Assurance of match from the state legislature or private sources;
 - Scope of interagency cooperation in both public and private sectors;
 - Approach to review and process requests that responds to potential technology user needs for a timely and streamlined system of financing; and
 - The degree to which the proposal emphasizes and expands consumer choice and control.

The Council recommends a funding level of 10 million dollars a year to stimulate the development of this alternative finance option.

4. Require an Annual Report to Congress on the status of assistive technology funding (see Recommendation 2).
5. Establish a National Center on Assistive Technology Legal Advocacy to specialize on funding issues (see Recommendation 11).
6. Establish a new Title IV to authorize the start-up funding of Assistive Technology Demonstration and Recycling Centers (see Recommendation 8).
7. Establish and collect uniform data sets across public programs (see Recommendation 1).

Response to: Findings 2, 5, 6, 7, 8, 9, 10

Implementation strategy: Reauthorize the Tech Act and strengthen it with a series of amendments

Jurisdiction: Senate Subcommittee on Disability Policy
House Subcommittee on Select Education

Recommendation 8

Establish Assistive Technology Demonstration and Recycling Centers nationwide in the capital city of each state and in the top 50 Standard Metropolitan Statistical Areas to be operated by existing Centers for Independent Living or other community-based organizations that are consumer controlled and directed to enhance consumer choice and control of assistive technology services and funding.

The Council heard repeatedly from witnesses at all three forums about the abandonment of equipment by persons with disabilities who had no opportunity prior to purchase to try it out or see it demonstrated. Recent research conducted by the National Rehabilitation Hospital and funded by NIDRR confirms the public testimony (Phillips, 1992).

The Council recommends the establishment of demonstration and recycling centers in every state capital to serve five primary purposes:

1. To provide a location in each state where individuals with disabilities who are current or potential technology users as well as providers can have a place to see, touch, and learn about the range of technology options from knowledgeable users with disabilities.
2. To help individuals with disabilities identify appropriate technology devices to respond to individualized needs and share strategies for successful funding.
3. To give the private and public sectors an opportunity to see assistive technology options demonstrated and to discuss approaches to utilizing assistive technology as a means to achieve reasonable accommodation as required by the Americans with Disabilities Act.
4. To help state agencies comply with the requirements of Section 508 of the Rehabilitation Act to create an electronically accessible office work environment.

5. To serve as a depository for used or no longer needed equipment that may be exchanged or recycled.

Each of these functions of the centers will help make the most of limited public resources in an environment that emphasizes consumer choice and direction. By locating such a center at existing Centers for Independent Living or other community-based organizations that are consumer directed and controlled, the Council's recommendation seeks to bring individuals with disabilities into the center of the evolving assistive technology service delivery system. The concept of such a center builds upon the successes of the Clearinghouse for Computer Accommodations operated in the General Services Administration. However, the concept is broadened beyond computer applications to a full range of assistive technology options, including communication, mobility, and Activities of Daily Living (ADL) and environmental controls.

The establishment of such a center in each state capital should enhance opportunities for policymakers to gain a fuller appreciation of the range of possibilities available to benefit persons with disabilities. The establishment of a second set of centers in the top 50 Standard Metropolitan Statistical Areas is intended to respond to the needs of individuals in population centers.

It is important that performance standards be developed to establish a consistent array of activities between centers nationwide. The Council recognizes the need to establish center specifications concerning range of technology assistance to be offered and types of expertise expected to be available. The Council believes that technology manufacturers may have a significant interest in lending or donating equipment for the demonstration of their products at the centers.

Input to NIDRR for setting center specifications should be solicited from Tech Act lead agencies, the Federal Interagency Coordination Council, Centers for Independent Living, technology manufacturers and vendors, persons with disabilities and their families, and community-based organizations. The specifications in draft form should be made available for public comment.

The Council proposes funding the centers with a combination of public and private resources. The Council recommends that Congress authorize 10 million dollars a year for establishing demonstration and recycling centers. Eligible applicants must provide assurances of public and private sector support of \$250,000 a year for five years in order to receive a one-time start-up grant of \$500,000.

If the centers function effectively, assistive technology decision making will be enhanced and limited resources will be preserved. If the concept of recycling used equipment can be developed, there will be major benefits to individuals with disabilities and to state agencies trying to preserve and maximize limited resources. For a small expenditure of federal dollars, additional funding can be leveraged in the public and private sectors. The national network of centers would, for the first time, provide the beginning structure of a distribution system for new devices that become available on the market and eliminate vendor monopolies.

Response to: Findings 1, 5, 7, 10

Implementation strategy: Amend the Tech Act and add a Title IV

Jurisdiction: Senate Subcommittee on Disability Policy
House Subcommittee on Select Education

Recommendation 9

Authorize the use of the Social Security Trust Fund as a financing source for purchasing assistive technology that enhances the capacity to work through an Individualized Employment Account (IEA).

All wage earners contribute to the Social Security Trust Fund through a payroll tax that goes for Social Security benefits after retirement and SSDI payments if one becomes disabled as a contributing adult or is a person with a disability who is dependent on a Social Security beneficiary.

The Social Security Trust Fund has been used exclusively as an income replacement fund for persons who cannot work. With the recognition that many people with disabilities—including SSDI beneficiaries who for the most part have work experience—might be able to enter the work force if they had appropriate supports, there is growing interest in expanding the function of the Social Security Trust Fund to provide financial assistance to persons with disabilities to help them achieve their work potential.

Since access to assistive technology could increase the work capacities of many people with severe functional impairments, the Council recommends authorizing the use of the Social Security Trust Fund as a no-interest loan fund to enable persons with disabilities to purchase employment-related assistive technology. This funding mechanism would enhance the ability of persons with disabilities to choose the kind of assistive technology they need.

This proposal does not have to be limited to current SSDI beneficiaries; it could also benefit other persons with disabilities who currently contribute to the Social Security Trust Fund as wage earners and persons with disabilities who are dependents on current Social Security contributors and beneficiaries.

The Council's research supports such a recommendation and documents the need for an alternative financing mechanism. Witnesses at all three forums stated that access to assistive technology could increase their capacity to work. However, access to assistive technology was limited by their lack of ability to pay for the needed equipment and by their inability to secure financing because of a lack of established credit. Additional documentation to support such a need is found in two sources:

1. The 1990 Supplement on Assistive Technology to the National Health Interview Survey (NHIS) found that approximately 2.5 million persons reported needing assistive technology that they did not have. Over 60 percent of those in this random sample of the noninstitutionalized population reported that they did not have the assistive technology because they could not afford it (La Plante, 1992).
2. As part of this study, in an exploratory cost-benefit analysis of 136 persons conducted through nine Tech Act programs, respondents were asked to identify types of assistive technology that could make a difference to the quality of their lives. NCD researchers found that the average cost of the equipment that respondents identified was \$5,645 and that respondents expressed a willingness to pay \$1,471 for the equipment.

The Council proposes the following implementation strategy:

Authorize expanded function of the Social Security Trust Fund to be used as a no-interest loan fund for employment-related assistive technology for persons with disabilities who are SSDI beneficiaries, working-age persons with severe functional impairments who are not SSDI beneficiaries, and persons with disabilities who are dependents of Social Security contributors or beneficiaries. The Social Security Trust Fund could function as a kind of Individualized Employment Account (IEA) for increasing access to assistive technology that enhances the capacity to work. The IEA would have the following components:

- Eligibility would be based on (1) persons who are current SSDI beneficiaries, (2) persons who meet the Social Security Administration's medical/functional definition of disability and have

paid into the Social Security Trust Fund through the requisite number of payroll contributions to be eligible for SSDI, and (3) nondisabled adults who have paid into the Social Security Trust Fund through the requisite number of payroll contributions and have a spouse or child who meets SSA's medical/functional definition of disability.

The justification for extending the Social Security Trust Fund loan program to children under 18 years who meet SSA's medical/functional definition of disability is that assistive technology can increase their future work potential.

- Benefits will be an interest-free loan for assistive technology that enhances the capacity to work.
- Pay-back requirement should not exceed 5 percent of the SSDI payment per month for an SSDI beneficiary and would be deducted from the SSDI payment after a six-month period. Instead of requiring SSDI beneficiaries to pay back their loan for assistive technology by reducing their future SSDI payments over time, it might be reasonable for SSA to forgive this loan as the beneficiaries become and remain employed. The loan could be reduced at a certain percentage per year or a certain amount per year for each year that the person is employed. This incentive for working would be justified by considering the actual savings to the Social Security Trust Fund that would be generated by an unemployed SSDI beneficiary who chooses to take the risk of entering the labor force and thus eventually becomes no longer eligible for an SSDI benefit.

Non-SSDI beneficiaries with severe functional limitations who have borrowed from the Social Security Trust Fund to pay for employment-related assistive technology would be required to file a separate IRS tax schedule for repayment of the loan over time. The IRS would then transfer those funds to SSA, as they do now with self-employment taxes (Schedule SE), and SSA would credit the Individualized Employment Account of the individual who has borrowed against his or her Social Security Trust Fund account.

- Applications for purchase of equipment with the no-interest loan would be reviewed by professionals trained to provide assistive technology to persons with disabilities; this would not be a function of a regular SSA claims representative.

- Decisions by the Social Security Trust Fund regarding no-interest loans for assistive technology would be subject to a consumer-friendly appeals process to be developed in cooperation with the Social Security Administration and the Federal Interagency Coordination Council.

This alternative finance mechanism has the potential of assisting over one million individuals with disabilities at minimal cost to the government.

Response to: Findings 7, 8, 10, 11

Implementation strategy: Amend the Social Security Act

Jurisdiction: House Committee on Ways and Means
Senate Committee on Finance

Recommendation 10

Establish a Technology Watch program patterned after the NCD's current ADA Watch activities to monitor compliance with enforcement of federal rights to or requirements for expanding technology access for children and adults with disabilities.

The National Council on Disability is an independent federal agency charged with reviewing all laws, programs, and policies of the federal government affecting individuals with disabilities. It is the only federal agency with the mandated responsibility to address, analyze, and make recommendations on issues of public policy that affect people with disabilities regardless of age, disability type, perceived economic need, or other individual circumstances. The Council is currently implementing an ADA Watch program to provide a visible forum for monitoring ADA compliance efforts in the public and private sectors. The ADA Watch has been structured to publicize to multiple audiences, including people with disabilities, critical abuses as well as successes by covered entities in responding to the requirements of ADA. These requirements include providing access to employment, public accommodations, transportation, telecommunications, and state and local government services.

A similar or parallel effort is needed to bring the objective, independent viewpoint of the Council to the problems of access to assistive technology that affect people with disabilities regardless of age, disability type, or perceived economic need. The impassioned testimony of individuals with disabilities and their parents at all three public forums held by the Council indicated a deep sense of frustration and confusion. The inconsistent and complex nature of

funding in the public sector and the health care system leaves potential technology users with a feeling of powerlessness and sometimes anger.

The unique position of the Council as an independent body charged with policy oversight makes it an ideal, credible candidate to conduct Technology Watch activities. Individuals with disabilities and their families want a place to turn to, to document problems and denial of rights to technology access. The Council has the authority and visibility to collect, review, analyze, and publicize such problems on a regular basis. With appropriate relationships in place with responsible federal agencies and the Congress, the Council can share identified system problems and seek resolution on an individual and system basis. Individuals with disabilities and their families, including hard-to-reach special populations who remain unserved and underserved by assistive technology, could be reached and assisted.

