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Technology for Independent Living

Layout and Design by Janette Alsford Owens

Project on the Handicapped in Science
American Association for the Advancement of Science
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Technology for Independent Living

Proceedings of the 1980 Workshops on
Science and Technology for the Handicapped

Stanford • Boston • Houston

Edited by
Virginia W. Stern and Martha Ross Redden

Project on the Handicapped in Science
American Association for the Advancement of Science

This book is based upon group participation and presentations given at three regional workshops on Science and Technology for the Handicapped, convened by AAAS in 1980, and funded by National Science Foundation Grant No. OPA7920290.

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Foreword

"If we can get an astronaut to the moon, then surely we can get a quadriplegic to the mall."

The prospect of space-age technology, which in the 1970's sparked the hopes of handicapped people and their able-bodied advocates, has so far raised more questions than answers:

- *Who decides when a device is needed?*
  (Doctor? Counselor? Handicapped person himself? And did anyone ask if he even wanted to go to the mall?)

- *Who designs the device?*
  (Engineer? Therapist? Next-door neighbor? Handicapped individual?)

- *What if the device isn't satisfactory?*
  (Doesn't work? Needs repairs?) (Client's needs have changed with time, and whose prerogative is it to evaluate and rule on its adequacy?)

- *Who pays for assistive technology?*
  (Client? Employer? Health care system? Government? Which agency has jurisdiction?)

- *How to avoid "re-inventing the wheel" with a 'new' device or technique? How to spread the word when a bright new idea really works?*
  (What about standardization, commercialization marketing, product liability? Who comprises the audience for "technology transfer"?)

This volume chronicles the efforts of the American Association for the Advancement of Science to ask and answer questions such as these. Led by Dr. Martha Ross Redden and supported by grants from the National Science Foundation, the AAAS launched its Project on Science and Technology for the Handicapped.

In 1978, at a workshop in Washington, DC, a *Research Agenda on Science and Technology for the Handicapped* was drafted. This was followed by a series

of workshops, held around the country in 1980, 1981, and 1982, which brought together groups of experts from a wide variety of fields. Bulletins were published and distributed widely. The workshops were stimulated immeasurably by Dr. Redden's recognition that the most knowledgeable expert is the individual who has the disability and must use the technology; and that often the *environment handicaps people more than any disability.* This recognition came as a result of continuing interaction with scores of disabled scientists, beginning in 1975 when AAAS began The Project on the Handicapped in Science.

These papers, distilled from the deliberations of "providers" with "consumers", will be a map to guide technological developments that will get handicapped people to the mall, school, church, park, work place, polling place and wherever else their abilities can take them.

Paul J. Corcoran, M.D.
Rehabilitation Institute
Tufts-New England Medical Center
Boston, Massachusetts.

Acknowledgements

The Proceedings which follow are the product of many contributors, some of whom did not present papers at the workshops but who played significant roles in developing themes for discussion and inviting participants to enrich the interdisciplinary character of the meetings.

We are especially indebted to the co-sponsors at each workshop site:

Dr. John Linvill, Chairman, Department of Electrical Engineering
Stanford University
Dr. Paul Corcoran, Chief of Rehabilitative Medicine
Tufts-New England Medical Center, Boston
Robert Kafka, Director, Office of Disabled Students,
University of Houston

They and their staffs contributed generously of their time and creativity in program planning, local linkages, and logistical arrangements. We are grateful also to the disabled and non-disabled persons from each community who served on planning committees as discussion leaders, and as rapporteurs for the small group sessions.

Mark Ozer helped to develop the small group format and trained the discussion leaders.

Janet Long served as project associate during part of the year, handling logistics for the Stanford Workshop.

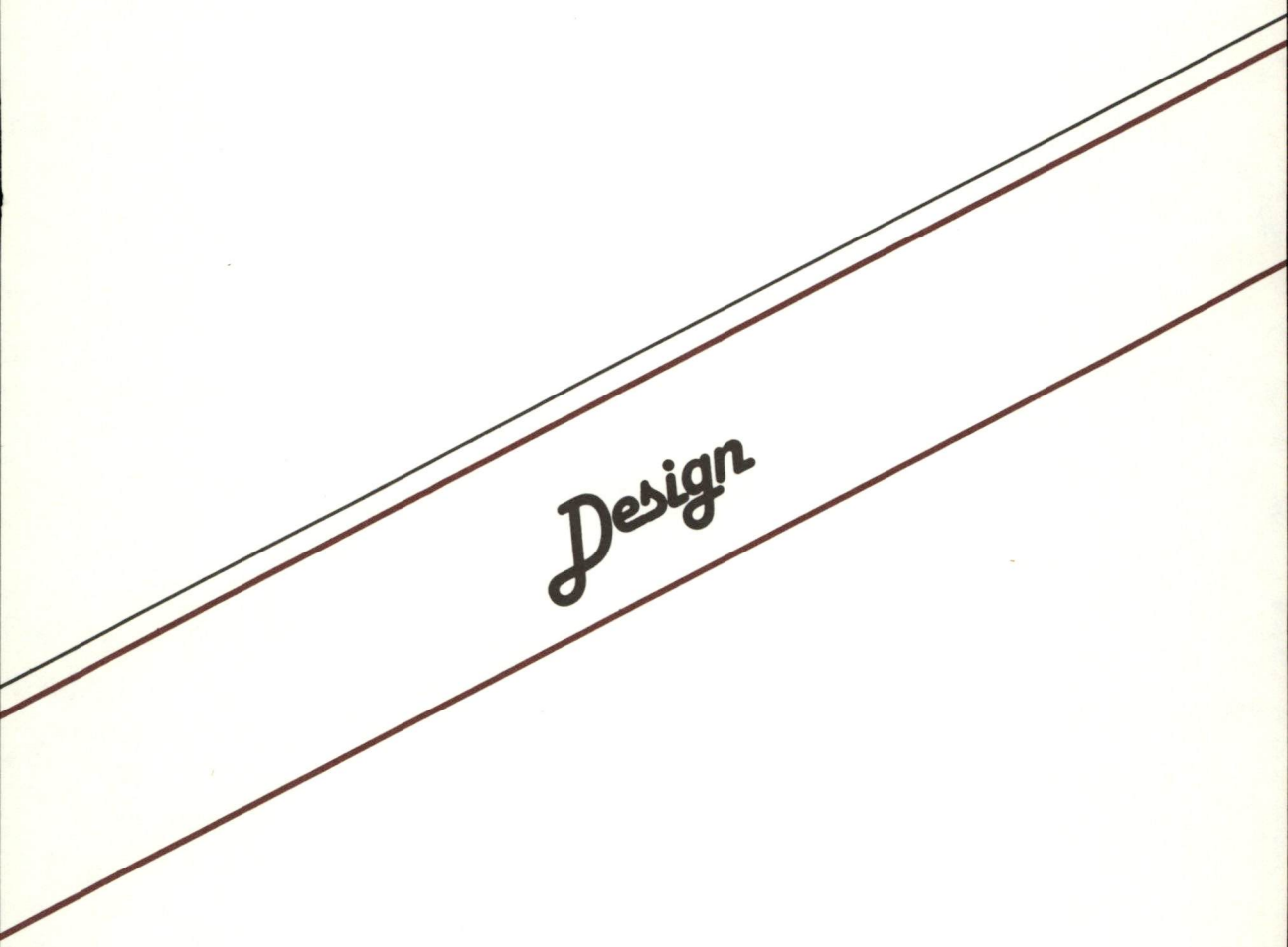
Jill Groce assisted in editing the manuscripts and summarizing the small group discussions.

Janette Alsford Owens was responsible for the design and production of the Proceedings, as well as the design of the *Bulletins* and the development of the *Bulletins* information exchange and circulation list.

Shirley Malcom, Head, AAAS Office of Opportunities in Science, offered invaluable guidance in all aspects of the project.

James Aller, Don McNeal and Lynn Preston of the National Science Foundation gave continuing encouragement, direction and support.

Finally, we wish to thank Lorraine Stillwell for establishing continuity among all the workshops of the project, assuring coordination of workshop registration, and tirelessly performing the follow-up activities including gathering the papers and other materials included in these Proceedings.


Design

Background

Since 1975, when the concerns of handicapped individuals in science were brought to the attention of the American Association for the Advancement of Science (AAAS) by a deaf biologist member, the AAAS Project on the Handicapped in Science (PHS) has been a national center of information on handicapped persons in science. The Project on the Handicapped is part of the AAAS Office of Opportunities in Science. A major thrust of the Project since its beginning has been the development of a Resource Group of Disabled Scientists. This group, now numbering over 1,000, consults on matters of handicapped individuals access to science education, architectural and laboratory accessibility, professional meeting accessibility, aids and equipment, and barriers to employment. All activities of the Project on the Handicapped in Science are directed toward the interrelationship of science and disability.

In 1980, the Project on the Handicapped in Science began a three-year program to increase the interaction between disabled and ablebodied scientists and engineers working on science and technology for the handicapped. A three-year series of regional workshops and *Bulletins* disseminated nationally which contained information from them, were funded by the National Science Foundation (NSF) through its Program of Science and Technology to Aid the Handicapped. The impetus for the workshops was based on a need to expand the findings of an earlier NSF-funded AAAS/PHS project and its resultant publication *A Research Agenda on Science and Technology for the Handicapped*. This agenda identifies priority research needs in science and technology for disabled individuals and suggests the type of exchange between disabled and non-disabled people which would result in effective research and development strategies to meet current pressing needs of handicapped people and to improve their quality of life.

The workshops provided a unique opportunity for disabled and non-disabled scientists and engineers to participate in the process of identifying current research, outlining requirements for innovative development, proposing new programs of research in technological aids, and methods of effectively sharing state-of-the-art information on devices to avoid re-invention of the wheel, and the wheelchair. Joining the scientists and engineers in their discussions were disabled consumers, parents of disabled youth, architects, designers, manufacturers of aids for disabled persons, physicians, nurses, occupational and physical therapists, rehabilitation counselors and administrators, communication specialists, representatives of small business and the insurance industry, and educators at the pre-college and college level. Each workshop had its own particular mix of individuals, reflecting both the institutions of the region, the existing educational, employment, and recreational opportunities, and the

networks that had previously developed. One of the major goals of the workshops was to expand these networks, to initiate communication between individuals from institutions that were within "shouting distance" of each other but were separated by traditional historical and attitudinal barriers. The workshops also provided a platform for private individuals who were independently developing aids and devices, with an opportunity for interchange with institutionally-affiliated persons researching in the same area. Notices in *Science* magazine alerted a wide audience of people to inquire about the workshops; many of these people were not part of the formal discipline of rehabilitation engineering and were able to bring experience from a different perspective.

Because the main objective of the workshops was to actively involve disabled persons in research and development of science and technology for the handicapped, a special effort was made to include a significant number of disabled people in each group of participants. Invitations were issued through local disabled consumer groups, parent organizations, disabled student officers on university campuses, and the AAAS Resource Group of Handicapped Scientists. Registration for each workshop was planned to include a wide representation from institutions of the region and also allow for unexpected registrants representing lesser known or newly established groups.