On a quarterly basis, a Technology Watch communication could be disseminated to key federal agencies, policymakers at the federal and state level, and Tech Act lead agencies. A Technology Watch provides an additional safeguard or approach to focusing attention on, and working toward, constructive solutions to the problems of technology access for Americans with disabilities.

Response to: Findings 1, 3, 5, 9

Implementation strategy: Legislative authority for the Council exists already. There would be a need for additional funding to appropriately conduct Technology Watch activities.

Jurisdiction: NCD

Recommendation 11

Authorize by statute the establishment of a National Center on Assistive Technology Legal Advocacy to specialize in funding issues.

There has been a very limited effort at federal and state levels to monitor and enforce the right to or requirements for expanding assistive technology access for children and adults with disabilities. The inconsistent interpretations of federal requirements in the same agency and between agencies in different states has left individuals with disabilities confused and angry. There is a paucity of expertise in applying rights protections to secure an individual's right to assistive technology across public funding streams. There is no single center or clearinghouse of information to offer assistance to

individuals, agencies, and organizations trying to work their way through the funding maze.

The National Council recommends the establishment of a National Center on Assistive Technology Legal Advocacy to serve three major functions:

1. Collect and disseminate information about assistive technology funding decisions nationwide based on actions taken at local, state, and national levels. Funding decisions may be made on an individual or systems basis through policy statements, regulations, administrative hearings, or litigation.
2. Provide technical assistance to states, federally funded protection and advocacy agencies, client assistance programs, legal services agencies, and parent training and information centers on interpreting funding decision precedents and representing individuals with disabilities who seek to protect their rights to assistive technology services and devices.
3. Assist individuals with disabilities to protect their rights to assistive technology services and devices in precedent-setting situations that will benefit a class of individuals similarly situated. Special emphasis should be placed on unserved and underserved populations.

Statutory authority for establishing the center could be added to Title II of the Tech Act. Funding would be authorized at a level of \$750,000 a year for three years, with the selection of a grantee being based on a competitive review of proposals.

The appeals process is an important protection for citizens using public programs. For example, Medicare beneficiaries win a large percentage of appeals against Medicare carriers. In FY 1991, 63.6 percent of appeals at the review stage, 58.8 percent of appeals at the fair hearing stage, and 67.0 percent of appeals at the administrative law judge stage reversed the decisions of the Medicare carrier and resulted in decisions favorable to the consumer (HCFA, 1991). However, the number of appeals is a fraction of the total number of denials. The problem is that most people do not have the knowledge or resources to make an appeal and therefore do not receive a favorable judgment. The establishment of a national center with very specific expertise will help protect the right to assistive technology for individuals with disabilities across the country. Its activities should lead to more consistent funding decision making at local and state levels. It should also stimulate greater federal agency oversight and monitoring.

The information coordination and technical assistance functions should greatly enhance system change activities at a state level under the Tech Act. It is expected during the first three years that a new group of trained attorneys and advocates will develop in the states based on collaborative activities with the national center.

Response to: Findings 1, 2, 3, 6, 9, 10

Implementation strategy: Amend the Tech Act

Jurisdiction: Senate Subcommittee on Disability Policy
House Subcommittee on Select Education

Recommendation 12

Develop statutory authority that requires private health insurers to apply medical necessity standards to durable medical equipment, prostheses, and orthotics that enhance function in activities related to health, safety, and Activities of Daily Living (ADLs).

While private insurance is an important payment source for certain types of assistive technology, it is difficult to say how it determines what types of equipment might be covered, who is eligible for coverage, and who makes the pertinent decisions.

Although approximately two-thirds of people with disabilities have private health insurance, their inability to get it to pay for assistive technology was repeated throughout the Council's forums, for the following reasons: (1) preexisting condition exclusions; (2) contract limitations on the scope, duration, and amount of covered services; (3) determinations of allowable charges; (4) subjective expectations of significant functional improvement within a limited period of time; (5) prior authorization requirements; (6) extracontractual case-by-case decisions based on cost savings to the insurer; and most important, (7) an acute-care definition of medical necessity. As a result, 67.3 percent of durable medical expenditures were paid out-of-pocket, 17.8 percent were paid by Medicare, and only 10.4 percent were paid by private health insurance in 1990, according to the Health Care Financing Administration.

Private health insurance covers many types of assistive technology that are classified as durable medical equipment (DME). Traditionally DME has been covered in hospital settings and coverage has gradually been extended to persons for a limited period of time after they have been discharged from a

hospital. The problem is that many persons with disabilities have permanent conditions that require access to assistive technology on an ongoing basis.

Private insurance often does not pay for aids for daily living and safety devices, home modifications, environmental control devices, sensory and communication aids, van modifications, driving and transportation aids, computers, and recreational aids. In addition, exploratory research on consumer abandonment of assistive technology is beginning to show that equipment purchased through private insurance has a higher rate of abandonment than assistive technology purchased directly by the consumers. Therefore, the Council proposes two recommendations that should be pursued to expand health insurance coverage for assistive technology:

One recommendation is to broaden the definition of medical necessity to include health and safety needs and ADL needs. Health insurance should cover all assistive technology that improves function of malfunctioning body parts (whether replaced or remaining in the body) and that is expected to improve health and safety. This includes environmental control devices, safety equipment, and communication devices that can facilitate interaction with medical personnel, assist in an emergency situation, and reduce mental health problems related to barriers to communication. At the same time, this definition of necessity should require insurers to recognize treatment billing codes that reflect the evaluation services provided by rehabilitation professionals who need to assess functional deficits in order to develop effective treatment plans to address functional impairments. Presently insurers recognize diagnostic treatment codes from a clinical perspective that is principally concerned with identifying the underlying medical conditions. In addition, the statute should require insurers to guarantee consumer choice and control.

The second recommendation is designed to counter the sources of resistance to the first recommendation by establishing the right to health care for all Americans at the federal level. This recommendation should include the following components:

- Minimum federal benefit standards that include access to adequate rehabilitation services and assistive technology and related services.
- A benefit for assistive technology that includes cost of assessment, evaluation, customization, training, repair, and replacement as well as the cost of the assistive technology.

- A broader definition of medical necessity that recognizes acute care, rehabilitation, and ongoing maintenance needs and an emphasis that shifts needs from cure to managing chronic conditions.
- A benefit for assistive technology that guarantees consumer choice and control.
- No preexisting condition exclusions.
- Financing mechanisms for health insurance that distribute health care costs equitably throughout the population and remove disincentives to serve persons with disabilities.

Response to: Findings 2, 4, 10, 11

Implementation strategy: Develop legislation at federal and state levels

Jurisdiction: Senate Committee on Finance
Senate Committee on Labor and Human Resources
House Committee on Ways and Means

Recommendation 13

Create a comprehensive set of fiscal incentives encouraging private industry to invest in the production, marketing, and distribution of assistive technology to benefit Americans with disabilities.

This recommendation seeks to respond to the problems of funding access to assistive technology from an alternative but complementary approach to the previous recommendations that have focused on refinements to the third-party payment system of public programs and private health care coverage. The goal of all the recommendations is to increase the possibility that individuals with disabilities have access to assistive technology that responds appropriately to their needs. Increasing the interest of the private sector to develop, produce, market, and distribute assistive technology devices would result in the following:

- Expanded consumer choice;
- Increased awareness by potential users with disabilities of the availability of a range of technology options that might meet their needs;

- Reduced cost to the end-user; and
- Expanded access.

Providing fiscal incentives for industry is a common approach in public policy to reducing the risk of doing certain types of business. By law, there are certain price protections for different kinds of farmers (e.g., peanuts, tobacco). Public policy is reducing the financial uncertainties associated with certain types of business. By law, there are tax incentives created to stimulate specific kinds of activities. The Low Income Housing Tax Credit stimulates private sector interest and activity that will result in affordable housing for individuals Congress seeks to assist. The Targeted Job Tax Credit stimulates the private sector to hire individuals who are disadvantaged, including individuals with disabilities. With each of these examples, public policy has attempted to reduce the financial uncertainties associated with some type of risk taking. Fiscal incentives allow private investors and businesses to increase the probability of a satisfactory return on investment.

In 1982 the Office of Technology Assessment (OTA) completed a study with recommendations to Congress on technology and handicapped people. OTA called for the "creation of a set of fiscal and regulatory incentives to encourage private industry to invest in the production and marketing of disability-related technologies." The incentives would include the following:

- Accelerated tax write-off of equipment and other capital investments.
- Modified capital gains taxes on investments in firms designated as producers of technologies that will benefit persons with disabilities.
- Extended carryover of losses for designated firms.
- Tax credits against profits for designated small businesses for a specified number of years.
- Targeting of research and development dollars to award contracts to small, profit-seeking businesses for the development and testing of relevant technologies.
- Expansion of efforts to guarantee markets to potential producers of a technology (e.g., Department of Veterans Affairs, vocational rehabilitation, Medicaid, and education) (Office of Technology Assessment, 1982).

Ten years later, the research conducted by the Council supports the compelling need to implement this type of recommendation. One of the prime social and economic goals of public policy remains the appropriate application of technologies to extend the capabilities of individuals with disabilities. The federal government is deeply involved in support of research and development of new technologies. Targeting a percentage of these resources to research and development for the benefit of individuals with disabilities would be responsive to multiple public policy goals.

The proposed package of incentives is timely in light of the post-ADA environment. Business and industry are grappling with requirements of equal opportunity and access. Assistive technology is a means of providing reasonable accommodation required by statute. The emergence of new technologies developed to respond to the varying needs of individuals with disabilities could help business and the private sector comply with the reasonable accommodation standard.

In addition to fostering ADA compliance and benefiting the end-user, the proposed incentive package would stimulate employment and have a positive impact on the economy.

Response to: Findings 7, 10, 11

Implementation strategies: Amend tax laws
Target research and development funding

Jurisdiction: Senate Committee on Finance
House Committee on Ways and Means
Senate Committee on Appropriations
House Committee on Appropriations

Recommendation 14

Amend Section 162 of the Internal Revenue Code to allow taxpayers with disabilities who do not itemize the option of claiming assistive technology expenses as above-the-line adjustments to income. Request the Department of the Treasury to develop a cohesive set of tax policies on assistive technology for persons with disabilities that clarifies national values and goals as articulated in the ADA and the Tech Act.

No study of financing options for assistive technology devices and services would be complete without an examination of the subsidies offered by the tax system to individual purchasers of technology. Tax credits and deductions represent an alternative means of government subsidy. If an

individual purchaser of technology can reduce his or her out-of-pocket costs through effective use of the tax law, the end result is little different from what would be achieved with a government check for the same amount as the savings.

Table 6, "Federal Income Tax Recommendations for Assistive Technology," summarizes the recommendations of the Council and describes the effect of the change.

All persons with disabilities, particularly individuals of limited income, should be able to benefit from tax policy. The present system affords greater opportunity to save income to those individuals of greater means who can afford to itemize their deductions. Persons with disabilities of low and moderate income have even more compelling reasons to benefit from an above-the-line adjustment to gross income for technology expenditures.