The overall theme chosen for the 1980 workshops was "Independent Living and Its Implications for Science and Technology for the Handicapped." Workshop locations were chosen where strong independent living activities were located: the San Francisco Bay Area (Stanford, CA), Boston, MA, and Houston, TX. Although speakers and other participants varied from workshop to workshop, topics overlapped and certain ideas were reenforced by the recognition that they surfaced more than once.

The formal papers published in these proceedings are, therefore, not organized chronologically by date and location of presentation but rather are grouped in categories which demonstrate the major secondary themes appearing at all of the meetings.

Included also in this volume are the programs of each workshop, Stanford, Boston, and Houston, complete lists of participants and a summary of the small group discussions that took place between the formal presentations.

The workshops were designed to be highly participatory. In addition to scheduled small group discussions, coffee breaks and evening social activities offered opportunities for informal exchange of experiences and resources. Everyone had something to contribute--there were no auditors or silent observers.

At the final session of each workshop, all registrants gave oral presentations of their own action plan developed during the course of the meeting. The action plans were not recommendations for a government bureau or outside agency to implement--they were individual practical proposals of activities to be carried out in the near future by the participants themselves in their own environment--university, laboratory, hospital, business, or community-at-large. Participants were encouraged to use the resources of AAAS to carry out their plans and to inform AAAS of their progress by sending notes to the information exchange of the *Bulletins*. Action plans were often made by groups of participants from different institutions in the same geographic area who had discovered at the workshops that they were working on parallel tracks in seeking solutions to problems.

The *Bulletins*, published by AAAS after each workshop, reported on selected speeches and small group discussions from the workshops. In addition the *Bulletins* contained notices of current and proposed research in technology, announced the most recent NSF grants on science and technology to aid the

handicapped, and gave details of new products, other meetings, and available resources. The *Bulletins* expanded the exchange of information from the project headquarters and the workshop groups to a mailing list of 5,000 disabled persons, scientists, engineers, consumer groups, government agencies, universities, laboratories, small businesses, and the Congress. The *Bulletins* have been a vital link in joining the various target groups throughout the country, and allowing for individuals to write in relevant comments and share information about new resources.

At the beginning of the project, an Advisory Committee was selected to plan the workshop sequence and themes, present and participate in the workshops, and give continuing guidance. The whole Committee met at the beginning of the project, and subcommittees met at the time of each workshop. Advisory Committee members, all of whom worked in various areas of disability or who were themselves disabled, were selected to represent the following areas of expertise: *engineering; industrial design; rehabilitation medicine; basic research; economics; psychology; law; teacher training; small business; manufacturing; insurance; consumer organizations; administration and counseling in rehabilitation programs; university teaching and administration.* Advisory Committee members represented or worked in the disability areas of hearing impairment, visual impairment, mobility impairment, and vocal impairment. A listing of Advisory Committee members appears on page 247.

Group Participation and Action Plans

The 1980 Workshops on Science and Technology for the Handicapped, combining expert speakers and discussion in small groups, opened a forum for the exchange of ideas that had not existed before. The small group format afforded the participants an opportunity to identify problem areas, tell of personal experiences, and learn from one another. During the workshop series, discussion of the issues facing handicapped people fell into four major subject categories: economics, information gathering and dissemination, co-invention, and networking. Ideas and action plans suggested by the participants will be listed under these four topics. The action plans are personal goals set by the participants to describe the activities they wished to pursue after the workshop, which would lead to the improvement of technology used by disabled people.

Economics

We need a sponsor with big bucks.

The primary economic issue in the development of assistive technology is the nature of the market that the potential manufacturer can anticipate. The market for assistive devices is so fragmented that some special mechanism must be found to deal with it. Mass production of assistive devices is difficult because of the special needs of the people comprising the market, and still a company manufacturing such devices must show a profit. The needs of a handicapped person might be met by adjusting the environment slightly, by developing a simple assistive technology, or by applying an elegant high-tech solution to the problem. These wide variations in possible solutions make the market very complex. Low volume of business, the need for specialization, and a limited market prevent corporations from manufacturing assistive devices.

Competition among suppliers is limited; therefore that alone will not increase availability of assistive devices, as happens in the larger economy. Consumers must make their demands known if the handicapped community is ever to be adequately served by manufacturers.

Action Plans on Consumer Involvement in Economic Issues

- Meet with state Rehabilitation Commission regarding standards for wheelchairs.
- Identify myself as a potential reviewer to government agencies that fund handicapped-related research; seek out agency divisions that form peer review panels and send them my professional vita.

- Write state representatives, indicating conflict areas of research funds and consumerism; request consumer input in the form of a panel to review government research funds to better serve the handicapped population.

- Include discussion in public health courses of community interaction issues faced by the disabled.

- Involve a handicapped individual in regular sessions of design classes for engineering students.

- Visit successful disabled persons at employment sites to find out what adaptations and/or devices they use on the job.

- Inquire of my professional organization the position they have taken with reference to accessibility and support for handicapped members.

Information

No matter where we go, we get back to information.

For consumer demands to be translated into market priorities and technological research recommendations, full and accurate information must be gathered and disseminated to the general public and to industry, as well as to the special community of handicapped users. Consumer research, writing, publication, and activism can contribute to attitude changes and can lay the foundation for business decisions favorable to handicapped persons by potential employers and by potential manufacturers of assistive devices.

Action Plans on Information Dissemination

- Develop a monthly column for local newspapers about rehabilitation consumers, engineers, and health professionals, bringing the viewpoints of these people to the public; contacting local newspapers about this idea.

- Publish information about technology for the disabled to computer hobbyists through their journals; present technology at their meetings.

- Approach *Consumer Reports* about the possibility of product testing articles and/or buyer's guides on devices for the disabled, e.g. wheelchairs, hearing aids, and nonvocal communication devices.

- Develop an amputee newsletter to open communication for consumer input on products, devices and research.

- Publish a booklet on locating and recruiting disabled people, including listings of newsletters, magazines, and information sources useful to anyone in the disability field.

- Compile a booklet on low-technology home modifications.

- Establish a viable information dissemination service for northern California.

- Compile information on current manufacturers of supplies and equipment, along with verifying usability.

Co-Invention

The handicapped person and the design engineer must work together like brothers.

Manufacturers who are developing equipment need "front-line" information to be able to manufacture equipment consumers need and can use. Engineers need to interact with established consumers of assistive devices, at all stages of the development process. Known as co-invention, this process is the best way to make sure that the devices manufactured will be effective in meeting the needs of handicapped people.

Action Plans on Promotion of Co-Invention

- Involve disabled consumers in testing the devices and products developed in my laboratory.
- Contact manufacturers of technology to alert them of the need to involve the disabled community in the development stage of new products.
- Contact various manufacturers to discuss the philosophy of co-invention and consumer involvement prior to marketing new items.
- Collect do-it-yourself designs created by disabled people, technicians, occupational therapists, and others, and seek a means of publicizing and distributing them.
- Offer my services as a hearing-impaired consumer in the development of the infrared light hearing aid.
- Promote electronic mail as a primary source of communication for the deaf-blind.
- Develop telephone jacks in urban areas which handicapped people can use from inside their automobiles.

Networking

This project will facilitate a dialogue among the scientific and disabled communities through a series of regional workshops and national newsletters.

These AAAS workshops were initiated, with the support of the National Science Foundation, to coordinate an exchange of information and ideas between the handicapped community and researchers, developers, and manufacturers of technology for handicapped persons. All participants agreed that their interests could be strengthened by sharing contacts in business, research, and the health service professions to provide a network that would serve as a support system.

Action Plans on Organizing Networks

- Develop a User Advisory Group to aid in psychosocial evaluation in addition to engineering evaluation of automotive adaptive equipment.
- Form a volunteer biomedical engineer bureau, matching consumers and project engineers on a one-to-one basis.
- Develop an Adaptive Devices Center to function as an equipment library and training center for rehabilitation counselors, occupational therapists, and industrial design students.

- Keep open a transportation institute laboratory for demonstration to handicapped people; hold workshops for driver education professionals.

- Explore the possibility of organizing a regional rehabilitation engineering consultation service.

- Develop an exhibit of new devices for the handicapped for Science and Technology Centers: investigate whether this has been done in other places; discuss with the exhibit department at the Boston Museum of Science, particularly questions of technical aissistance and funding.

- Organize a grassroots rehabilitation technology conference in the Houston area.

- Hold a small local workshop on potential use of technology in communication problems for counselors and consumers.

- Organize a reunion picnic for workshop participants for social interaction and development of specific projects.

- Help to organize a national system for providing technical aids and devices.

- Write about what our center has done successfully and not so successfully so that others may learn from our experience.

- Work for state and federal legislation to open up funding for provision of communication aids and expanding research and development funding.

Workshop Programs

Stanford

INDEPENDENT LIVING AND ITS IMPLICATIONS
FOR RESEARCH IN SCIENCE AND TECHNOLOGY FOR THE HANDICAPPED

July 22-25, 1980
STANFORD UNIVERSITY
STANFORD, CALIFORNIA

presented by

THE AMERICAN ASSOCIATION FOR THE ADVANCEMENT OF SCIENCE (AAAS)
with support from THE NATIONAL SCIENCE FOUNDATION

* * *

Tuesday, July 22

8:00 - 10:00 p.m. OPENING SESSION

Welcome: *John Linvill*, Chairman, Department of Electrical Engineering, Stanford University
Martha Redden, Director, Project on the Handicapped in Science, AAAS

Keynote Address: "Strength Through Disability: Was it Worth It?"
Ed Roberts, Director, Office of Rehabilitation, of California
Zona Roberts, Family Counselor, Center for Independent Living, Berkeley, CA

Wednesday, July 23

8:00 - 8:45 a.m. Registration

8:45 - 9:45 a.m. PANEL DISCUSSION: "The Consumer and Basic Rehabilitation Engineering Research"

"High Technology by Design for the Handicapped"
Larry Leifer, Stanford University, and Director Veterans Administration Rehabilitation Research Center, Palo Alto, CA
"The Consumer and Basic Rehabilitation Engineering Research"
Deborah Kaplan, Disability Rights Education & Defense Fund, Center for Independent Living, Berkeley,CA
Ralf Hotchkiss, Disability Engineering Consultant Oakland, CA

9:45 - 10:00 a.m. Break

10:00 - 11:15 a.m. PANEL DISCUSSION: "Grassroots Rehabilitation Technology"

"Grassroots Rehabilitation Technology and the Delivery System"
James Tobias, Center for Independent Living, Berkeley, CA
"Grassroots Rehabilitation Technology: A Need for Encouragement and Information Transfer"
Larry Busch, Southern Illinois University, Carbondale, IL
"Delivery of Assistive Devices through a Client-Oriented Approach"
Albert Cook, California State University Sacramento, CA
Reactor: *Lennis Jones*, Center for Independent Living, Berkeley, CA

11:15 - 12:30 p.m. SMALL GROUP DISCUSSIONS
Group Leaders: *Paul Corcoran, Mark Ozer, Virginia Stern, Martha Redden*

12:30 - 1:30 p.m. Lunch (Wilbur Hall)

2:00 - 3:15 p.m. PANEL DISCUSSION: "Using Technology to Provide Access to Education and Industry for Hearing Impaired Individuals"