The Council believes that making assistive technology purchases subject to carryover provisions would also be of significant benefit to persons with disabilities. Such a provision allows individuals with disabilities to purchase assistive technology with funds from savings or loans during a year of limited or no income and carry the deduction to a prior or succeeding year. The carryover provision creates an incentive for the timely acquisition of assistive technology without loss of tax benefits.

To ensure the maximum advantage from these two tax amendments, it is important that the Internal Revenue Service clarify that the purpose of assistive technology service and devices is to increase functional capacity and productivity rather than merely substitute for a missing or malfunctioning body part as under current medical deduction regulations. It is strongly suggested that for the purpose of the proposed amendments, the IRS adopt the broad definition of assistive technology devices and services that was first defined in the Tech Act.

The Council also requests that the Department of the Treasury establish a commission that includes people with disabilities who are users of assistive technology, economists, representatives of other federal agencies, and others to evaluate current tax policies and their adverse impact on individuals with disabilities and their families, and explore new options that clarify national values and goals as articulated in the ADA. Two areas should be explored:

Table 6

**FEDERAL INCOME TAX RECOMMENDATIONS
FOR ASSISTIVE TECHNOLOGY**

Provision	Nature of Change	Effect of Change
Adjustments to income	Under the medical expense and impairment-related work expense rubrics, treat assistive technology device/services purchases as above-the-line adjustment to income, rather than as below-the-line itemized deductions.	Would allow the deductions to be secured irrespective of whether taxpayer is in a position to itemize.
Timing of deductions	Make assistive technology purchases subject to carryover.	Would permit taxpayers to benefit from deductibility when expenses incurred in years in which income is insufficient to absorb the deduction.
Review of regulations	Systematically evaluate existing tax law and regulations to identify provisions that adversely impact people with disabilities but that have no revenue justification for their perpetuation.	Would eliminate nomenclature that creates confusion as to the scope of deductible technology expenses; would remove language that projects an image identifying disability with illness and incapacity; would ensure that the interests of people with disabilities are taken into account in future policy debates.

- Reestablishing the charitable contribution deduction for nonitemizers to encourage private funding support for the purchase of assistive technology.
- Creating expanded tax incentives for businesses to contribute assistive technology devices to public and private nonprofit agencies to benefit individuals with disabilities.

Tax policy offers an opportunity to stimulate research and development activities as described in Recommendation 13, stimulate small business and industry expenditures on assistive technology to comply with ADA as approved by Congress in 1990, and expand benefits to the end-user as described in this recommendation. Tax policy is not the ultimate answer to the funding dilemma; however, it represents a viable alternative financing mechanism to encourage the acquisition of assistive technology to respond to individual needs.

Response To: Findings 7, 8, 10, 11

Implementation strategy: Amend the tax code.

Jurisdiction: Senate Committee on Finance
House Committee on Ways and Means

Recommendation 15

Authorize by statute universal product design guidelines for application in the manufacturing of electronic equipment and other products to enhance accessibility by individuals with disabilities.

Functional limitations prevent and restrain individuals with disabilities from being able to perform daily activities. Electronic equipment in the home and workplace serves as a critical means to increased productivity and independence. There are three distinct types of functional limitations that can restrain or prevent the use of electronic equipment as diverse as the computer and the telephone. The three types of limitations are:

1. Physical/motor problems that limit an individual's ability to manipulate controls;
2. Sensory problems that limit an individual's ability to receive information and feedback; and

3. Cognitive limitations that adversely affect an individual's ability to process information.

The concept of universal product design is an approach that responds to the needs of individuals with functional limitations in the design stage of product development and eliminates or reduces the need for additional or specialized equipment. According to Carl Brown, a technology consultant and former IBM executive who testified before the Council, universal product design is defined as a design that can be readily understood and easily used by all people regardless of physical ability, language, age, sex, or any other human attribute. He explained that universal product design is generally impossible for 100 percent of the population, but "designers and manufacturers can accomplish a great deal if their awareness to people's abilities and their sensitivity to impairments are increased."

The principles of universal design have been introduced in public policy with the addition of Section 508 of the Rehabilitation Act in 1986, the passage of the Telecommunication Accessibility Enhancement Act of 1988, and the passage of the Decoder Circuitry Act in 1990. Section 508 directs the General Services Administration (GSA) to develop federal procurement guidelines that would ensure accessibility to electronic office equipment by individuals with disabilities. The intent of the legislation is either to build standard options into the design of electronic office equipment that respond to the needs of individuals with varied functional limitations or to design equipment embracing the concept of compatibility with specialized equipment. With Section 508, Congress is relying on the federal government's strength and status as the largest purchaser of office equipment in the United States to effect change in the basic design of products to benefit persons with disabilities.

In 1988, the Telecommunications Accessibility Enhancement Act (P.L. 100-542) extended accessibility guidelines to ensure that individuals with hearing and speech disabilities were able to communicate with and within the federal government. With both of these legislative mandates, GSA has oversight responsibilities to ensure that all federal agency procurement actions adequately address GSA accessibility guidelines and that industry is making progress in providing accessible technology.

The Tech Act extends the requirements of Section 508 to state procurement practices. Section 508, through federal and state procurement policies and practices, has great potential to impact the design of equipment for individuals with varying abilities and to eliminate the need for and cost of specialized equipment.

A universal design approach of a somewhat different nature was incorporated by Congress in 1990 with the passage of the Decoder Circuitry Act. This law requires televisions with screens larger than 13 inches to include decoder circuitry. By flipping a switch on the television, persons with hearing impairments will be able to see captioned programs. The added cost to the manufacturing of televisions is estimated at three to five dollars per set. This new design feature will eliminate the need for a separate piece of equipment that now costs \$150 to \$200 to achieve the same function.

The Council believes strongly that the universal product design concept can reduce the need for specialized equipment, eliminate unnecessary expenditures of limited resources, and create an affirmative obligation on designers and manufacturers to build in standard options and compatibility with specialized equipment.

The Council recommends adding a new Section to Title V of the Rehabilitation Act to expand the universal product design policies already in place through Section 508. The new Section would authorize NIDRR—in concert with the proposed Federal Interagency Coordination Council, the Clearinghouse on Computer Accommodation, private industry, and persons with varying disabilities—to develop and implement universal product design guidelines for the manufacturing of electronic equipment to enhance accessibility by individuals with disabilities. Such guidelines would be developed over an 18-month period with timelines for implementation to extend these universal design guidelines to all electronic equipment for sale in the United States. The Council recognizes the formidable challenge presented by the development of such guidelines. Standard design features must not jeopardize the affordability of products. However, such accessibility guidelines must respond to three major concerns:

1. Is the product or service compatible with other devices or services with which it has to work?
2. Has the product design responded to the need for access, use, and information in redundant forms such as text and speech and multiple operating systems?
3. Are there ways to enhance the user-friendly features of the product or service?

In a post-ADA environment, public policy must continue to explore the nexus between civil rights and accessibility. The ADA has set a new standard for access in employment, public accommodations, transportation, and communications. Accessibility in buildings, telephone services, and places of

employment will be achieved through a range of "reasonable accommodations" required under the Act. Assistive technology will continue to be a critical tool to achieve reasonable accommodation. The Council believes it makes good sense to extend the concept of "reasonable accommodation" back to the point of product design as part of the umbrella of civil rights protections now afforded Americans with disabilities.

Response to: Findings 1, 10, 11

Implementation strategy: Amend Title V of the Rehabilitation Act

Jurisdiction: Senate Subcommittee on Disability Policy
House Subcommittee on Select Education

Recommendation 16

Amend the Communications Act of 1934 to establish and implement a national policy of available, affordable, and accessible telecommunication services to Americans with disabilities.

The term *telecommunications* has become synonymous with any method used to deliver and communicate information electronically. With emerging technologies, no longer can the definition of the term be limited to telephones. It is a term now associated with the merging and overlapping areas of computers, cable, television, radio, and microwaves and cellular transmission. At issue is the transfer of information in multiple mediums and formats. Without affordable access to information in its myriad forms, individuals with disabilities will not enjoy the full benefits of American social and economic life.

In the following set of recommendations, the Council believes a logical sequence of legislative actions can be encouraged that will lead to establishing and implementing an overarching national policy of access to telecommunications by and for individuals with disabilities:

1. Seek an executive order to mandate full access to the Federal Telephone System for voice communications and all forms of information transmission, processing, and exchange. Affected individuals include those with limitations in vision, motion, and cognition as well as hearing and speech. The Office of GSA Information Resources Management and the Clearinghouse On Computer Accommodation (COCA) should continue to take the lead with training, technical support, and information exchange activities across federal agencies. An executive order would reaffirm the

highest level of commitment to advancing access to information technology for persons with different kinds of disabilities who are government employees or beneficiaries of government services. With the assistance of COCA, the federal government can set an example for private business and industry and state and local government.

2. Encourage the Federal Communications Commission (FCC) to assign an expert on telecommunications issues and their impact on individuals with physical, cognitive, and sensory disabilities. The FCC will be making major decisions in the next three years through its technical rule-making actions on the scope and standards for emerging telecommunications products and services. The Commission should immediately invite knowledgeable individuals with disabilities to examine new technologies and proposed products and services with the intent to evaluate ease of use, redundancy features of access, and affordability. These issues should be considered by the FCC as it sets new policies and grants authority for the provision of expanded services to the telecommunications user.
3. Amend the Communications Act of 1934 to clearly incorporate universal product design guidelines in the manufacturing of telecommunications equipment and the provision of services, including information networks. As discussed in Recommendation 15, focusing attention on design features that maximize ease of use by persons with varying functional limitations and responding to diverse needs with redundancy of input and output modalities will ultimately make the emerging expanded telecommunications network accessible to Americans with disabilities. The challenges are formidable. Lack of information accessibility will give rise to a new type of second-class citizenship for persons with disabilities— isolation of the "information poor." The cost of universal access in light of a post-ADA environment must be a shared cost of all telecommunications users. Much like the shared cost of relay service required under Title IV of the ADA, the concept of universal telecommunications access is a logical next step to define the full rights of citizenship for persons with disabilities.
4. At the state level, encourage public utility commissions, in conjunction with the National Association of Regulatory Utility Commissioners (NARUC) and the disability community, to develop consistent definitions of individuals with disabilities with respect to use of telecommunications, eligibility for services, and specialized customer premises equipment under mandated or permissive state

legislation and to develop a model program based upon the best features of existing state programs for the distribution, training, and maintenance of specialized customer premise equipment.

The ADA focuses on eliminating barriers to full participation by persons with disabilities in the mainstream. The goal of the ADA is not to "cure" the person with a disability but to cure the problems in the environment that serve as barriers to participation. Title IV of the ADA guaranteed access to one segment of the disability population by requiring a nationwide system of relay services for text telephone users. In a post-ADA environment, the needs of Americans with disabilities should not be ignored by the changes taking place in the telecommunications industry.

Telecommunications is a highly regulated industry at the state and federal levels. A dialogue has just begun and must continue among disability organizations, the telecommunications industry, and regulators. The dialogue must continue with NARUC to push for elimination of present inconsistencies among states in the provision, cost, and availability of specialized customer premises equipment and services. Equipment in the future will be defined broadly to include in addition to text telephones, other types of communication devices, terminals, and monitors that provide access solutions to individuals with various types of disabilities. In more than 20 states, all telephone customers are supporting, through a user surcharge, a specialized customer premise equipment loan program at no or limited cost to the user with a disability. State utility commissions should be encouraged to require local common carriers to provide such equipment and value-added services (VAS) at affordable rates, with a variety of finance options to individuals with disabilities.

The Council also recommends the passage of state legislation to protect the access interests of individuals with disabilities regarding the provision of state and local publicly operated telecommunications programs and services such as information kiosks, electronic town halls/meetings, voting, or other such interactive services.

The Council has targeted the multiple challenges of access to the new emerging technologies, their interaction, and service options in telecommunications as an area in need of further study and research.

Response to: Findings 1, 5, 7, 8, 10, 11

Implementation strategy: Amend the Communications Act of 1934. Work closely with COCA and the FCC to implement proposed activities as described above. Seek the support and interest of NARUC,

knowledgeable persons with disabilities, and the telecommunications industry to develop universal product design guidelines and proposed state level activities.

Jurisdiction: Senate Committee on Commerce, Science and
Transportation
House Committee on Energy and Commerce
Federal Communications Commission
State Public Utility Commissions

TOPICS FOR FURTHER RESEARCH

Lack of awareness and knowledge of appropriate assistive technology solutions and funding options among individuals with disabilities, family members, and advocates, as well as professionals, providers, and policymakers, continues to be identified as a major barrier to access. The suggestions that follow focus on the need for additional policy research that recognizes the interrelationship between the knowledge gap and the current shortcomings of the funding picture.

Cost Benefits of Assistive Technology

As part of this study, the Council conducted an analysis of the costs and benefits of providing assistive technology devices and related service for a random sample of more than 136 individuals with physical, sensory, or multiple disabilities (see Supplementary Reading, Report 7). The findings from this small sample are clearly indicative of positive cost-benefit; however, the sample numbers must be expanded to validate further the research findings. Therefore, the Council recommends the funding of a larger study with more individuals who are users of assistive technology. Information is needed as background for decisions on financing policy and in particular on the relationship between assistive technology and the need for and use of services. The role of assistive technology should be reviewed in relation to:

- Income maintenance versus employment;
- Hospitalization/nursing homes/institutional care versus living at home in the community;
- Full-time home health and personal assistance services versus intermittent assistance or assistance that phases down; and
- Short-term versus long-term outcomes.

Research on the costs and benefits must be tied to quality-of-life issues for individuals with disabilities. There is a need to learn more about the impact on health status, independence, productivity, community inclusion, satisfaction, and prevention of secondary disabilities. Expanded knowledge about the impact of assistive technology in people's lives should favorably influence policymakers and funding decision makers at all levels who are faced with the difficult choices of resource allocation and diverse unmet needs. Such research must not be limited solely to dollar issues. NCD, working closely with NIDRR and a broad-based advisory committee, would be an appropriate partnership to conduct this type of cost-benefit research.

Individual Choice and Control

The typical method of purchasing assistive technology (other than personal financing) is through cumbersome, time-consuming, professionally driven procedures. Consistent with the findings of this study and the tenets of the ADA for empowerment of people with disabilities, the Council recommends that demonstrations should be conducted on voucher programs and other mechanisms that give maximum choice and control to individuals with disabilities and to their families, as appropriate. One approach is to compare individual outcomes, including user satisfaction, in voucher versus more traditional assistive technology financing programs.

Research should also be conducted on the effectiveness of peer support and self-advocacy in increasing access to financing for assistive technology and on strategies to focus on individual choice and control within the planning mechanisms of existing individual programs.

Selection and Funding Approval

For the potential technology user with disabilities, nothing is more difficult than the sense of powerlessness in a third-party funding system that has unpredictable and inconsistent standards for assistive technology devices and services selection and funding approval. Research is needed to define and quantify the reported inconsistencies and to develop and field test a set of procedures for decision making on assistive technology that is more predictable and consistent within individual and across federally funded programs. The findings from the research could then be translated into a set of field-tested, competency-based training modules and standards for all providers and decision makers across third-party funders, including persons with disabilities and parents of children with disabilities. This research project should be completed with the assistance of a broad-based advisory committee.

Telecommunications Access

The rapidly changing field of telecommunications raises important issues for all persons with disabilities. New technologies offer opportunities for speech input and output and the availability in one's home of a vast array of information and other services. Functional limitations must not be a barrier to access if people with disabilities are to have the equal opportunity promised in the ADA. Additional research should be conducted to define what is needed to make the emerging telecommunications network more accessible to and affordable for a person with a disability. The research needs to focus on universal product design. Recent court rulings and pending legislation make it a critical time to define universal access for all Americans. NCD, in concert

with the FCC and a diverse advisory committee, should take a lead role in such a research effort.

Tax Issues

In Recommendation 13 of this study, the Council asked the Department of the Treasury to develop a cohesive set of tax policies on assistive technology for persons with disabilities that clarifies national values and goals as articulated in the ADA and the Tech Act. Before comprehensive policies can be developed, research is needed on the impact of current tax policy on families who have dependents with disabilities, including accurate information on the extraordinary costs of caring for a dependent with disabilities.

CONCLUSION

If all individuals with disabilities had ready access to reliable information on assistive technology devices and services, to provide referral points to a distribution or service delivery system that is obligated to not turn away any customers, there would be no need for this study and report.

If individuals with disabilities and their families had effective purchasing power, the competitive forces in a free market system would respond with a distribution and service delivery system that places a premium on customer needs. These needs would include easy access, reasonable price structure, a well-trained and informed sales force, reliable maintenance and repair services, and a user-friendly and dependable product line.

The distinguished Advisory Panel to the National Council for this study shared a vision of access to assistive technology devices and services that was as attractive and accessible as a neighborhood hardware store. The sales force was responsive to customer questions and could compare the benefits and limitations of different product lines. Products were demonstrated and customers were allowed to have a hands-on experience in the store or at home, with a trial loan on a short-term basis. Selected products were available on a rental basis in addition to purchase and financing options. Trade-ins were encouraged, and repair service contracts were offered for all products. Appropriate referrals would be made for group and individualized instruction on more difficult to learn products. Product modification and customization services, to respond to individualized needs, would be available by appointment. The one-stop Assistive Technology Shop would be conveniently located in shopping malls in population centers across the country, with a diverse product line of aids and equipment to enhance functional abilities in mobility, communication, education, employment, and independent living.

Without personal purchasing power, individuals with disabilities are unlikely to benefit from such a distribution system. However, the experiences and viewpoints of individuals with disabilities and their families heard by the Council at three regional forums present a clear picture of what might be possible with the promotion and acceptance of the principle of a technology imperative. We live in a world where technology assistance is pervasive and becoming more routine and easier to use in the home, the classroom, and workplace. For Americans without disabilities, technology makes things easier.

For Americans with disabilities, technology makes things possible. The technology imperative principle recognizes the value of assistive technology in the life of an individual with a disability as a necessity for inclusion and

independence. The combination of options offered by these 16 recommendations provides a blueprint for systems change.

The urgent voices of families, complemented by the cogent statements of professionals, emphasized the simple but subtle distinction between understanding and insisting upon access to assistive technology as a necessity rather than a luxury.

In 1982, the Office of Technology Assessment raised many of the same implications for reform of federal policies and programs that have been addressed in this report. (Office of Technology Assessment, 1982) Systematic analysis of the proposed policy options contained herein must be brought to bear on these issues as a basis for action to avoid repetition of this exercise in the year 2002.

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APPENDIX A

**Biographical Information:
Members and Staff of the National Council on Disability**

NATIONAL COUNCIL MEMBER AND STAFF BIOGRAPHIES

National Council Members

John A. Gannon, Acting Chairperson

John Gannon of Cleveland, Ohio, and Washington, D.C., founded John A. Gannon and Associates. His firm has offices in Columbus and Cleveland, Ohio; Denver, Colorado; and Washington, D.C. A fire fighter for more than 30 years, Mr. Gannon was an active leader of the International Association of Fire Fighters (IAFF) Local 93. Starting as a member of the local IAFF committee, he eventually became president, a position he held for 10 years before being elected to national office.

In September 1988, Mr. Gannon was elected IAFF President Emeritus. He had served as president of the 170,000-member organization since 1980. Under his leadership, the IAFF expanded its role in occupational safety and health. Concerned about the hazards of his profession, he guided and directed a series of programs to promote greater safety and health protection. One program sponsored research on safer garments and equipment for fire fighters. Mr. Gannon also fostered development of the IAFF Burn Foundation, which raises funds for research on the care of people who have experienced severe burns. In 1985, the Metropolitan General Hospital in Cleveland dedicated a John Gannon Burn and Trauma Center in recognition of his support for the hospital.

Mr. Gannon was elected vice president of the AFL-CIO, with which the IAFF is affiliated. Within the AFL-CIO he is vice president of the Public Employee Department. On the Executive Council, he is a member of several committees. He serves on the board of the National Joint Council of Fire Service Organizations and in 1982 served as its chairman. He is a member of the board of the Muscular Dystrophy Association. Mr. Gannon attended Miami University in Ohio and Glasgow University in Scotland, and studied at Baldwin-Wallace College and Cleveland State University.

Kent Waldrep, Jr., Vice Chairperson

Kent Waldrep has been involved with disability issues on the local, state, and national level since suffering a spinal cord injury in 1974 while playing football for Texas Christian University. Since 1981, Mr. Waldrep has served on the National Council by presidential appointment. He is National Council vice chairperson and chairman of the Research and Prevention

Committee. He was instrumental in formulating the National Council initiative on preventing primary and secondary disabilities.

Mr. Waldrep, one of 15 original drafters of the Americans with Disabilities Act, gave the legislation its name. He has lectured nationwide on subjects ranging from national disability policy to medical research targeted at curing paralysis. He founded the American Paralysis Association and the Kent Waldrep National Paralysis Foundation. He has appeared on *Good Morning America*, the *Today Show*, the *NBC Nightly News*, and CNN, and been featured in *People*, *Look*, *USA Today*, and other magazines.

He was selected by the U.S. Jaycees as one of 1985's ten Outstanding Young Men in America and received a special award from the Texas Sports Hall of Fame and a sports/fitness award from the President's Council on Physical Fitness. Kent Waldrep Days have been celebrated in four Texas cities and Birmingham, Alabama. He serves on many boards, including the Texas Rehabilitation Commission. He is past chairman of the Texas Governor's Committee for Disabled Persons and the Dallas Rehabilitation Institute. He also is chairman of Turbo-Resins, Inc., a family-owned and -operated aviation repair business. He lives in Plano, Texas, with his wife Lynn and two sons, Trey and Charles Cavanaugh.

Linda Wickett Allison

Linda Allison of Dallas, Texas, is a long-time advocate of people with disabilities. She is a board member of the National Paralysis Foundation and a trustee for the International Spinal Research Trust. Mrs. Allison, who grew up in Fort Worth, has three children. Her daughter Marcy was paralyzed from the waist down in a 1979 automobile accident. Marcy graduated from the University of Texas School of Law in 1986 and practices law in Austin. Mrs. Allison's late husband, James N. Allison, Jr., owned the *Midland Reporter Telegram* and other newspapers in Texas and Colorado and was former deputy chair of the Republican National Committee.