"Technology and Access to Education for the Hearing Impaired"
Harriet G. Kopp, San Diego State University, San Diego, CA
"Telecommunication Devices in the Education of Deaf Adults"
William Castle, National Technical Institute for the Deaf, Rochester, NY
"The Role of Technology in the Employment of Hearing Impaired Individuals"
Steven Jamison, International Business Machines, San Jose, CA

3:15 - 3:30 p.m. Break

3:30 - 5:00 p.m. SMALL GROUP DISCUSSIONS

Thursday, July 24

8:30 - 9:30 a.m. "Economics of Technology for the Handicapped: A Manufacturer's Viewpoint"
James Bliss and *Rick Plescia*, Telesensory Systems, Inc., Palo Alto, CA

9:30 - 10:15 a.m. "Product Development for the Handicapped Community: A Dual Purpose Telephone Terminal for the Deaf"
David Fylstra, SRI International, Menlo Park, CA

10:15 - 10:30 a.m. Break

10:30 - 11:45 a.m. SMALL GROUP DISCUSSIONS

11:45 - 12:30 p.m. Introduction to Tours of Local Facilities
Virginia Stern, Senior Program Associate, AAAS

12:30 - 2:00 p.m.	Lunch (Wilbur Hall)
2:00 - 5:00 p.m.	TOURS OF LOCAL FACILITIES Telesensory Systems, Inc. Western Blind Rehabilitation Center Children's Hospital at Stanford U. S. Geological Survey
6:00 - 7:00 p.m.	Reception (Stanford Faculty Club)
7:00 - 9:00 p.m.	Dinner Stanford Faculty Club
	Dinner Presentation: "Rehabilitation Technology Linkages: The Device, The Person, The Environment" *Maurice LeBlanc, Sandi Enders,* and *John Preston, Jr.,* Children's Hospital at Stanford, Stanford, CA

Friday, July 25

9:00 - 10:30 a.m.	GROUP PLANNING: POST-WORKSHOP ACTION PLANS
	Mark Ozer, George Washington University School of Medicine, Washington, DC
10:30 - 10:45 a.m.	Break
10:45 - 11:45 a.m.	SMALL GROUP REPORTS
	Paul Corcoran, Tufts University R&T Center, Boston, MA
11:45 - 12:00 noon	WORKSHOP EVALUATION - ADJOURNMENT
	Martha Redden, Director, Project on the Handicapped in Science, AAAS
1:45 - 4:00 p.m.	PROJECT ADVISORY BOARD MEETING (Wilbur Hall)

Workshop Programs — Boston

YANKEE INGENUITY AND THE INDEPENDENT LIVING MOVEMENT:
APPROPRIATE TECHNOLOGY FOR THE REIMBURSEMENT REALITIES OF THE 1980's

September 7-10, 1980

TUFTS UNIVERSITY MEDICAL REHABILITATION RESEARCH AND TRAINING CENTER
BOSTON, MASSACHUSETTS

presented by

THE AMERICAN ASSOCIATION FOR THE ADVANCEMENT OF SCIENCE (AAAS)

with support from

THE NATIONAL SCIENCE FOUNDATION

* * *

Sunday, September 7

7:30 - 9:00 p.m.	OPENING SESSION Welcome: *Paul Corcoran*, Chief, Tufts University R&T Center *Virginia Stern*, Senior Program Associate, Project on the Handicapped in Science, AAAS Keynote Address: "Involving the Consumer in the Rehabilitation Process--Easier Said Than Done!" *Irving Zola*, Brandeis University, Waltham, MA
9:00 p.m.	Reception

Monday, September 8

8:15 - 8:45 a.m.	Registration
8:45 - 10:00 a.m.	"Who is Independent? Devices, Medicine, and the American Way of Life" *Paul Corcoran*, Tufts University Medical R&T Center
10:00 - 10:45 a.m.	"Economic Considerations in the Development of Technology" *Monroe Berkowitz*, Rutgers University, New Brunswick, NJ

10:45 - 11:15 a.m. Break

11:15 - 12:30 p.m. SMALL GROUP DISCUSSIONS
Group Leaders: *Paul Corcoran, Frederick Fay, Virginia Stern, Barry Unger*

12:30 - 1:30 p.m. Lunch

1:30 - 3:00 p.m. PANEL DISCUSSION: "Engineering Service Delivery: Models of Technical Service"

"University Based Rehabilitation Engineering Consultation Service"
Richard Foulds, Tufts University Medical R&T Center
"Job Development Laboratory-Modifying the Work Site to Meet the Physical Requirement of the of the Individual"
Kali Mallik, George Washington University, Washington, DC
"Delivery of Technical Services Within a State Human Service Agency"
Timothy Casey, Belchertown State Hospital, MA

3:00 - 3:30 p.m. Break

3:30 - 5:00 p.m. SMALL GROUP DISCUSSIONS

Tuesday, September 9

8:30 - 10:00 a.m. PANEL DISCUSSION: "Technology for Communication"

"Communication Aids for the Deaf"
Arthur Boothroyd, Clarke School for the Deaf, Northampton, MA
"Simple vs. Advanced Technology in Communication Augmentation"
Gregg Vanderheiden, Trace Research and Development Center, Madison, WI
Reactors:
Robert Danahy, Governor's Commission on the Handicapped, Boston, MA
James Viggiano, Consumer Evaluator, Tufts University Medical R&T Center

10:00 - 10:30 a.m. Break

10:30 - 12:00 Noon PANEL DISCUSSION: "Kurzweil Reading Machine-From the Idea to the Consumer."

"The Development of the Kurzweil Reading Machine"
Raymond Kurzweil, Cambridge, MA
"High Technology for the Handicapped: Roles for Consumer Involvement and the Small Business Sector"
Barry Unger, President, Innovation Support, Arlington, MA
"The Consumer Testing Project for the Kurzweil Reading Machine"
Michael Hingson, Director, NFB Consumer Testing Project, Kurzweil Computer Products, Inc., Cambridge, MA

12:00 - 1:00 p.m. Lunch
INFORMAL DEMONSTRATION: MIT/LOGO Group
Sylvia Weir, Massachusetts Institute of Technology
Michael Murphey, Student, Cotting School, Boston, MA

1:00 - 2:00 p.m. "From Laboratory to Use: A Retrospective on Technology Transfer on Aids for the Visually Impaired"
Robert Mann, Massachusetts Institute of Technology, Cambridge, MA

2:00 - 4:00 p.m. SMALL GROUP DISCUSSIONS

7:00 p.m. RECEPTION AND DINNER
Howard Johnson Hotel

Dinner Address: "Rehabilitation Engineering Through Marketing - Getting from Here to There"
Elmer Bartels, Commissioner, Massachusetts Department of Rehabilitation

Wednesday, September 10

8:30 - 10:00 a.m. PANEL DISCUSSION: "Fitting Technology to the Handicapped Human Being"

Moderator: *Ray Nickerson*, Bolt, Beranek and Newman, Cambridge, MA

"Everything That is Transitory is Symbolical Only"
Hadi Madjid, Scientific Researcher, Concord, MA
"Fitting Technology to the Handicapped Human Being"
Frederick Fay, Tufts Rehabilitation R&T Center
"Technology for the Sensory Impaired: Present and Future"
Barbara Wagreich, Associate Programmer, Bolt, Beranek and Newman

10:00 - 10:30 a.m. SMALL GROUP REPORTS

10:30 - 12:00 noon ACTION PLANS and WORKSHOP EVALUATION
Paul Corcoran, Tufts University Medical R&T Center
Virginia Stern, AAAS

12:00 noon Adjournment

Workshop Programs

Houston

DELIVERY SYSTEMS: HOW THEY AFFECT
RESEARCH AND DEVELOPMENT IN SCIENCE AND TECHNOLOGY FOR DISABLED INDIVIDUALS

December 4-5, 1980
UNIVERSITY OF HOUSTON
HOUSTON, TEXAS

presented by

THE AMERICAN ASSOCIATION FOR THE ADVANCEMENT OF SCIENCE (AAAS)

with support from

THE NATIONAL SCIENCE FOUNDATION

* * *

Thursday, December 4

8:30 - 9:00 a.m.	Registration
9:00 - 9:30 a.m.	OPENING SESSION Welcome: *Martha Redden*, Director, Project on the Handicapped in Science, AAAS *Robert Kafka*, Director, Disabled Student Services, University of Houston
9:30 - 10:30 a.m.	"Delivery Systems - Definition and Survey" *Jim Tobias* and *Barbara Nevins*, Center for Independent Living, Berkeley, CA
10:30 - 10:45 a.m.	Break
10:45 - 11:00 a.m.	"Delivery Systems - Economic Issues" *Jeffrey Rubin*, Rutgers University, New Brunswick, NJ
11:00 - 12:30 p.m.	SMALL GROUP DISCUSSIONS
12:30 - 1:30 p.m.	Lunch

1:30 - 3:15 p.m. PANEL DISCUSSION: "Specific and General Issues in Delivery Systems for Disability"

"A Service Delivery System Model"
A. Bennett Wilson, Rehabilitative Engineering, University of Texas, Dallas, TX
"Service Delivery to the Deaf Community"
Michael Moore, Austin Resource Center for Independent Living
Reactor: *Larry Scadden*, National Institute for Handicapped Research, Washington, DC

3:15 - 4:00 p.m. "The Prehensile Hand--An Example of Technology Development and Marketing"
Robert Radocy, Therapeutic Recreation Systems, Boulder, CO

4:00 - 6:00 p.m. NO-HOST DINNER at a nearby restaurant (transportation provided)

Friday, December 5

8:30 - 9:00 a.m. Coffee

9:00 - 10:00 a.m. "The Artificial Sphincter"
Brantley Scott, St. Luke's Hospital, and Consultant to Texas Institute for Rehabilitation and Research (TIRR)

10:00 - 10:30 a.m. "Infra-Red Transmission Hearing Aid"
Barry Leshowitz, Arizona State University, Tempe, AZ

10:30 - 10:45 p.m. Break

10:45 - 12:45 p.m. PANEL DISCUSSION: "Delivery Systems Abroad"

Moderator: *Joyce Frieden*, Consumer and Consultant, Houston, TX

Lex Frieden, Texas Institute for Rehabilitation and Research, Houston, TX
Bruce Curtis, Houston Center for Independent Living, Houston, TX
Milan Dimitrijevic, Yugoslavia
Derek Lancaster-Gaye, Spastic Society, Great Britain
Sven Olaf Brattgard, University of Gothenberg, Sweden

12:30 - 1:30 p.m. Lunch

1:30 - 2:00 p.m. "Perspectives on Economic Issues"
Jeffrey Rubin, Rutgers University, New Brunswick, NJ

2:00 - 3:15 p.m. SMALL GROUP DISCUSSIONS

3:15 - 4:30 p.m. SMALL GROUP REPORTS AND ACTION PLANS
Martha Redden and Virginia Stern, AAAS

4:30 p.m. Adjournment

Presentations

1 Delivery Systems Past and Present

Timothy W. Casey

Delivery of Technical Services within a State Human Service Agency

Efforts to transfer known technology in North American society to the needs of handicapped individuals are at an impasse. The White House Conference on Handicapped Individuals, held three years ago, articulated the need: the vast and burgeoning technological knowledge and capacity produced by this country's industrial establishment must become more available to handicapped persons on a day-to-day basis. What was being asked for, and where the greatest gap lies, is in availability of devices and special materials which meet adaptive needs. The need is most acute for products and services which are not available through mass production and marketing, but which in many cases are relatively simple technically. These needed products, and the technology and services that go with them, are not being transferred to handicapped individuals adequately for a number of reasons:

- The tendency toward technical overkill on the part of medical and technical personnel.
- The funding pattern for scientific development and research.
- The predominance of vocational rehabilitation to the exclusion of other equally urgent needs and priorities.
- Inadequate education of professionals to understand and address needs.
- And most important, the continued use of research-oriented, cure-oriented, and academically-oriented concepts and strategies to address a range of needs which are primarily adaptive.

What can be observed today is a system of responding to the needs of handicapped persons which continues to perpetuate the various strengths and weaknesses of an approach which was conceptualized about two decades ago to focus on the needs of one very significant segment of the handicapped population; that is, the employable victims of injury or disease. The independent living movement, coupled with the vocational rehabilitation thrust of federal and state government activity, has produced a funding and research establishment which, while having proved to be tremendously effective in terms of basic research, demonstration, training, and high-tech development, continues to repeat itself, and continues to commit the same errors in concept and vision, when dealing with issues of technology transfer and service delivery.

One can repeatedly witness the persistent mistake made by the medical, academic, and federal rehabilitation establishment in applying research, cure-oriented, and academic methods to problems which are not primarily in those areas of concern.

Various paradigms continue to be misapplied:

- The medical model is not adequate to address the full range of developmental and adaptive needs of many handicapped individuals. It is also conceptually barren in regard to persons for whom there is no reasonable expectation of "cure". This model should not be used to form the dominant conceptual framework for addressing issues of technology transfer.

- The research model will not work in solving what is primarily a service delivery problem. Persons adept in research will not necessarily provide effective leadership in delivery system design.

- The phenomenon of professionalism can, in addition to assuring specialized competencies, have a crippling effect on areas where teamwork and shared responsibilities of persons from varied backgrounds is essential. This has a particularly deleterious effect on the design of adaptive aids, since it is so important that the varied inputs of many professionals be included in the development of a product which must perform against wide-ranging objectives.

- Designers and engineers and therapists are not being educated sufficiently regarding the needs of persons with developmental disabilities, and regarding the adaptive needs of all handicapped individuals. They do not receive the field experience in this area which is required. This is especially true of the design and engineering professions where education is geared toward industry. In terms of educational field work, the inordinate caution with which design for the disabled is approached by academicians stifles rigorous involvement with the needs of the handicapped. Department heads are fearful of exposing undergraduates to the real problems of handicapped individuals. This is expressed in cautionary terms regarding danger to the handicapped person by becoming involved with inexperienced neophytes who may produce a dangerous product or involve the person in hazardous activities. There is parallel worry about the capability of undergraduates to deal with any real-world problems until they are well grounded in design concepts. The "purity" of design and engineering education seems to be a necessity through undergraduate matriculation. This is an unfortunate assumption. To withhold direct problem-solving experience from design students until they are finished with their professional training is to provide them with a barren educational experience; to further distance them from at least a minimal awareness of both the needs and the professional possibilities of designing for handicapped persons is a further diminishment of their opportunity for learning and professional growth.

- The private sector remains passive-for-profit. The private rehabilitation-aids industry continues to develop marketing methods far in advance of its delivery, service, repair, and parts-replacement capacity; it remains extremely conservative in design concept and product development. It fails to understand that the product that the purchaser is essentially buying

is not, for example, a wheelchair, but rather, *mobility*. Therefore, what is being paid for in the mind of the consumer is not essentially a *thing*, but a *function made possible*. Consequently, the need is not just for devices, but for the services that go with them.

- Consumer involvement and advocacy regarding technical aids has lagged behind its effectiveness in other areas. This is largely due to the often esoteric nature of the technical issues involved, and the inadequacy of consumer input in the establishment of the dominant paradigms guiding broad policy and individual decision and behavior.

The present situation, though replete with such obstacles to appropriate development, is alive with possibilities. A clear course must be charted in the federal, state, consumer, private, and higher education sectors. This will require, first, a conceptual redrafting and redefinition of the nature of the situation, the real goals to be attained, and the real constraints on attaining them; then, a course of legislative, budgetary, policy, and management actions to move forward.

Private industry must develop a new responsiveness to consumer needs, an increased awareness of the size and characteristics of the consumer market, and a renewed sense of business ethics and responsibility. This must include a more advanced definition of "cost-effectiveness".

Consumers must strengthen their knowledge of technical and service delivery issues, and thereby their effectiveness in dealing with them. They must aggressively inform and modify existing paradigms and assumptions.

The educational establishment must educate itself as to the social task, the technical content, and the job market.

Federal and state agencies must genuinely work together to develop appropriate, balanced strategies of basic and applied research, product development, and service delivery.

Federal research funders have an initial obligation to lead and set a priority on advancing the analytical data-base for further action.

What is needed is a conceptual redrafting of government and private sector understanding and definitions of the needs of handicapped individuals. This must include a look at the habilitative as well as rehabilitative needs of persons; the behavioral as well as functional needs and objectives of persons; the adaptive as well as orthotic, prosthetic, and medical needs of persons; the services, as well as the devices, that are needed; the validity of middle-level technology; the actual complexity of individualized design; and the real constants and variables at work which sustain the status quo.

In order for cohesive planning and future actions, significant research and data collection *are* needed, but not of a clinical nature. Study must be specifically aimed at *service delivery* questions such as these:

- How much, in terms of products and their design, *can* be feasibly transferred to mass production and mass marketing?
- How can the extremely labor-intensive and costly methods for individualized production be supported?
- How much do these services cost on average? How much should they cost? How much are they worth? (This is different from how much they cost!)

- What is the best constellation of federal/state/private and third-party funding, to provide the full range of research, training, and applied technology which is needed?

- What are the policies and planning steps needed to create, in a given region or state, the basics of a viable service delivery system?

- What changes/additions to design, engineering, therapeutic, and technical trades curricula are needed to develop individuals with appropriate expertise for successful careers on this field?

These questions are not new. They appear at every conference and workshop on technology and the needs of handicapped persons. These same questions must be repeated until they are answered within the right conceptual framework:

- Within the realization that what is being done now is, in fact, working the way it was designed, consciously and/or unconsciously, to work; the results are just not acceptable. Therefore, doing a better job of the same thing won't ameliorate the situation.

- Within the awareness that new and better and more information is needed regarding the real constants and variables functioning to keep us where we are--those attitudes, mandates, priorities, and limitations of the present structure which continue to continue. As a part of review and further planning, useful models should be identified and examined.

In the state of Massachusetts, a number of significant actions have occurred in the attempt to reverse this trend. As part of the momentum on behalf of developmentally disabled, institutionalized, and "mentally retarded" persons by various lawsuits and federal decrees, the Division of Mental Retardation has established a number of design and engineering shops for the expressed purpose of delivering usable adaptive aids to as many persons as possible.

These centers differ significantly from the typical research/training/demonstration center in their basic purpose, methods, and standards for service delivery; at the same time, they are very similar to the established R&T and R&E Centers in many of the products and services which they provide. The important structural differences are these:

- The shops are attached to an administrative structure which is based on the developmental, rather than medical, model of services.

- The mandate of these shops is primarily service delivery. Research and training activities are carried out only to the extent that they enhance the capacity of the shops to deliver services.

- The shops are funded on an annual budget cycle of the state agency, combining state funds with federal reimbursement under Title XIX.

- The driving force for work priorities and schedule is the Individual Service Plan mechanism. Each resident of these facilities is entitled to an Individual Service Plan, which becomes a binding contract between the agency and the client. This plan includes major behavioral and functional objectives which must be met. Equipment is designed and delivered in an order of priority

which supports these objectives for each individual. Overall priorities are determined by an aggregate of these individualized needs as they're listed and prioritized on an individual basis.

- The agency addresses the full range of functional, cognitive, philosophical, educational, vocational, recreational, and residential needs of the person. No single objective is given priority; rather, the overall living goals of the person define a range of functional and learning objectives.

- The severely disabled and multidisabled, under the ISP system and definitions of Active Treatment, tend to become first in line for this service. This is a significant reversal of past trends.

These and other important characteristics in the historical development and present objectives of these facilities account for a much higher level of direct service and overall productivity than is typically found in most research-oriented facilities. The typical shop is serving a population of about 200-300 individuals, all of whom may need services within the same 12-month period. Staffing of the facilities is multidisciplinary, and teamwork is essential. This has required tremendous efforts to overcome the various communication, identity, and "turf" barriers which often exist between engineers, designers, therapists, technicians, and medical and programmatic personnel.

The products of these shops vary greatly; customized wheelchair inserts, lapboards, communication aids, environmental adaptations, non mobilized positioning aids, postural supports, devices to assist in eating, dressing, bathing, and personal hygiene, and educational aids are included in the list of special products, modifications, and designs which are put forth out of these centers. While the variety of services is great, and while concentration varies depending on needs of the client population, services share some common characteristics in addition to those which set them apart from the typical federally funded rehab engineering or voc-rehabilitation shop. All of the shops are working within a developmental model, have a multidisciplinary staff and transdisciplinary design methods, work within an intermediate level of technology, and focus on service.

The network is tied to sources of advanced technology and expertise through affiliation and cooperative information sharing and training. The R&T Center at Tufts, and various departments at MIT, Massachusetts College of Art, the University of Massachusetts, Boston Children's Hospital, and Shriver Medical Center offer continuous input and assistance.

Consumer involvement has been strong ever since the initial planning for growth of the network. It is being reinforced through consumer representation on various advisory and planning boards and committees.

Working in this way, one state agency has demonstrated an unprecedented capacity for transferring known technology to the needs of individual persons. However, even this is not the best and final model. It is not the best or most feasible overall solution to the larger problem of technology transfer to all handicapped individuals in need of assistive aids and devices. The current level of success in service delivery within the Massachusetts Department of Mental Health represents an important demonstration of one component of what must become a solid, effective, and balanced coalition of consumer, federal, state, nonprofit, and profit-making organizations.

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Albert M. Cook

Delivery of Assistive Devices through a Client-Oriented Approach

The title of this session is "Grass Roots Rehabilitation Technology." This brings several images to mind. Grass roots implies a firm foundation with the people. I feel that this perspective is particularly important in dealing with solutions to problems faced by disabled individuals in daily living, education, and employment. A second implication of grass roots is that the effort is in touch with real needs. This perspective is also critical if advances in technology are to serve the needs of the disabled rather than the needs of the researchers and engineers for grant support.

Client Services

I am director of client services for the Assistive Device Center (ADC). We use the term client because it implies a partnership between the provider and the receiver of the service. This partnership is crucial if solutions are to be meaningful to the disabled consumer and if they are to play a major role in ameliorating disabling conditions. The Assistive Device Center provides services on a referral basis from local agencies. The service is available on a fee-for-service basis. The ADC also has ongoing research programs, most of which are oriented toward improving the delivery process. For example, current research is aimed at improving assessment and evaluation methods for non speaking individuals to better match their needs to augmentative systems. We also evaluate communication devices, and we are developing new devices and new applications for microcomputers. An additional service offered by the ADC is a resource center for access to scientific and engineering curricula for students with disabilities in the 19-campus California State University and Colleges (CSUC) system. This resource center includes a computer data base organized by classroom and laboratory skills required for successfully completing science and engineering courses. Each skill that is entered results in a listing of resources (devices, altered instructional formats, bibliographic citations, resource persons, and service agencies) available for solving the student's access problem. The resource center also provides device evaluations of equipment intended for educational access, provides consultation to the CSUC campuses, and acts as a clearinghouse for information on science and the handicapped.