Ellis B. Bodron

Ellis Bodron of Vicksburg, Mississippi, has been a practicing attorney since 1947. He served 36 years as a member of the Mississippi legislature, one term in the House of Representatives and eight terms in the Mississippi Senate. He also chaired the Senate Finance Committee from 1961 until 1983.

Mr. Bodron, who is blind, is associated with several civic organizations, including the Vicksburg Lions Club, Vicksburg Chamber of Commerce, and the

University of Mississippi Alumni Association. In addition, he is a member of the Advisory Board of Directors, Deposit Guaranty National Bank.

Mr. Bodron has also been a member of the Agriculture and Industrial Board, which preceded the Board of Economic Development, and the Committee of Budget and Accounting and Board of Trustees of the Mississippi Public Employees Retirement System.

Ellis Bodron graduated with a Bachelor of Arts and a Bachelor of Law Degree from the University of Mississippi. He is married with two children.

Larry Brown, Jr.

Since 1981, Larry Brown of Potomac, Maryland, has been the Xerox business and community relations manager for the Mid-Atlantic Region, Coastal Operations, Custom Systems Division. In 1991 he became Government and Community Relations Manager with Integrated Systems Operations.

Mr. Brown was a running back for the Washington Redskins for eight years. During that time he received many awards, including Most Valuable Player in the National Football League for 1972. He was inducted into the Washington, D.C., Touchdown Hall of Fame in 1991.

After retiring from football in 1977, he worked at E.F. Hutton as a personal financial management adviser. He has been special assistant to the director, Office of Minority Business Enterprise, Department of Commerce. He is involved with youth, people with disabilities, and senior citizens. Mr. Brown has spoken at schools, colleges, and universities on topics such as motivation, discipline, and camaraderie. He works with many organizations, including the Friends of the National Institute on Deafness and Other Communication Disorders, the Deafness Research Foundation, and the Vincent Lombardi Foundation.

Mary Ann Mobley Collins

A former Miss America who lives in Beverly Hills, California, Mary Ann Collins has a career in film and television and on Broadway. She has co-hosted the National March of Dimes telethons with her husband, Emmy-award-winning actor Gary Collins; she is a member of the National Board of the March of Dimes Foundation and is national chair of the Mother's March against Birth Defects. She is a member of SHARE, a Los Angeles-based women's organization that has raised more than \$6 million for the Exceptional Children's Foundation for the Mentally Retarded. She serves on the National Board of the Crohns and Colitis Foundation.

Mrs. Collins helped raise funds for the Willowood Foundation in her native Mississippi, which provides homes for young adults with mental and physical learning disabilities. She has received many awards and honors, including the 1990 International Humanitarian Award from the Institute for Human Understanding, Woman of Distinction 1990 from the National Foundation for Ileitis and Colitis, and the HELP Humanitarian Award of 1985 from HELP for Handicapped Children. She has filmed documentaries in Cambodia, Ethiopia, Mozambique, Somalia, Kenya, Sudan, and Bolivia on the plight of starving children and people with disabilities.

Anthony H. Flack

Anthony Flack of Norwalk, Connecticut, is president of Anthony H. Flack & Associates. He has been a member of the board of Families and Children's Aid of Greater Norwalk and has worked with the Child Guidance Center of Greater Bridgeport, the Youth Shelter in Greenwich, Hall Neighborhood House in Bridgeport, and the Urban League of Greater Bridgeport. Mr. Flack is a member of the Allocations and Admissions Committee, United Way of Norwalk, and received the Bell Award for outstanding service in the field of mental health at the Bridgeport Chapter, Connecticut Association of Mental Health.

John Leopold

John Leopold of Pasadena, Maryland, has 18 years' experience in elected state office. He was elected to the Hawaii State House of Representatives in 1968 and was re-elected in 1972. In 1974, Mr. Leopold was elected to the Hawaii State Senate. In 1982, he became the first Republican in Maryland history elected from District 31 in Anne Arundel County to the Maryland House of Delegates, where he served until 1991.

An advocate of people with disabilities, Mr. Leopold is a member of the Learning Disabilities Association of Anne Arundel County, the Anne Arundel County Committee on Employment of People With Disabilities, and the University of Maryland Hospital Infant Study Center Planning Advisory Board. He has served in other appointed and elected positions, including the Hawaii State Board of Education in 1968, the National Advisory Council for the Education of Disadvantaged Children in 1977, and the Maryland State Accountability Task Force for Public Education in 1974.

Mr. Leopold has written and produced cable television commercials in Maryland, written a weekly interview column for a local publication, and hosted and produced a weekly radio public affairs program. He graduated from Hamilton College in Clinton, New York, with a B.A. in English.

Robert S. Muller

Robert Muller of Grandville, Michigan, began his career with Steelcase, Inc., in 1966 and is now an administrator in human resources. He is an adjunct professor in the Department of Psychology at Aquinas College and in the Department of Education at Calvin College in Grand Rapids. He serves on the board of trustees for Hope Network and Foundation in Grand Rapids, which serves 1,700 adults with disabilities. In April 1981, he received an honorary degree in educational psychology from the Free University in Amsterdam, the Netherlands.

Mr. Muller holds a B.S. in business administration from Aquinas College and in 1978 was voted Outstanding Alumnus of the Year. He has lectured at colleges and universities nationally and internationally. He is a board member for several national, state, and local organizations.

In May 1987, Mr. Muller and his wife Carol hosted a first-time event at the White House with the vice president. The Celebration of Disabled Americans at Work was co-sponsored by several major corporations. Mr. Muller now serves as president of the National Roundtable on Corporate Development for Americans with Disabilities. In 1985, he received the Liberty Bell Award from the Grand Rapids Bar Association. In 1988, he was national co-chair of the Disabled Americans for President Bush Campaign and in 1992 was an honorary national member of the Bush/Quayle Disability Coalition Campaign. In November 1992, Mr. Muller was appointed to the Governor's Commission on Handicapped Concerns for Michigan.

George H. Oberle, P.E.D.

Dr. George Oberle of Stillwater, Oklahoma, has more than 40 years' experience in the field of health, physical education, and recreation. He began his career as a high school teacher and coach, and has been a professor and director of the School of Health, Physical Education and Leisure at Oklahoma State University since 1974. Dr. Oberle is a consultant to many organizations in the area of administration and adaptive physical education. In 1988, he worked with the Kennedy Foundation to organize and direct a new program of Unified Sports for the Special Olympics.

Dr. Oberle chaired the College and University Administrators Council (1980-82); was president of the Association for Research, Administration, Professional Councils and Societies (1984-87); and served as a board member of the American Alliance of Health, Physical Education, Recreation and Dance (1985-89). Awards include the 1985 Centennial Award from the American

Association of Health, Physical Education, Recreation and Dance; and Meritorious Service Awards from Indiana and Oklahoma.

He was selected for *Men of Achievement* in 1975 and recognized in *Who's Who of the Southwest* in 1977. Dr. Oberle received his doctorate from Indiana University in administration and adapted physical education. He lectures extensively about wellness promotion, adapted physical activity, sports, and recreation for people with disabilities.

Sandra Swift Parrino

As a member and former chairperson of the National Council, Sandra Swift Parrino has played an active role in key issues affecting the lives of people with disabilities. Nominated by President Reagan in 1982, appointed chair by the President in 1983, and reappointed by President Bush, Sandra Parrino has supported the rights of people with disabilities before Congress, in the media, and before groups nationwide. Under her leadership, the National Council has been a driving force to create public policies that affect the nation's people with disabilities.

During her tenure as chair, the National Council worked for the creation and enactment of legislation for people with disabilities; issued a policy statement, *National Policy for Persons With Disabilities*; convened hearings nationwide to solicit comments and recommendations from people with disabilities about how to eliminate discrimination; issued a major report, *Toward Independence*, that outlines key components of a comprehensive civil rights law protecting people with disabilities; initiated the first national survey of attitudes and experiences of Americans with disabilities, in conjunction with Louis Harris and Associates, Inc.; issued *On the Threshold of Independence*, a report outlining specifics of the Americans with Disabilities Act; created and developed the Americans with Disabilities Act; participated with President Bush at the signing of the Americans with Disabilities Act; conducted the first National Conference on the Prevention of Primary and Secondary Disabilities; issued reports on minorities with disabilities and personal assistance services; and planned reports on health insurance, financing assistive technology, and educating students with disabilities.

Before becoming National Council chair, Sandra Parrino founded and directed the Office for the Disabled, in Ossining and Briarcliff Manor, New York, where she created a regional program for public and private organizations that focused on programs for people with disabilities and compliance with 504. She has more than 25 years' experience on boards, councils, commissions, committees, and task forces at the federal, regional,

state, and local levels and as an expert witness, community leader, organizer, and activist.

Mrs. Parrino has represented the U.S. government on disability issues in many countries. She has been invited by the Department of State to represent the United States at the Meetings of Experts in Finland and China, and represented the United States at the United Nations Center for Social Development in Vienna several times. In 1990, 1991, and 1992 she was a delegate at the Third Committee on Social Development of the United Nations. In 1991, she was invited by the People's Republic of China to assist them in their efforts to help people with disabilities. At the request of the government of Czechoslovakia, she and the National Council were invited to conduct the Eastern European Conference on Disabilities for participants from Czechoslovakia, Poland, and Hungary.

Mrs. Parrino graduated from Briarcliff College with a B.A. in history, and completed courses at Bennett College, GuildHall School of Drama in London, and the Yale School of Languages. In 1992, Mrs. Parrino received an Honorary Doctorate of Humane Letters from St. John's University in New York. Her husband Richard is a rheumatologist. They have three children, two of whom have disabilities. Sandra Parrino was born in New Haven, Connecticut, and lives in Briarcliff Manor, New York.

Mary Matthews Raether

Mary Raether of McLean, Virginia, is associated with St. John's Child Development Center, a nonprofit organization providing instruction, employment training, and independent and group home living skills for people with severe mental disabilities, especially autism. Mrs. Raether has been an officer and trustee of St. John's since 1985, has chaired the public relations committee, and participated on the executive, nominating, investment, and development committees.

Mrs. Raether has been active in civic, educational, and religious organizations in the Washington metropolitan area. While community vice president of the Junior League of Washington, she developed emergency grant procedures and fund-raising information services for small and emerging nonprofit organizations. Mrs. Raether has 10 years' experience as legislative assistant to Reps. George Bush and Barber Conable. She specialized in tax, social security, medicare/medicaid, and trade issues. She considers her efforts in clarifying the tax status of lobbying by nonprofit organizations an outstanding career accomplishment. She received a B.A. from the University of Texas at Austin in 1962. She is married and has two children.

Anne Crellin Seggerman

Anne Crellin Seggerman of Fairfield, Connecticut, is the founder of Fourth World Foundation, Inc., a company engaged in the development of interfaith media.

A member of the Bridgeport Urban Gardens and Youth at Risk/Breakthrough Foundation, Mrs. Seggerman founded and serves as the chairman of the board of the Fairfield County Chapter of Huxley Institute for Biosocial Research. She previously was a member of the President's Committee on Mental Retardation.

Mrs. Seggerman is listed in *Who's Who of American Women* and has received numerous honors including an Honorary Doctor of Humane Letters Award from Sacred Heart University, the Association of Knights and Ladies of the Holy Sepulchre, and the American Association of the Order of Malta. She was previously appointed to serve on the Housing of Handicapped Families of the Department of Housing and Urban Development.