Technology and the Disabled

Many physical barriers to the full participation of persons with disabilities in recreation, education, employment, and independent living are imagined by the able-bodied. Persons with disabilities have developed many coping

strategies that allow them to function quite well despite handicapping conditions that would appear to preclude their active participation in many areas. Additionally many social barriers are imposed by the fear of the able-bodied of "being like that." This fear is born of ignorance. It is being slowly overcome by the more obvious presence of persons with disabilities in public places and in professional roles.

I believe that technology can help overcome these imagined and real barriers if several conditions are met. First and foremost, technology must be appropriate to the need. Despite the increasing availability of complex technology, many problems are most effectively (and cheaply) solved with very simple technology. For example, many communication problems can be effectively dealt with using simple pointing boards. This is not to say that highly complex (e.g., computer-based) systems are never appropriate. Often, however, the philosophy of "the computer can do anything" is employed rather than evaluating appropriateness first.

Second, the technology must be cost effective. This of course is like apple pie, motherhood, and the flag; no one would dare to disagree with such a noble concept. However, the rub comes in determining cost effectiveness rather than merely cost. Long-term benefits must be factored in. The adaptability of technology to changing needs and the costs of use (fatigue, mental stress) are also important factors. There have been many analyses based on decreased dependence and therefore decreased public expenditures when technology is applied to the solution of problems of the disabled. These analyses, while compelling, have two major shortcomings. First, they are always based on a large number of debatable assumptions. Second, and most important, they are only applicable to a total rehabilitation program, not to the use of individual assistive devices. Thus, it may be true that a person is "less expensive to society" if he or she is independent, but the specific role of a communication device (for example) in this process is unclear.

Third, technology applied to the disabled must take advantage of technology developed for mass markets. As Dr. John Eulenberg of Michigan State University has pointed out, the automatic transmission, power brakes, and power steering made driving available to the disabled in the same way that the home computer is making vocational, communication, and educational skills available to them.

The economies of scale do apply. High technology is expensive in small quantities, but it is incredibly cheap in large quantities. By making use of products and technologies designed for the mass market, we can provide much greater capability in assistive devices at lower costs than if the technology were developed directly for the disabled. Note that I said lower cost, not necessarily low cost. Complexity and versatility of function will still be expensive, and the degree of modification required to allow a disabled person access to the technology may be expensive. Nevertheless, the end result will be much greater function for equivalent cost.

Finally, technology can be of use to the disabled if we keep the person at the focus rather than the technology. Another platitude, right? Wrong! There are many examples of rehabilitation engineering centers throughout this country and abroad that appear to exist exclusively to entertain engineers looking for "hard problems" to solve. Unfortunately, some of the problems that the disabled have do not have hard solutions; rather, they have incredibly simple solutions. These problems do not always capture the interest and imagination of engineers. For example, many of the problems faced by disabled persons involve weakness in the arm and hand. Simple adaptations for doors, faucets, toilets, eating utensils, etc., need to be designed *and delivered.* Delivery is a major problem, since most of the information is only contained in catalogs available to "professionals". Another problem is that a unique

solution done for one person in New York may never be published or made available to a person in California.

Summary

Grass roots rehabilitation technology is delivered technology. Devices that never leave the laboratory never solve real problems. There is effectively no delivery system for assistive devices in many parts of this country. The concepts outlined in this presentation are, I believe, central to the effective delivery of these devices. A key element in any delivery scheme is the active participation of the consumer in the process. The medical model in which a "professional" makes a pronouncement that is to be followed by a "patient" does not apply. The partnership between user and provider of devices must be established before any solutions can evolve. The consumer must be able to reject solutions without losing the participation of the provider in the solution process. The engineer must be capable of explaining options in clear terms so that intelligent decisions can be made. Together providers and consumers can solve problems that neither can handle alone.

Paul J. Corcoran

Rehabilitation: Definitions and Concepts

It is obvious to everyone who works in the health care system that physical disabilities are on the increase in the United States. Many people who take pride in the accomplishments of American medicine are understandably frustrated by this trend. People have the expectation that medical progress will tend to decrease or eliminate disability and chronic disease from the population. Similarly, the health care delivery system, the medical education and research establishment, and the health insurance industry all tend to focus on acute disease, and pay relatively little attention to chronic disease and permanent disability.

Medical progress actually has an effect opposite to this general expectation of diminished disability. Every advance in acute medicine or surgery leads to the survival of a new category of patient who formerly would have succumbed to his or her disease or injury. Prominent examples of this in the past 40 years include spinal cord injury; peripheral vascular disease; stroke; prematurity and congenital brain damage; and recently, cancer. For an individual patient, however, the price of survival is often a permanent disability, resulting either from the disease itself, as in the case of spinal cord injury or stroke, or from the life-saving treatment for the disease, as in amputation for gangrene or cancer.

Another result of medical progress is the increasing life expectancy, which leads to an aging population. People who in former times would have died of some now preventable or curable disease such as pneumonia or typhoid fever, today have the luxury of living long enough to contract cancer or have a stroke. Certain nonlethal disabling conditions such as arthritis and visual and hearing loss also become more prevalent as the population ages.

At the other end of the age spectrum, the advances in neonatology have led to the routine survival of premature infants weighing less than two pounds, who only 20 years ago would not have survived. These children are at greater risk of cerebral palsy and other disabilities related to low birth weight and prematurity. In the teen-aged and young adult age groups, the increasing complexity of our civilization is leading to more disabilities related to accidents, trauma, and stress.

As a result of these trends, some 41 percent of hospital patient days and 27 percent of physician-patient contacts now are the result of chronic rather than acute disease. Many of these patients need rehabilitation services. This is a fact which the health professions and the general public either have not grasped or have failed to translate into program and policy changes.

This paper will examine the definitions and concepts behind the following terms: *impairment; disability; abilities; normal; independent; handicapped;* and *rehabilitation.*

Impairments

A patient is generally understood to be a person who has something wrong with him. Medicine in general tends to look at pathology, at what is wrong with the patient. Health professionals deal with impairments: lesions, dysfunction, deficits, altered physiology, the subnormal or the abnormal. Lip service is paid to the concept of "treating the whole patient," but in practice the patient is likely to be referred to as "the stroke in Room 300" or "the ulcer we admitted last night." Medical students and interns compare notes about which hospitals offer "the best pathology" when deciding where to pursue their postgraduate training. Patients with minor illnesses or psychosomatic complaints are of little interest.

While the patient is expected to be quite ill in order to live up to the doctor's expectations, a curious fact is that he or she is also expected to recover. Young people enter medical school or study other health professions out of a desire to cure people, to stamp out disease. The patient who does not recover completely is generally considered to be a failure. Students and interns commonly adopt unflattering terms such as "gork," "gomer," or "crock" to describe patients who fail to recover or are left with chronic disease or disability. These pejorative terms are no doubt used to shift the responsibility for the failure from the physician to the patient, making it easier to deal with feelings of guilt and failure on the part of the cure-oriented health professional.

Rehabilitation is unlike other areas of medicine in that it deals with patients whose pathology is generally permanent or irreversible; our patients are those who, in less delicate times, were called "cripples" or "incurables." Most of us are regularly asked whether it isn't rather depressing working in a rehabilitation center with all those hopeless, helpless cases. Perhaps nowhere is the image of rehabilitation more negative than in certain quarters of the health care industry itself. This is reflected in the minimal amount of curriculum time for rehabilitation in medical and nursing schools; the lack of coverage for rehabilitation services in most health insurance plans; and in the name and location of rehabilitation facilities. We may have dropped some of the old names, such as "Hospital for the Ruptured and Crippled" (now renamed Hospital for Special Surgery, in New York City); but we still tend to locate our rehabilitation facilities on islands and mountaintops, or in forests and parks. This negative or devalued view of rehabilitation is understandable in the context of a health care system oriented toward acute, curable disease and focusing on pathology, on what's wrong with the patient.

Rehabilitation is concerned with what's *right* with the patient (Figure 1), with residual abilities, resources and skills that can be developed or enhanced, to adapt or compensate for impairments of the structure or function of the patient. This orientation allows the rehabilitation professional to maintain a positive attitude toward persons with disabilities.

An *impairment,* then, is *an alteration of anatomy or physiology, of structure or function, caused by disease, injury, or developmental failure.*

Disability

Some impairments have no consequences, good or bad. Examples are the structural impairments of gray hair, moles, and freckles, or the functional impairments of hiccups, sneezing, or hoarseness. These are so common that society accepts them as normal, and may even attach positive value to them.

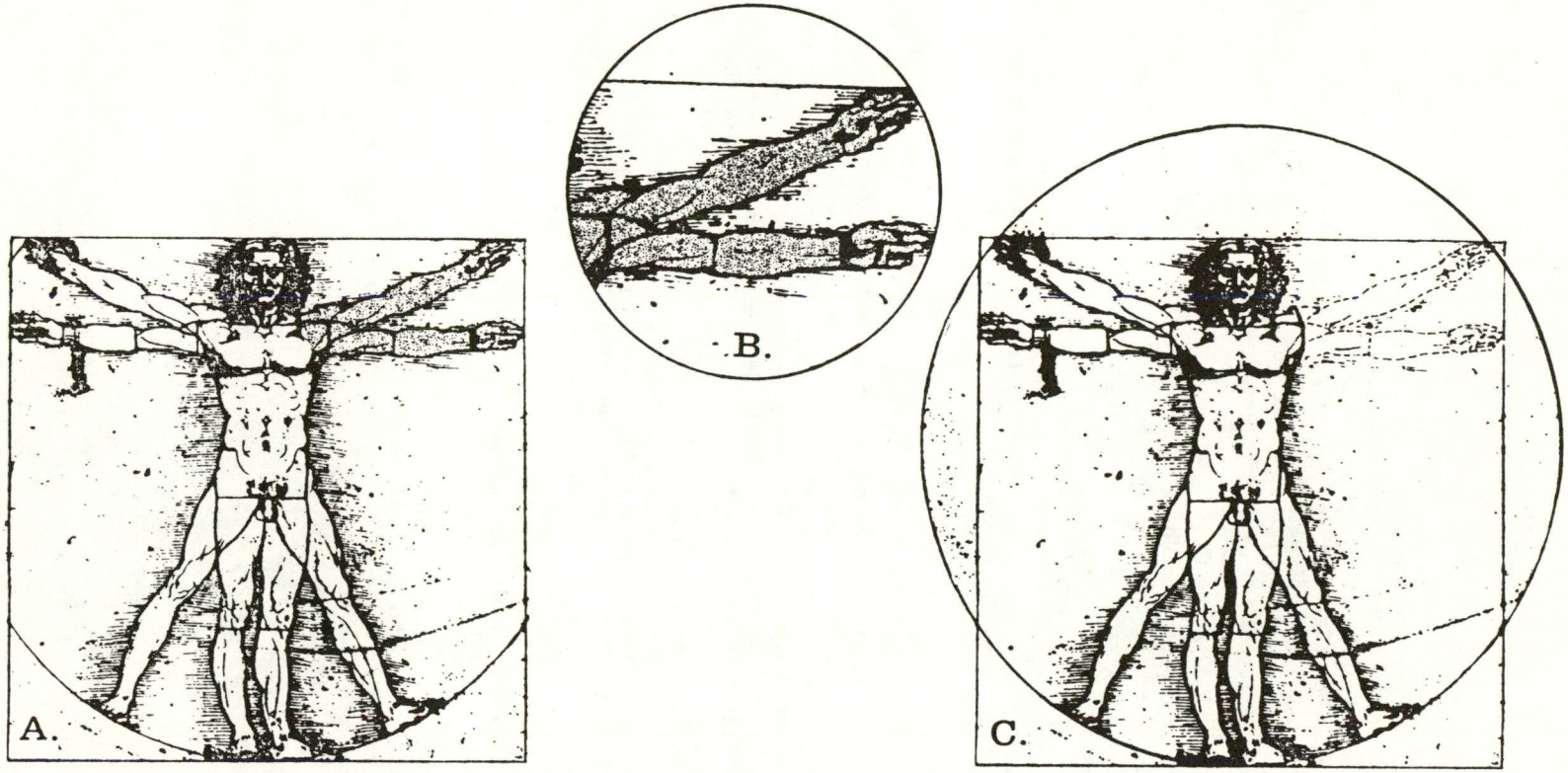


Figure 1: Differences Between General Health Care and Rehabilitation

A. A patient is a person who has something wrong with him, i.e., an impairment of structure or function.

B. The health care system generally tends to focus on the impairment or pathology, i.e., on what's wrong with the patient.

C. The rehabilitation process is concerned with what's *right* with the patient, i.e., the residual abilities, skills, and resources that can be developed or enhanced.

Other impairments produce severe cosmetic or social consequences, but do not interfere with function. Examples would be the structural impairment of facial scarring or disfigurement, or the functional impairment of urinary or fecal incontinence.

Still other impairments actually interfere with our ability to perform various activities. Thus a disability may be the consequence of an impairment of structure (e.g., a limb amputation) or of function (e.g., paraplegia or hemiplegia). A *disability*, then, is *a cosmetic or functional limitation which is the consequence of an anatomical or physiological impairment of the patient.*

Abilities

Abilities include everything that people do or are capable of doing. They are generally divided into the categories of mobility, communication, and activities of daily living (ADL) (Table 1). Each of these categories of ability can be subdivided into inwardly-directed personal or survival activities, and outwardly-directed activities involving an interaction with other people or the community. Rehabilitation programs have tended to focus on the first group, the personal survival activities such as self-care and indoor mobility. As our patients are more and more severely disabled and with the recent emphasis on independent living, the outwardly-directed, social activities are becoming more important. Rehabilitation programs, and functional assessment scales which measure their effectiveness, need to place more emphasis on this second category.

Abilities, then, are *the levels of performance of the mobility, communication, and daily living activities which people do, both to maintain their bodily survival and health, and to interact with other people and the environment.*

Normal

A "normal" person is said to be one who can "do everything," who is "independent" and who "needs no help." This, of course, implies that there is some standard against which one's performance can be judged. Consciously or unconsciously, we tend to consider ourselves as "normal." Our own perceived abilities, lifestyles, and behaviors are what we judge others by. We tend to be intolerant of those who talk, walk, or think slower than we do. Society can be quite harsh toward groups who require or demand "special adaptations" such as accessible rapid transit, modified toilets, or special education programs, especially if they raise our taxes.

Most of us need periodically to be reminded how relative is the term "normal." Normalcy relates primarily to age, education, and culture (Figure 2). A middle-aged adult is not expected to have the speed or endurance that is normal for teen-agers. On the other hand, children are not expected to have the communication skills that would be normal for a middle-aged adult. Education also colors what we accept as normal, especially in activities requiring verbal or manual skills. Culture exerts perhaps the greatest influence on our criteria of normalcy. A normal Australian aborigine is expected to perform certain mobility and self-care activities that would kill an American. Even in our own communities, ordinary citizens of 200 years ago were expected to do many things that a normal adult of today cannot do, such as produce their own fuel and food, or travel long distances on horseback.

Far fewer personal services and mechanical assistive devices were needed by the "normal" person of 200 years ago, or are needed by the "normal" person of most other parts of the world today. The extensive network of transportation, communication, and personal services that Americans take for granted must be included in a definition of "normal" for a person from the United States culture. Thus a *"normal"* person is *one who can perform mobility, communication,*

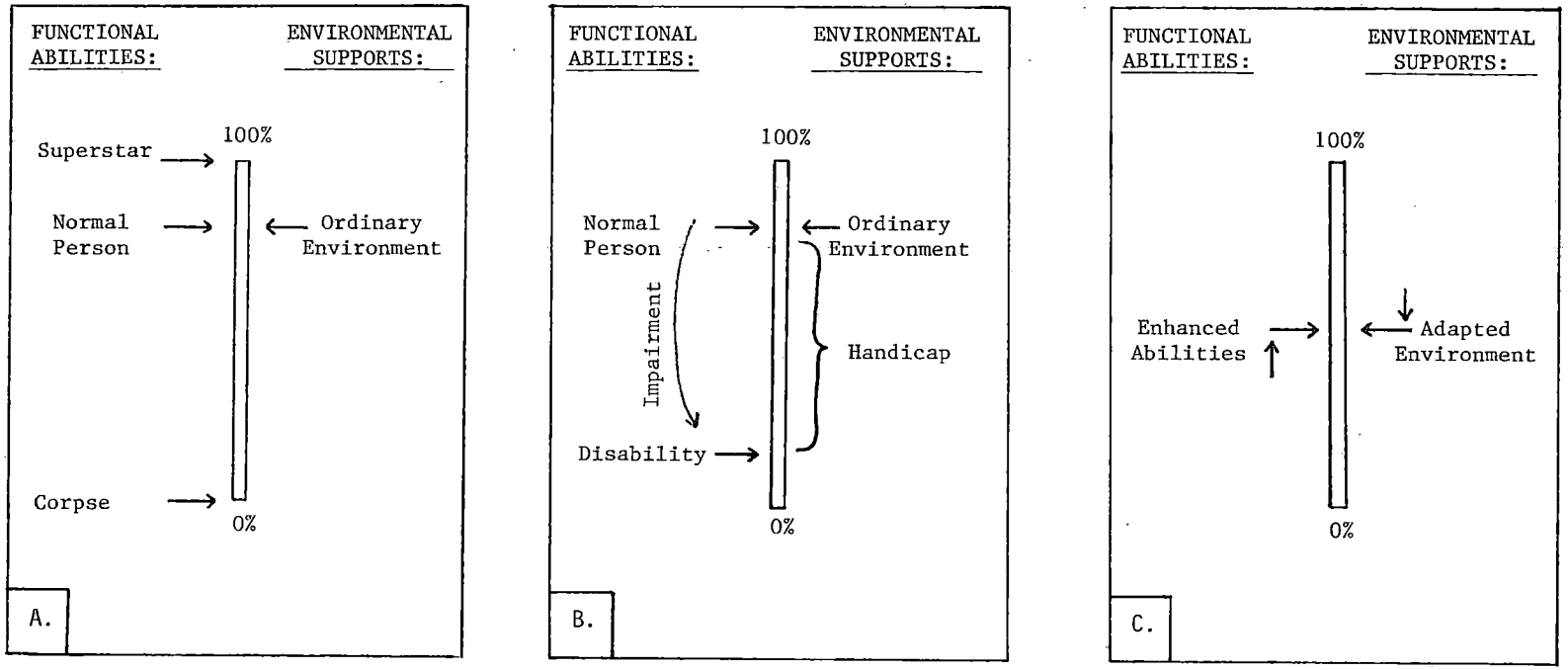


Figure 2: Relationship Between Functional Abilities and Environmental Demands

A. A "normal" person is one who can perform the activities that are expected for his age, education, and culture; he is "independent" because our ordinary environment provides a network of support services and assistive devices.

B. An impairment may diminish one's functional abilities, producing a "disability"; until the environment is appropriately modified, there will be a handicap, i.e., a disparity or gap between the functional abilities of the individual and the demands or expectations of the environment.

C. Rehabilitation is successful when a match has again been reached between one's enhanced residual abilities and the reduced demands of an adapted environment; at this point, the disabled individual is no longer handicapped. Like able-bodied people, he is now "independent" in the sense that he has access to, and utilizes, the necessary environmental services and equipment.

and daily living activities as quickly and easily as an ordinary person of the same age, education, and culture.

Independent

Most healthy adults consider themselves to be normal, independent people who perform their mobility, communication, and daily living activities without assistance. This notion of the "independence" of us "normal" people deserves some further examination. It is instructive to consider the previous 24 hours in one's life, and the normal activities which have been performed.

Most of us traveled to the upper stories of our homes or other buildings in the past 24 hours. This did not require scaling walls or jumping to great heights, because adaptive devices called stairs or elevators were available. Most of us travel long distances at high speeds in a typical day, using complex and expensive vehicles called cars, trains, and planes, often with the assistance of trained technicians to operate them.

One may feel that he or she bathed, dressed, and ate breakfast on a typical day without any assistance or special adaptations. Further reflection, however, shows an infrastructure of thousands of persons who grow, process, deliver, and in some cases prepare our food. Our grooming and personal hygiene require a network of utilities terminating in special adaptive devices within our own homes. Our clothing is manufactured in large factories and is laundered and pressed by machines, often operated by others. While some of our communication is done without assistance, much of it involves the help of a network of electronic aids (telephones, television) or printing and publishing systems requiring extremely complex equipment and the assistance of thousands of technicians.

Thus it really isn't accurate to define the disabled as those persons who require special adaptations or human assistance to perform their mobility, self-care, and communication activities. We all require a great deal of help to do these things. Power failures, strikes, and natural disasters periodically remind us how pervasive is our dependence on human and mechanical assistance.

Independence, then, for both disabled and able-bodied persons in the United States culture, means *having access to, and utilizing, the necessary mechanical devices and human helpers to perform ordinary mobility, communication, and ADL activities.* A disabled person may use slightly more assistive devices or human help that a normal able-bodied person but is still classified as "independent" if these additional devices and services are in fact available and are utilized in the performance of ordinary activities.

Handicap

To understand handicap, it is necessary to go back to the concept of "normal" and relate it to the environment.

Functional abilities can be thought of on a scale from 0 for a corpse to 100 for one who can do everything in the *Guinness Book of World Records* (Figure 2). While we may admire or glorify the accomplishments or attributes of beauty queens, athletes, and daredevils, we don't expect every "normal" person to duplicate them. "Normal" is that arbitrary point on the scale that matches the expectations for someone of the same age and education in the same cultural environment. An impairment of structure or function may diminish our functional abilities on such a scale. A handicap is the disparity or gap between one's impaired functional abilities and the expectations or demands of a normal person in our environment. An able-bodied American would be handicapped in the America of colonial times or in the Australian bush country today. An able-bodied novice at golf or tennis is given a "handicap" to allow him to compete in the environment of skilled athletes. A wheelchair user, on the other hand,

is not handicapped in an environment which includes elevators, curb cuts, hand controlled cars, and accessible parking spaces.