Mrs. Seggerman is experienced in providing care, treatment, and rehabilitation to people with schizophrenia and has extensive experience with alcoholics and children with learning disabilities. She is married and has six adult children.

Michael B. Unhjem

Michael Unhjem of Fargo, North Dakota, is president of Blue Cross Blue Shield of North Dakota. He is the youngest person ever elected to the North Dakota House of Representatives, a member of the National Conference of Commissioners on Uniform State Laws, and he served in 1988 as president of the National Mental Health Association.

Mr. Unhjem has been involved in local and national organizations, including the Advisory Mental Health Council of the U.S. Department of Health and Human Services; the Governor's Commission on Mental Health Services; the National Alliance for Research on Schizophrenia and Depression; and the National Mental Health Leadership Forum. Awards include the 1989 Special Presidential Commendation from the American Psychiatric Association, the 1988 Distinguished Leadership Award from the North Dakota Psychological Association, and the National Excellence in Leadership Award from North Dakota.

He has been recognized by *Who's Who in American Politics*, *Who's Who in North Dakota*, *Who's Who in the Midwest*, *Personalities of America*, and *Men of*

Achievement. Mr. Unhjem graduated magna cum laude with a B.A. in history and political science from Jamestown College in North Dakota in 1975. In 1978, he earned a J.D. with distinction from the University of North Dakota School of Law in Grand Forks. He is married and has two children.

Helen Wilshire Walsh

Helen Walsh of Greenwich, Connecticut, is a board member of the Rehabilitation Institute of Chicago, the largest U.S. rehabilitation center. She has been involved in disability advocacy for many years and has been associated with the Institute of Rehabilitation Medicine at the New York Medical Center, where she served as associate trustee. She has served as vice president, president, and chairman of the board of Rehabilitation International USA.

Ms. Walsh has been a member of the President's Committee on the Employment of People With Disabilities, and was appointed by the President to serve as a member of the National Advisory Council of Vocational Rehabilitation. In 1976, Ms. Walsh received the Henry J. Kessler Award for outstanding service in the rehabilitation field. She has received the Rehabilitation International Award for Women and the Anwar Sadat Award for outstanding work in the field of rehabilitation.

National Council Staff

Andrew I. Batavia

Andrew I. Batavia is executive director of the National Council on Disability. He formerly served as research director for Disability and Rehabilitation Policy at Abt Associates. Prior to joining Abt, he was associate director of the White House Domestic Policy Council, where he was responsible for coordinating federal policy on health care, disability, housing, education, and veterans affairs. He received his bachelor's degree in economics and sociology from the University of California, his master's degree in health services research from Stanford Medical School, and his jurisdoctorate degree from Harvard Law School.

After law school, Mr. Batavia served for two years as an attorney for the U.S. Department of Health and Human Services. He left that position in 1986 when he was awarded the Mary E. Switzer Distinguished Research Fellowship in Medical Rehabilitation Finance from the National Institute on Disability and Rehabilitation Research (NIDRR) of the U.S. Department of Education. He then served for four years as associate director for Health Services Research at the National Rehabilitation Hospital Research Center in Washington, D.C. In that

capacity, he wrote 2 books and more than 20 other publications on issues of disability and health care policy.

In 1987, Mr. Batavia was made a Fellow of the Washington Academy of Sciences. In 1988, he was awarded the Distinguished Disabled American Award from the President's Commission on Employment of People with Disabilities. In 1989, he received an International Fellowship from the International Disability Exchanges and Studies (IDEAS) Program of NIDRR, and conducted research on how the Dutch Health Care System affects people with disabilities. In 1990, he was appointed a White House Fellow by President Bush and served as special assistant to Attorney General Richard Thornburgh at the U.S. Department of Justice.

Mr. Batavia is the founding associate editor of the *Journal of Disability Policy Studies* and a cofounding board member of Independent Living Assistance, Inc. He is an adjunct assistant professor at the Georgetown University School of Medicine and a member of the Bar of the U.S. Supreme Court, the Bar of the District of Columbia, the State Bar of California, and Georgetown's Kennedy Institute of Ethics.

Billie Jean Hill

Billie Jean Hill joined the staff of the National Council on Disability as program specialist in March 1992. Previously, Ms. Hill was director of communications and editor for the Blinded Veterans Association and earlier served as founding director of a statewide broadcast service for persons with reading disabilities with Mississippi Educational Television in her home state. She was appointed to work on a governor's commission in Mississippi to report on the needs of children and youth in rural Mississippi who are disabled. Ms. Hill studied journalism and education at Mississippi University for Women and at the University of London in England. She serves as chairperson of the Board of Publications for the American Council of the Blind.

Mark S. Quigley

Mark Quigley joined the staff as a public affairs specialist in May 1990. He previously served as a consultant to the U.S. National Commission on Drug-Free Schools. He is a former program coordinator at the U.S. Interagency Council on the Homeless and former director of communications at the White House Conference on Small Business. Mr. Quigley graduated *magna cum laude* in 1979 from Northern Virginia Community College in Annandale, Virginia, with an A.A. in general studies. He received a B.A. in government and politics in 1983, and an M.P.A. in public administration in 1990 from George Mason University in Fairfax, Virginia.

Brenda Bratton

Brenda Bratton, executive secretary for the National Council, was formerly employed as a secretary at the National Transportation Safety Board. Ms. Bratton graduated from Farmville Central High School and the Washington School for Secretaries.

Stacey S. Brown

Stacey Brown is staff assistant to the chairperson and has been employed by the National Council since 1986. Prior experience includes employment as a receptionist and clerk with the Board for International Broadcasting and with the Compliance and Enforcement Unit of the Architectural and Transportation Barriers Compliance Board, where he was a student assistant. Mr. Brown is a graduate of Howard University in Washington, D.C., where he earned a B.A. in political science in 1987.

Janice Mack

Janice Mack, who serves as the administrative officer for the National Council, was formerly employed with the National Oceanic and Atmospheric Administration. Ms. Mack graduated from Calvin Coolidge High School.

Lorraine Williams

Lorraine Williams is office automation clerk for the National Council. She graduated from Valdosta High School in Valdosta, Georgia, and attends Strayer College, where she is majoring in computer information systems science.

APPENDIX B

List of Participants at Three Regional Public Forums

**National Council on Disability
Public Forums on Assistive Technology Funding
for Children and Adults With Disabilities**

**Los Angeles, California
March 21-22, 1991**

Opening Statement

Sandra Swift Parrino
Chairperson

National Council on Disability
Washington, DC

Moderator

Dr. George Oberle

Chairperson, Committee on Technology
National Council on Disability
Washington, DC

Panel I

Children and Technology

Martin and Eva Sweeney
Los Angeles, California

Suzanne Feit, Director
Special Awareness Computer Center
Simi Valley, California

Laurel and Stacy Gainok
Lakeside, California

Ron Thorkildsen, Ph.D., Co-Director
Utah State Program for Technology
Related Assistance for Individuals
With Disabilities
Utah State University
Logan, Utah

Rachei Wobschall, Executive
Director
Governor's Advisory Council on
Technology for People With
Disabilities – Minnesota State
Planning Agency
St. Paul, Minnesota

Panel II

**Selected Title I Program Directors
and Funding Experts**

Andrew Winnegar, Director
New Mexico Technology Assistance
Project for Individuals With
Disabilities
Division of Vocational Rehabilitation
Santa Fe, New Mexico

Panel III

**Providers, Suppliers and
Manufacturers of Assistive
Technology**

Anna Hofmann, Marketing
Coordinator
Phonic Ear Inc.
Mill Valley, California

Margaret Barker, Head
Communications/Control Services
Rehabilitation Engineering
Department
Childrens Hospital at Stanford
Palo Alto, California

Frank DeRuyter, Ph.D., Director
Communication Disorders
Department
Rancho Los Amigos Medical Center
Downey, California

Pat Moore, Western Regional
Rehabilitation Sales Manager
Invacare Corporation
Poway, California

Marc Stenzel, Director of National
Sales
Telesensory Systems Inc.
Mountain View, California

Panel IV
Private Health Insurers

Mary Foto, OTR, FAOTA, Senior
Allied Health Consultant
Blue Cross of California
Woodland Hills, California

H. Paul Brandes
Kaiser Foundation Health Plan, Inc.
Oakland, California

Marlys Seversen, R.N., B.S.N., Vice
President
S.C.M. Associates, Inc. (Specialized
Case Management)
Cypress, California

Michael Chee, Senior Public
Relations Specialist
Blue Cross of California
Van Nuys, California

Panel V
Public Program Representatives

Mary Ann Glicksman, Development
Director
Computer Access Center Serving
People With Disabilities
Santa Monica, California

John Duganne
Computer Access Center Serving
People With Disabilities
Santa Monica, California

Judy Montgomery, Ph.D., Director of
Special Education
Fountain Valley School District
Fountain Valley, California

Margo Dronek, Special Education
Consultant
California Department of Education
Los Angeles, California

George Delavan, M.D., State
Director of Programs for Children
with Special Health Care
Needs/Children Special Health
Services
Salt Lake City, Utah

Jeffery Graham, M.D., Medical
Director
Division of Medical Assistance
Department of Social and Health
Services
Olympia, Washington

Panel VI
Creative Solutions for System
Change

Jacquelyn Brand, Executive Director
and Founder
Alliance for Technology Access
Albany, California

Neil Scott, Special Project Engineer
Office of Disabled Students
California State University
Northridge, California

Shelley Bergum, Executive Director
Deaf and Disabled
Telecommunications Program
Oakland, California

Alan Brightman, Ph.D., Manager
Worldwide Disability Solutions
Group/Apple Computer Inc.
Cupertino, California

**Portland, Maine
July 11-12, 1991**

Opening Statement

Moderator

Dr. George Oberle
Chairperson
Committee on Technology
National Council on Disability

Panel I

Consumer Panel: Birth to Age 17

Patricia Wiltshire
Kennebunkport, Maine

Karen and Andrew Norton
Marston Mills, Massachusetts

Elaine Clemm
Warwick, Rhode Island

Catherine Huggins
Pepperell, Massachusetts

Panel II

Consumer Panel: Adults

Anne Bunker
Fair Haven, Vermont

Tom Owens
Portsmouth, New Hampshire

Melanie Stiles
Concord, New Hampshire

Rogera Robinson
Federation for Children with Special
Needs
Boston, Massachusetts

Arthur Redman
Augusta, Maine

Panel III

**Selected Title I Program Directors
and Funding Experts**

Kathleen Powers, Project
Coordinator
Maine CITE Coordinating Center
University of Maine at Augusta
Augusta, Maine

Judith Brewer, Project Coordinator
Massachusetts Assistive Technology
Project
Children's Hospital
Boston, Massachusetts

Ricki Cook, Project Director
North Carolina Assistive Technology
Project
Division of Vocational Rehabilitation
Services
Raleigh, North Carolina

Lewis Golinker, Funding
Coordinator Project Mentor/UCPA
Ithaca, New York

Panel IV

Providers

Colleen Haney, Coordinator
Pennsylvania Assistive Device
Center
Harrisburg, Pennsylvania

Linda Meyer, Ph.D., Director of
Communication Services
Woodrow Wilson Rehabilitation
Center
Fisherville, Virginia