A *handicap*, then, for able-bodied and disabled persons alike, is *a disparity or gap between the functional abilities of the individual and the expectations or demands of the environment.*

Rehabilitation

Persons with permanent impairments of structure or function will presumably never reach the "normal" point on the scale shown in Figure 2. They will always have a disparity or gap between their abilities and the culturally determined norm of their particular environment. Effective rehabilitation programs thus require a twofold attack on this disparity: the residual abilities of the patient must be enhanced, and the handicapping barriers of the environment must be reduced.

The acute, cure-oriented nature of the health care funding system is a major obstacle to effective rehabilitation programs. The health care system is much more oriented to correcting impairments through acute hospitalization, surgery, etc. It is less interested in enhancing residual abilities, but under some circumstances will pay for therapy or devices to improve the performance of personal survival activities listed on the top half of Table 1. In general, the health insurance industry is not at all interested in paying for training in the outwardly directed social and community activities listed in the bottom half of Table 1, nor in reducing the handicapping constraints of the environment. Every rehabilitation professional regularly encounters the dilemma of a rehabilitated quadriplegic for whom the health insurance industry is willing to pay hundreds of dollars per week for traditional services and institutionalization, but is unwilling to make even a modest one-time investment to reduce the handicapping demands of the environment through such measures as home modifications or adapted vehicles.

Obviously, the more severely disabled is the patient, the more one has to adjust downward the demands of the environment, through provision of adaptive equipment, rehabilitation engineering devices, and personal care assistance. Training to enhance the residual abilities of a severely disabled patient places less emphasis on muscle strength and endurance training and more on the development of proper attitudes and skills that allow the severely disabled individual to supervise and relate well to his or her personal care attendants, operate the adaptive equipment that has been provided, and function in a suitably modified environment.

Rehabilitation programs, to be effective, must be designed so as to simultaneously enhance the residual abilities of the disabled person, and reduce environmental barriers. The very severely disabled individual, such as a high level quadriplegic person, requires significant adaptations to perform mobility, communication, and daily living activities. Several hours of personal care assistance may be a part of this requirement. (When compared with the highly complex adaptive equipment and large numbers of technical assistants used by the average able-bodied American, the increased adaptations for the quadriplegic seem rather insignificant). Once provided with these environmental adaptations, and the training to use them, the severely disabled quadriplegic may perform quite well in most of the "normal" activities listed in Table 1.

Rehabilitation, then, is *a twofold process of enhancing the residual abilities in the patient, and reducing handicapping barriers in the environment*, to permit the patient to use the required amount of human assistance and adaptive equipment that will allow each task or activity to be performed.

Pejorative Terms

A discussion of rehabilitation terminology and concepts would be incomplete without mention of some of the damaging terminology sometimes used in connection with disabled people. One often hears disabled persons described as "crippled", or "sufferers" of arthritis, or stroke "victims". These are negative, pejorative terms which have no place in a rehabilitation medicine service. Similarly, the use of the expressions "the disabled" or "the blind" tends to set them apart as a separate class of people who are abnormal, or subnormal.

If we have an honest appreciation of the relativity of normalcy, we will use positive terms like "people with disabilities" or "visually handicapped persons."

Referring to a disabled person by the diagnostic name ("an arthritic" or "a spinal cord injury") is also a bad practice. If we learn to focus on abilities rather than on pathology, we will say "a spinal cord injured person" or "the man with arthritis."

Another common semantic sin is to say "confined to crutches" or "wheelchair bound." The unrehabilitated impairment may confine or bind the person; the crutches and wheelchair liberate the person. Acceptable alternative terms are "wheelchair user," "crutch walker," or "person in a wheelchair."

The nondisabled person should not be referred to as "normal" or "healthy" when drawing a distinction from the disabled population. This tends to suggest that disabled people are sick, subnormal, or abnormal. The preferred terms to describe the nondisabled population are "the able-bodied" or "an able-bodied person."

Summary

All indications are that continued medical progress will lead to a growing percentage of disabled people in the population. The health care system must be made to recognize and deal with this trend. Medical and nursing students and others studying in the health professions must learn how to relate positively to and serve the needs of persons with chronic disease and disability. The health care system must provide and reimburse for services to remedy all of the consequences of chronic impairment, whether through enhancing residual abilities of the patient or correcting the handicapping barriers of the environment.

We have reviewed the definitions and concepts behind some of the common terms used in rehabilitation: *impairment, disability, abilities, normal, independent, handicap,* and *rehabilitation.* Finally, we have reviewed the damaging pejorative terms that reflect negative attitudes, and have suggested some positive terms and expressions to use in their place.

Table 1

FUNCTIONAL ABILITIES REQUIRED FOR INDEPENDENT LIVING

	I. MOBILITY	II. COMMUNICATION	III. DAILY LIVING (ADL)
	Indoor Mobility	*Receptive Communication*	*Self-Care Activities*
A. Inwardly-directed personal survival and health activities	1. bed mobility	13. hearing	25. eating and drinking
	2. bed to chair transfers	14. seeing	26. bowel and bladder
	3. up-time (normal=16 hrs/day)	15. watching TV	27. bathe/groom/dress
	4. ambulation	16. orientation	28. obtain food/shelter
	5. toilet and tub transfers	17. finding one's way	29. obtain health needs
	6. stairs	18. reading	30. sexuality
	Outdoor Mobility	*Expressive Communication*	*Community Activities*
B. Outwardly-directed social and community activities	7. curbs/ramp	19. talking	31. social contacts
	8. uneven terrain	20. social behavior	32. helping others
	9. adverse weather	21. telephoning	33. school/training
	10. private car	22. managing money	34. job seeking/retention
	11. taxi or wheelchair van	23. writing/typing	35. doing useful work
	12. public transportation	24. business/legal affairs	36. earning money

Paul J. Corcoran

Independent Living in Berkeley and the Bay Area of California

In the past decade, Berkeley, California, has acquired the reputation of being one of the most accessible and desirable places in the United States for a disabled person to live. It has become something of a magnet for severely disabled individuals, especially wheelchair users. Some were handicapped students at the University of California who remained in the city after graduation. Many others have been attracted to Berkeley as a place to live, although they have no formal connection with the university. The result has been the emergence of a handicapped community that is internally supportive of its members and quite well accepted and integrated into the larger community.

The origins of this phenomenon can perhaps be traced back to the year 1962 when a high school graduate named Ed Roberts was accepted as a student at the university, although he slept in an iron lung and used a power wheelchair for daytime mobility because of childhood polio. His acceptance was a radical departure from previous convention, and resulted from intensive lobbying efforts by himself and his mother. Another key factor in his acceptance at the university was the willingness of Dr. Henry Bruyn, the medical director of Cowell Hall (the university's infirmary), to allow Mr. Roberts to live in the infirmary rather than in the usual dormitory space. Ed Roberts was successful as a student at Berkeley, and before long there were approximately 10 wheelchair students living in Cowell Hall, which by then had converted one nursing unit to function as a dormitory for these students. Their personal care service needs were met by able-bodied students from the campus.

In the radical campus atmosphere of the 1960's, it was not long before the disabled students at Berkeley had organized a group called the "Rolling Quads". This organization lobbied university and town authorities for the changes that were necessary to permit the disabled students full access to necessary facilities. Rolling Quads also served as a vehicle for important mutual support, consciousness-raising, and social skill training for many of its members. The program grew and was absorbed by the university into the present Physically Disabled Student Program, which is now a routinely funded part of the student academic support services on campus. The present program is housed in a two-story building with a full-time paid staff and a budget for student orientation, counseling, personal care attendant screening, wheelchair repairs, device fabrication, and braille and electronic aids for blind students. (For further information, write or call Physically Disabled Student Program, University of California at Berkeley, 2515 Channing Way, Berkeley, CA 94720, (415) 642-0518.)

As disabled students graduated from the Berkeley campus and in many cases remained in the community, the need arose for a non-university center to provide

some of these same needs for handicapped citizens who were not eligible for student services. The Berkeley Center for Independent Living (2539 Telegraph Avenue, Berkeley, CA 94704, (415) 841-4776), created to meet this need, now has a staff of several dozen people and a budget of well over a million dollars. It owns its own building, a former automobile dealership on the main street of Berkeley, a few blocks from the campus. The Berkeley CIL provides many of the same services as the Physically Disabled Student Program, and also has a large van modification shop, wheelchair maintenance facilities, a device fabrication shop, and skill training and advocacy services for persons with a variety of disabilities.

Another factor in the growth of the handicapped community in California was a provision of the State Department of Welfare that handicapped persons could receive personal care and chore services without having to live in nursing homes. This unique program, begun in the 1950's, is funded through Title XX funds supplemented by state financial support. Cash for reimbursement of personal care attendants is given in advance to the disabled individual by his or her county welfare office, after a determination of need is made by the welfare caseworker. Thus disabled people for more than two decades have had the option of living outside of an institution in their own home, hiring and paying attendants who were thus accountable to them directly rather than to an agency. Many in the Berkeley disabled community developed sharing arrangements with roommates, housemates, or friends to get the greatest benefit from their PCA money. This in turn increased the cohesiveness of the handicapped community in the area.

Today in the San Francisco Bay Area, severely handicapped people, including many in electric wheelchairs, are commonplace in stores, restaurants, and theaters, on the sidewalks and freeways, and in schools, homes and workplaces. The low-rise garden apartment and ranch housing style has made it easier to locate accessible housing. Curb cuts are quite uniformly available, especially in commercial neighborhoods. The new Bay Area Rapid Transit System is completely accessible, with elevators or ramps to each of the 34 stations in the system, and it is hard to travel very far on the system without encountering disabled people routinely using it. People in wheelchairs from Berkeley think nothing of a shopping trip to a downtown San Francisco department store or a night out for dinner and the theater in another city of the Bay Area, traveling with friends or alone on the BART system. The combination of power wheelchairs and curb cuts makes it possible to live several blocks from the nearest BART station and still use it rather than a hand-controlled car or van for routine transportation. Being an automobile-oriented area, many disabled people also use cars and vans, and some ingenious space-age van-control systems have been provided for drivers with extremely limited physical capacities.

The following is an analysis of why things work so well for disabled people in the Berkeley area. These conclusions are not based on scientific research but rather on several visits over the past 12 years; working relationships and friendships with a number of disabled Berkeley citizens; and several prolonged brainstorming sessions on the subject:

1. The climate, terrain, and housing stock are <u>not</u> the major determining factors. The terrain is quite hilly in places, there is quite a bit of rain, and much of the housing was built in the first few decades of this century. Many other cities could be cited, especially in the "sun belt" of the United States, that provide a better climate, flatter terrain, and more modern accessible housing than Berkeley, but have far fewer disabled people living independently.

2. Surely a critical mass of talent is assembled at and around the University of California Berkeley campus. Berkeley is the tip of a huge state university pyramid, and each entering class represents a few thousand of the most talented students from a population base of 30 million people. Many creative able-bodied people on the campus have also turned their

attention to disability and rehabilitation issues. The resulting critical mass of talent in one small but gregarious community accounts for much of the progress that has been made there.

3. Key people in the right places at the right times have been willing to take risks, as did Dr. Henry Bruyn at Cowell Hall in 1962.