Diane Huss, Director of Physical
Therapy
Woodrow Wilson Rehabilitation
Center
Fisherville, Virginia

Russ Holland, Director
Techspress Resource Center for
Independent Living
Utica, New York

Marcia Nunnally, MEd. OTR/L,
Private Practice
Occupational Therapy
Spartanburg, South Carolina

Panel V

Manufactures and Suppliers

Todd Brickhouse, Vice President
Hygeia Design Associates
Carle Place, New York

Barry Romich, President
Prentke Romich Co.
Wooster, Ohio

Sheron Rice, Special Projects
Administrator
American Foundation for the Blind
New York, New York

Panel VI

Insurance

Private Insurer

Richard Chamberlin, M.D.,
Corporate Medical Officer
Blue Cross of Maine
Portland, Maine

Kaye McDevitt, Director of
Rehabilitation
Disability Management Services
UNUM Life Insurance Company
Portland, Maine

Durable Medical Equipment

Vendor

Susan Grant, General Manager
Wheelchairs Unlimited
South Portland, Maine

Panel VII - Part I

**Creative Solutions for System
Change**

Joel Mittler, Ed.D, Interim Dean
School of Education
Long Island University
Brookville, New York

Jamal Mazrui, Data Base
Administrator
Harvard University
Kennedy School of Government
Alumni Office
Cambridge, Massachusetts

Panel VII - Part II

**Creative Solutions for Systems
Change**

John DeWitt, President
DeWitt & Associates
Glen Rock, New Jersey

Michael Rosen, Ph.D., Principal
Research Scientist
Newman Laboratory for
Biomechanics for Human
Rehabilitation
M.I.T.
Cambridge, Massachusetts

Alexandra Enders, OTR/L, Associate
Director
Rural Institute on Disabilities
University of Montana
Missoula, Montana

Steve Tremblay, Executive Director
Alpha One
South Portland, Maine

John Williams, Publisher/Senior
Editor of Special and Individuals
Needs Technology
Sterling, Virginia

Iris Judkins, Information Director
Department of Rights for Virginians
With Disabilities
Richmond, Virginia

**Minneapolis, Minnesota
October 17-18, 1991**

Moderator

Dr. George Oberle
Chairperson, Committee on Technology
National Council on Disability

Panel I
Senior Citizens With Disabilities
at Home and in the Community

Dennis LaBuda, President
Technology and Aging Group
Miami, Florida

Linda Wray, Co-Principal
Investigator
Fernando Torres-Gill, Ph.D.,
Principal Investigator and President,
American Society on Aging
Professors of Social Welfare
University of Southern California
Los Angeles, California

Margaret A. Christenson,
President/CEO
Lifease, Inc.
St. Paul, Minnesota

Diana Kubovecik, Options Program
Manager
Central Ohio Area on Aging
Columbus, Ohio

Panel II
Persons With Disabilities in
Institutions

Robert Prouty, Coordinator of the
National Recurring Data Set Project
on Community Integration
University of Minnesota
Minneapolis, Minnesota

**Kathleen Carmody, MSW, Director
of Choice and Integration Project
Illinois Planning Council on
Developmental Disabilities
Chicago, Illinois**

Anna Clark
Springfield, Illinois

Robert Patterson, Ph.D., Assistant
Principal Minnesota State Academy
for the Blind
Faribault, Minnesota

Panel III
Consumers: Barriers to Funding
Assistive Technology in Minority
Populations

Jean Wright, Director of Community
Service
St. Paul Society for the Blind
St. Paul, Minnesota

Sharon Johnson, Career
Rehabilitation Counselor
Government Service Center
Duluth, Minnesota

Ann and Rachel Esparza
Mendota Heights, Minnesota

Panel IV
Interagency Collaboration and
Systems Change: State Agency
Initiatives to Promote Use of
Assistive Technology as a Model
for Other States

Rachel Wobschall, Executive
Director
Governor's Advisory Council on
Technology for People With
Disabilities
Minnesota State Planning Agency on
Developmental Disabilities
St. Paul, Minnesota

Martha Beckwith, Acting Supervisor
Prior Authorization Section
Health Care Programs
Administration
St. Paul, Minnesota

Diane Mutchler, Rehabilitation
Program Specialist
Division of Rehabilitation Services
St. Paul, Minnesota

Marilyn Sorensen, Assistive
Technology Specialist
Department of Education
St. Paul, Minnesota

Donna Petersen, MHS, ScD, Chief
Department of Human Services
Services for Children with
Handicaps
Minneapolis, Minnesota

Karin Sandstrom, MSW, Acting
Deputy
Minnesota Board on Aging
St. Paul, Minnesota

Panel V
Private Health
Insurance/Medicare

Bob Griss, Senior Health Policy
Researcher
United Cerebral Palsy Associations,
Inc.
Washington, DC

Diane Baranik, Funding Specialist
STAR Program
St. Paul, Minnesota

Martin Carlson, Chairman
Consumer Task Force on Insurance
STAR Program
St. Paul, Minnesota

Barbara Bender, Director of Benefit
Alternatives
Medica, Inc.
Minneapolis, Minnesota

Steven W. Richards, M.D., Medicare
Medical Director
Blue Cross/Blue Shield of
Minnesota
St. Paul, Minnesota

Panel VI
Alternative Models for Access for
Assistive Technology

Curtis Chong, Senior Systems
Programmer
IDF Financial Services
Minneapolis, Minnesota

Jeffrey Lerner, Ph.D., Vice President
for Strategic Planning
E.C.R.I.
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Panel VII
Protecting the Right to Assistive Technology

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Virginia Richardson, Parent Training
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Panel VIII
**Telecommunications: Potential
for Improving Awareness and
Access to Technology for
Individuals With Disabilities**

Janina Sajka, General Manager
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Gregg Vanderheiden, Ph.D., Director
TRACE R&D Center
University of Wisconsin
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Carl Brown, President
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Purdys, New York

Panel IX
**Big Picture Systems Change:
Discussion Beyond ADA and Other
Issues**

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Rehabilitation Engineering Center
Electronic Industries Foundation
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Nell Bailey, Assistant Projector
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APPENDIX C

**Recent Public Policy Experience in the Area
of Assistive Technology**

During the past seven years, Congress and federal agencies have made dramatic progress in public policy that improves access to assistive technology (see Table 2, page 37). An effective funding and financing strategy must now be designed in light of 17 significant public policy developments that have occurred since 1986.

1. Amendments to the Rehabilitation Act (P.L. 99-503)

- A. In 1986, for the first time, a definition of rehabilitation engineering was added to the Act to "include a range of services and devices which can supplement and enhance individual functions...." The Amendments require each state vocational rehabilitation agency to describe in its three-year state plan how rehabilitation technology services will be provided to assist an increasing number of individuals with disabilities. The Amendments also require the application of rehabilitation technology services when making determinations of eligibility. This is particularly important for individuals who might otherwise be found ineligible for vocational rehabilitation services. The Amendments further include rehabilitation engineering technology as one of only four services that *must* be provided by the state rehabilitation system without consideration of comparable services and benefits—a clear indication of congressional recognition both of its importance and of the need for public systems to provide funding support to enable people who can benefit to be able to access these important supports.
- B. An important new direction in public policy was accomplished with the addition of Section 508 to the Act, without imposing any significant new financial burdens on government, business, or employees. Federal agencies must provide workers with and without disabilities equivalent access to electronic office equipment. As a result of Section 508, the federal government, with the GSA taking the lead, has changed its rules for purchasing/leasing information technology. New guidelines for functional performance can be accomplished if manufacturers of computers "build in alternative capabilities such as single keystroke commands or provide hooks for the addition of adaptive peripheral equipment such as a one-handed keyboard or a braille printer" (Resna TA Project, 1990). As implementation of Section 508 proceeds, it is expected that accessibility-related equipment and support services will become an integral aspect of federal agency acquisition. It is anticipated that these new accessibility procurement guidelines by the federal government, which is the single largest purchaser of computers, will

stimulate the accelerated development, manufacturing, and marketing of accessible or adaptable office automation systems.

2. Early Intervention for Infants, Toddlers and Families (P.L. 99-457)

In 1986, Congress enacted P.L. 99-457, within which was included a new Part H amendment to the Individuals With Disabilities Education Act (formerly Education for the Handicapped Act). This public policy declaration dramatically advanced national efforts to provide appropriate services to infants and toddlers with disabilities *and their families*. The statutory definition of early intervention services states that it is "designed to meet a handicapped infant's or toddler's developmental needs in any one or more of the following areas:" which include physical development, cognitive development, language and speech development, psychosocial development, or self-help skills. Amplification of congressional intent occurred in the Department of Education's final regulations issued on June 22, 1989, at 34 CFR Part 303, which includes the following:

"Occupational therapy" includes services to address the functional needs of a child related to the performance of self-help skills, adaptive behavior and play, and sensory, motor, and postural development. These services are designed to improve the child's functional ability to perform tasks in home, school, and community settings, and include:

- (i) identification, assessment, and intervention; and
- (ii) adaptation of the environment, and selection, design, and fabrication of assistive and orthotic devices to facilitate development and promote the acquisition of functional skills.

This new legislation and regulations constitute a major leap in assistive technology public policy by creating an entitlement to such services for infants, toddlers, and their families. A five-year planning process was replaced in 1992 by a new entitlement to services.

3. Employment Opportunity for Disabled Americans Act (P.L. 99-463)

The greatest public expenditures on behalf of persons with disabilities remain income maintenance programs. The two largest are Supplemental Security Income (SSI) and Social Security Disability Insurance (SSDI). In 1986, Congress approved new legislation to make it easier for people with disabilities to work and not lose their SSI benefits. As part of this public policy goal, Congress permanently authorized the Plan for Achieving Self-Support (PASS) program. An individual who is

receiving SSI or who would qualify for SSI by setting aside income from his or her paycheck is eligible to develop a PASS. Each plan must be approved by the Social Security Administration and can be used to purchase work-related assistive technology equipment or devices. The plan must state a clear and realistic vocational goal and explain how the sheltered income will be spent within a specific timetable. This policy approach recognizes the importance of assistive technology to achieve the goals of independence and self-sufficiency and gives special consideration from a tax or income perspective to the extra costs associated with acquisition.

4. Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1987 (P.L. 100-146)

The Developmental Disabilities Assistance and Bill of Rights Act reflects emerging "best-practice" supports and services within a value-based context for individuals with developmental disabilities and their families. During the 1987 reauthorization process, Congress added assistive technology as a priority for state planning and funding for system development and system change. In the 1990 amendments to the Act (P.L. 101-576), Congress modified the definition of assistive technology to conform to the definition in the Tech Act. With this legislation, public focus on the financing of assistive technology was further advanced within a state system for planning and systems advocacy.

5. Older Americans Act of 1965, as amended (P.L. 100-175)

In 1987, the Act was amended (P.L. 100-175) to include several provisions related to older persons with developmental disabilities and/or mental health needs. Among the provisions are the following requirements:

- Planning linkages will be established between HHS Commissioners of Aging, Developmental Disabilities and Alcohol, Drug Abuse, and Mental Health;
- The Commissioner on Aging will consult and cooperate with the Commissioner of the Rehabilitation Services Administration in planning Older Americans Act programs; and
- In evaluating OAA programs, the Commissioner on Aging will consult with developmental disability organizations whenever possible.

Title III, Part B, Grants for Supportive Services, Nutrition and Other Activities, helps older individuals avoid institutionalization and helps individuals in long-term care institutions who are able to return to their communities, including client assessment through case management, and integration and coordination of community services.

Client assessment through case management includes the provision of assistive technology.

Assistive technology is defined as engineering methodologies or scientific principles appropriate to meet the needs of, and address the barriers confronted by, older individuals with functional limitations.

Grants are awarded to states to develop and strengthen services systems on aging. State plans include several assurances, including assurances associated with access to services (i.e. transportation, outreach, information, and referral).

Information and referral includes information regarding assistive technology.

6. Medicaid Amendments of 1988 for Special Education Related Services
(P.L. 100-360)

The Medicare Catastrophic Coverage Act (P.L. 100-360) contains a significant technical amendment to Medicaid law, which was not repealed with the Catastrophic Act. This legislation was intended to resolve a historical dispute in which the Health Care Financing Administration had declared that any service within a child's individualized education program (IEP) was the financial responsibility of the education agency and could not be billed to Medicaid. The 1988 amendment and accompanying report language explicitly offered states the option of including special education and related services under Part B of IDEA, and those services included under Part H of IDEA as Medicaid reimbursable services under the state's Medicaid plan. With this policy, Congress provided a major opportunity for states to access federal Medicaid funds for a full range of individual assistive technology services without adding additional burdens to the local and state special education budgets.

7. Technology-related Assistance Act (P.L. 100-407)

This federal mandate provides financial assistance to states on a competitive grant basis to plan and implement a consumer-responsive

system of technology services for individuals of all ages with disabilities. Technology services and devices are defined in a broad context to stimulate creative problem solving, interagency coordination, and professional consumer collaboration. In the first two years of implementation of the Act, 23 states have competed successfully for funding. States have broad discretion to target their funds to training, public awareness, service demonstration, policy analysis, and systems change. Unlike existing public programs, this federal initiative represents the first time Congress targeted new public resources exclusively to expand access to assistive technology.

8. Telecommunications Accessibility Enhancement Act of 1988
(P.L. 100-542)

The purposes of the Act are to implement an interim telecommunications relay system to serve the needs of individuals who are hearing impaired and speech impaired for access to federal departments and agencies; to equip all federal departments and agencies with TDDs or facilities to accommodate portable TDDs; to provide for the assembly, publication, and maintenance of a TDD directory for federal departments and agencies; and to publish government TDD access numbers in other existing directories.

The Act also required the FCC, in consultation with the Architectural and Transportation Barriers Compliance Board, to establish and implement a telecommunications system for individuals who are hearing impaired and speech impaired within the federal government that serves as an interface between the TDD user and federal departments and agencies.

9. Medicaid Early and Periodic Screening, Diagnosis and Treatment Amendments of 1989 (P.L. 101-238)

Included in the massive Omnibus Budget Reconciliation Act of 1989 (OBRA '89, P.L. 101-238), Congress enacted major changes in the Medicaid program Early and Periodic Screening, Diagnosis, and Treatment (EPSDT), required in all states. Although EPSDT has been one of nine-state Medicaid-mandated services since its enactment in 1967, the states have had great discretion in interpretation and implementation of this benefit. As of April 1, 1990, the EPSDT Medicaid benefit was "federalized" and mandates that all children from birth to 21 years of age receiving or eligible to receive Medicaid are entitled to the "medically necessary" diagnostic and treatment services for any physical or mental impairment identified during such screening or assessment. Such services would be reimbursable under Medicaid if such "treatment"

is coverable under federal Medicaid law, even if these "treatments" are not in the state's Medicaid plan; e.g., augmentative communication devices, wheelchairs, hearing aids, and optical aids including glasses. As a result of this Amendment, a significant number of children with physical, sensory, or mental disabilities now have a right to assistive technology. Because of established practices within Medicaid, many challenges remain in assuring this right in concert with the second, and often overlooked, statutory purpose of Medicaid: "to furnish rehabilitation and other services to help such families and individuals attain or retain capability for independence or self-care" (P.L. 90-248, 42 USC 1396, Sec. 1901).

10. Americans with Disabilities Act (ADA) (P.L. 101-336)

Signed into law by President Bush on July 26, 1990, the Act protects more than 40 million Americans with disabilities from discrimination in employment, public services, transportation, public accommodations, and telecommunications. Each Title of the Act specifically references assistive technology equipment or devices as a means to achieve access and equal opportunity. In Titles I and III, the purchase or modification of equipment and devices is included within the definition of "reasonable accommodation." However, the removal of architectural, physical, or communication barriers through "reasonable accommodation" is not an absolute civil right. On a case-by-case basis, access to employment opportunity or public accommodations must be weighed against a defense of "undue hardship," an evolving standard to evaluate the degree of difficulty and expense to a particular business.

Title IV of the ADA expands access rights to the important area of telecommunications. Telephone services offered to the public in every state must include interstate and intrastate telecommunications relay services so that these services provide individuals with speech and hearing impairments access to communications equivalent to those provided to individuals able to use voice telephone systems.

In multiple approaches, ADA will *begin* to redefine the inclusion of assistive technology within the core and penumbra of civil rights to be enjoyed by citizens with disabilities. 1991 was a critical year for regulatory development that has begun to define more solidly the limits of access to assistive technology as part of "reasonable accommodation" in the workplace, commercial buildings, and public arenas.

11. ADA Tax Credit (P.L. 101-508)

Under the Omnibus Budget Reconciliation Act of 1990, a new tax credit was created for small businesses, to provide additional incentives and assistance to meet the access requirements under ADA. The credit amount allowed a tax year is 50 percent of expenditures, to a maximum of \$10,250. Acceptable expenses include removal of architectural, communication, or transportation barriers. Coverage does include the purchase or modification of adaptive equipment or assistive devices as part of an effort to improve access to persons with disabilities. To qualify, a business must have gross receipts of less than one million dollars or fewer than 30 full-time employees.

12. Decoder Circuitry Act of 1990 (P.L. 101-431)

In yet another approach to expand public policy, new requirements are mandated for the manufacturers of television sets with screens 13 inches or larger sold in the United States after July 1, 1993. Televisions will be required to have built-in decoder circuitry to be compatible with current closed-captioned signals. This new mandate will ensure that people with hearing impairments will be able to see captions on programs that provide them by merely flipping a switch on their television. Mass production of the built-in decoders will cost an estimated three to five dollars per television. The potential audience for closed-captioned programming for individuals with communication disabilities is estimated to be more than 24 million.

13. Policy Letter: Office of Special Education Programs

On August 10, 1990, Dr. Judy Schrag, director of the Office of Special Education Programs, issued a policy letter that clarifies the rights of children with disabilities to access assistive technology. This policy letter states clearly and unequivocally that assistive technology services and devices may be considered special education, related services, or supplementary aids and services to enable a student with a disability to remain in the regular education classroom. In other words, as part of the requirements of a "free, appropriate public education" (FAPE), assistive technology needs must be considered when developing a child's individualized education program (IEP). Needed assistive technology devices and services must be appropriately included as part of the IEP. In response to the requirements of the least restrictive environment principle and as special education or related services, children with disabilities have a right to assistive technology. These requirements were further reinforced in the reauthorization of the Education of the

Handicapped Act (now IDEA). On October 30, 1990, President Bush signed into law the Individuals with Disabilities Education Act (IDEA), P.L. 101-476, which, for the first time, includes definitions of assistive technology devices and services identical to those included in the Tech Act. In report language, there is further emphasis on the right to assistive technology as part of special education and related services.

The reauthorization language and the policy letter should result in more consistent access to assistive technology by school-age children with disabilities nationwide.

14. Policy Memo: Rehabilitation Services Administration

On November 16, 1990, Commissioner Nell Carney issued a policy directive to all state vocational rehabilitation agencies that sets important new guidelines concerning implementation of the 1986 rehabilitation technology amendments. Each state must develop written policies to address the need for assistive technology during the entire rehabilitation process, as part of determination of eligibility, evaluation of rehabilitation potential, extended evaluation, services provided under the individual written rehabilitation plan (IWRP), annual reviews of ineligibility, and post-employment services. An assessment of an individual with disabilities should consider how assistive technology devices and services can increase or supplement function and modify environments to accommodate individual abilities in the home and workplace. This added policy direction to implement the intent of Congress should place new demands on a major public resource program to allocate funds to increase access to technology.

Analysis of these public policy developments reflects a number of approaches that have been utilized to increase availability of and access to assistive technology. These approaches include a range of activities designed to influence all aspects of policy development and implementation.

Table C1

RECENT PUBLIC POLICY DEVELOPMENTS

Year	Action	Approach
1. 1986	Amendments to Rehabilitation added definition, expanded program requirements	Clarified and expanded Act: program benefit of major public program
2. 1986	Amendment to Rehabilitation Act, Section 508: new guidelines for federal procurement of computers	Changed procurement impacted manufacturers' expectation of accessible design standards at lower cost
3. 1986	Early intervention: created new entitlement, expanded program benefits	Established major public program
4. 1986	Social Security Amendments	Tax sheltering of income to purchase technology
5. 1987	Amendments to Developmental Disabilities Act: expanded program requirements	New priority within existing public program
6. 1987	Older Americans Act Amendments: created new provision of assistive technology within existing program; defined assistive technology	Expanded existing program benefit
7. 1988	Medicaid Amendments: clarified funding options and mandates	Clarified and expanded existing program benefit
8. 1988	Tech Act: created statewide systems of technology assistance	Created new funding, new public program
9. 1988	New Telecommunications Access Law	Established new TDD access requirement within federal agencies

Table C1

RECENT PUBLIC POLICY DEVELOPMENTS
(continued)

Year	Action	Approach
10. 1990	ADA: employment, transportation, public accommodations, telecommunications	New access requirements of private sector; access technology by expanding concept of civil rights
11. 1990	ADA Tax Credit for Small Businesses	Created tax incentives to expand access to assistive technology
12. 1990	Decoder Circuitry Act: designed standard for televisions	Required new manufacturer standard for access
13. 1990	Policy Letter Special Education	Clarified rights under existing major public program
14. 1990	Policy Memo Rehabilitation	Clarified rights under existing major public program
15. 1990	Amendment to IDEA: added definitions of assistive technology devices and services	Clarified rights under existing public program
16. 1991	Amendment to Part H of IDEA: added definitions of assistive technology services and devices	Clarified rights under existing public program
17. 1991	Policy Letter Special Education	Clarified right to take technology home from school

Table C2

POLICY APPROACHES

- Redirect or increase resource allocation under existing public programs.
- Modify entitlements under existing public programs.
- Clarify existing policy to mandate and monitor more consistent practices.
- Modify discretionary priorities under existing public programs.
- Establish new public programs.
- Establish new laws to expand definition of civil rights.
- Alter procurement practices of government.
- Alter existing tax incentives or create new ones.
- Allow tax sheltering of income.
- Require new design standards for manufacturers of equipment to displace need for specialized equipment purchases.

While these policy approaches do not reflect all of the avenues available to direct the public policy arena toward increased access to assistive technology, they certainly provide excellent examples of approaches that have been successfully utilized to begin movement in that direction. In addition, they provide important information on approaches that should be considered when developing additional strategies for the acquisition and financing of assistive technology services and devices in the future.



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