4. Undoubtedly a major factor in the successfully independent lives of severely disabled citizens in Berkeley is the availability of design, fabrication and maintenance services for their adaptive equipment. For example, the wheelchair repair shops at PDSP and BCIL are open 16 hours a day, 7 days a week, for both routine and emergency repairs. In Berkeley, a flat tire or broken axle does not have to mean a day or a week lost from work or classes. Other equipment can be serviced and maintained without delays. Other standard or custom adaptive devices are also provided. Many student research projects have involved devices or environments for disabled people. The cost of equipment repairs for students is borne by the PDSP program. For nonstudents, BCIL is a vendor which can obtain reimbursement from the California Medicaid program and other third parties, and actually make some modest profit on its wheelchair and equipment repair service. The handicapped grapevine works very well in Berkeley, and disabled individuals learn of available adaptations and device ideas by word of mouth. Often simple adaptations are built by the disabled individual or a friend. Many elegantly simple devices may be seen in homes and in use on the streets. In other cases, some advanced and sophisticated environmental controls and vehicle modifications may be seen. The opportunity to obtain "appropriate technology" is readily available in Berkeley, in marked distinction to most other parts of the United States.

5. Perhaps a major share of the credit should be given to California itself. The "laid back" mellow lifestyle, the leisurely gregarious atmosphere, and the tolerance for people who deviate from the norm, are well-known characteristics of California in general, and the Bay Area in particular. Attitudinal barriers seem to be more rare to the visitor from outside California, and acceptance and integration occur more routinely. Tradition and convention do not seem to matter very much in California. This has made it possible for disabled people to evolve whatever lifestyle best meets their own unique needs for independent living.

Frederick A. Fay

Fitting Technology to the Handicapped Human Being

Let us hope that 1981, the International Year of Disabled Persons, will be the start of major progress and improvements in the lives of disabled people. Ultimately, what needs to happen in the 1980's is a partnership among the various constituencies of handicapped people to better their living opportunities at a time when resources are becoming even tighter than they have been in the past.

The thing Martha Redden has done through the AAAS Workshops that is really exciting is to bring together not only disabled people from different disability groups to become more aware of each other's needs and to be able to advocate on behalf of each other, but also to bring together the third parties--the rehabilitation providers, the pharmaceutical companies, the salesmen and so forth--to establish dialogues and to become aware of each other's concerns and constraints.

A greater involvement by disabled people and a stronger link between researchers, developers, manufacturers, and marketers are essential. One of the great challenges of the 1980's will be to make the marketplace more receptive to the devices that are needed and to entice private companies into the area of devices for disabled people. One possibility in this regard is to "piggyback" devices to benefit disabled people onto devices available in the general marketplace. Take for example, the *Speak and Spell*, a toy that is marketed by Texas Instruments for children. You can tie that little item onto the back of a nonverbal communication device and create an output device.

By making the device attractive to the general public you can tap a much larger market and produce an item at minimal cost to the consumer and maximum profit to the company by virtue of the mass market process. Similarly, wheelchair technology might be tied in with other transportation developments, such as electric cars and golf carts. A device similar to an electric wheelchair might even become a regular mode of transportation in some non-handicapped contexts.

The next step, of course, is for handicapped people to become more involved in the political process. We can learn a lot through the civil rights movement, where gains have been made through various minority groups banding together. By bringing together the leadership of the blind, deaf, paraplegics and other disability groups, the American Coalition on Citizens with Disabilities (ACCD) has had a phenomenal impact on Congress and the Administration in connection with various policies. It's been said that civil rights and mainstreaming legislation has done more to get technology available as part of reasonable accommodation than has any particular research or design project. Currently the Cleveland Amendment, which threatens the transportation access section of 504, brought more letters

and phone calls into Representative Cleveland's office than he has received on any other issue in the 18 years he has been in Congress, which is an indication of how concerned disabled people are about this particular issue.

The National Institute on Handicap Research (NIHR) has put together a five-year plan that sets up funding for Rehab Engineering Centers and Rehabilitation Technology Centers around the country. NIHR also now has a broad mandate through an interagency committee to work with BEH, NASA, the Veterans Administration, and the National Science Foundation. The committee will play a coordinating role, increasing cooperation among different federal agencies that are involved in funding projects related to disabled people. This five-year plan, mandated by Congress, is critically important. It's going to determine the direction that the future of rehabilitation research takes, and I'm concerned that disabled people haven't seen fit to be involved, either in the committee's work or in the appropriations process, just as I am concerned that rehabilitation providers and professionals haven't become involved in disability issues.

My point is that working together, there is very little that we can't do. I would urge that the kind of relationships developed through the AAAS Workshops should continue, for these relationships will build linkages that will make the 1980's the decade of independent living.

Richard A. Foulds

Rehabilitation Devices: Can We Understand the Costs?

The primary theme of this workshop has been the concept of "appropriate technology." Exactly how one defines that term seems to have been the subject of many of the discussions here. I would like to suggest that underlying nearly all of our personal feelings about the word "appropriate" is the issue of cost. In many of the sessions in which I participated there was concern regarding the expense of rehabilitation devices and technical service. It would appear that unless we can arrive at an understanding of how and why devices for the disabled cost what they do, we will find the issue of "appropriateness" continually clouded by the emotional issues derived from the perceived "high cost" of rehabilitation devices.

Commercially Available Rehabilitation Devices

We may begin our examination of the cost of devices by considering the commerical marketplace. An obvious fact is that appliances which are uniquely sold to the disabled population do cost more than do appliances of similar complexity which are marketed to the general public. A comparison between the wheelchair and the bicycle illustrates this argument.

What is the cause of this apparent discrepancy? Shortly before this conferernce, a writer for the *Wall Street Journal* sought information from me for an article on "ripoffs" in the rehabilitation device industry. She was reasonably convinced that the "high cost" of devices could be attributed to deviant behavior on the part of someone or some people within the industry.

My response to this was to give her a list of consumers and manufacturers and to suggest that she could provide a valuable service by interviewing them and publishing their responses. What the rehabilitation community needed at that time was for someone to begin to identify the difficulties of purchasing and producing. The article was quite successful and has influenced both my presentation at this workshop and the ideas that follow in this paper.

The Size of the Marketplace

As a researcher and clinician in rehabilitation engineering, I have come to understand that the rehabilitation marketplace is unlike any other to which I have been exposed. While there are large numbers of disabled people in our country, the actual number who can benefit from a particular device is rather small. The wheelchair is the device with perhaps the largest single demand, with an estimated 300,000 sold annually. If we compare this "giant" of rehabilitation with bicycles, toaster ovens, and automobiles, we find that this annual demand

is quite small. When we consider the demand for such devices as communication aids, environmental controls, and driving aids, the comparative market size shrinks still further.

It should be clear to the reader that from a strict manufacturing perspective the cost per item should go down as more of an item is produced. Mass production and other potentially cost-reducing techniques can be employed in large-volume production only if large-volume sales dispose of the inventory. If the rehabilitation marketplace can only support a limited sales volume, then the industry must retain the inherently costly production techniques mandated by low-volume manufacture. No one can disagree that the automobile would be many times more expensive if it were still manufactured using techniques that were developed for production numbering in the thousands rather than in the millions.

Human Factors Design of Products

In addition to the small volume, manufacturers of rehabilitation devices face an often overlooked difficulty. When an engineer designs an appliance for the mass market, he or she can make certain assumptions about the intended population. There will be certain common or "universal" attributes of the population that will enable large numbers of people to use the same device. Users of a calculator are assumed to have appropriate eye-hand coordination to make successful key strikes. The designer is confident that each user will be able to read the display with sufficient clarity to avoid unwanted error.

It is quite possible that the designer of a device for the disabled population may not share this "luxury." A physical disability defines physical differences. In many instances there may be a medical classification that results in widely ranging function among members of the population. A consequence of that is that each device that purports to provide increased function must remain flexible and adaptable to match the existing functions of the individual users. This added flexibility adds to the cost of the device in terms of both design and manufacture.

The Cost of Selling a Device

When we look more closely at the rehabilitation device market, other differences become apparent. Assistive devices are not sold in the same way that other devices are sold. One might expect to find sections of a department store that sell shoes, riding lawn mowers, and calculators. No one really walks into that store and expects to find departments selling braces, electric wheelchairs, and reading machines for the blind. The typical rehabilitation marketing strategy employs a salesperson traveling from rehabilitation center to rehabilitation center or from house to house demonstrating and delivering devices to individuals. The growth of modern department stores and supermarkets in our society ended an era when food, milk, pots and pans and even clothing were sold door to door or by appointment.

When the consumer travels to the source of the products, the costs come down. The traveling salesperson has been retained in only a few industries. The computer industry, which markets individual items such as minicomputers and word processing machines that have prices in the many thousands of dollars, has recognized the large cost attributed to its sales approach. That industry has recently promoted the concept of retail computer stores.

Within the rehabilitation device industry there are few self-service stores. Many of the devices require medical prescriptions or at least some form of clinical recommendation. A typical scenario for a device placement requires several visits by the salesperson. Often the device must be brought to the clinic or client for an initial demonstration. If the prescriber is "serious" a second demonstration/evaluation is often requested. The salesperson may be asked to make a third visit to assist in finding funding for the device or to help in

justifying it to a third-party payer. Finally, the device must be delivered and set up for the intended client. Should there actually be a successful sale, these four visits would necessarily be built into the selling price. This time could easily be more time than it took to make the actual device. The above assumes that the sale was successfully executed. Based upon my clinical experience, I would say that a good sales record would be about 30 percent. The reasons for an unsuccessful sales effort include lack of funds and inappropriateness of a device to a particular customer.

While my scenario may not be exactly accurate, the reader can begin to understand that considerable time can be consumed in the selling of the device. The cost of this effort, added to the selling price, is an added cost of doing business in the rehabilitation device industry.

Custom-Made Devices

Until this point I have discussed the portion of the device market where there are at least enough potential users to warrant even modest commercial enterprise. In many instances there are such small numbers that no commercial device meets the needs of the user. Often we find that the only reasonable solution is to fabricate a custom appliance.

When the idea of custom construction is introduced, the cost of the device grows dramatically. The cost to design one unique device may not differ significantly from the design costs if hundreds were to be built. The portion of the design cost passed on to the customer is roughly the total design cost divided by the number of items made. A single custom-designed device must therefore carry all of the development costs.

Few of us can afford to have our own personal clothing designers. The cost of a garment designed especially for one of us would carry an enormous price tag. The idea of custom tailoring, while not as expensive, is still a costly concept. Although the tailor may not invent the three-piece suit, and does not weave his own cloth, the personal touch of one person spending time measuring our height and girth, our bumps and curves, is very labor intensive. Most of us just go to Sears and take something off the rack.

We cannot always use the "off the rack" analogy with the severely disabled. The mass production of clothing is based upon the anthropometric idea that relatively few sizes can accommodate most of the population. With the disabled population the number of options for workstation modifications, for example, would be so numerous that it may approach the size of the population seeking those modifications.

What Can We Do About the High Cost of Rehabilitation Devices?

Possibly the question should be asked, "Can we do anything about the high cost of rehabilitation devices?"

There are certain circumstances that can lower the cost. Often a mass market opens that includes the formerly closed rehabilitation market. The sonic focusing camera manufactured by Polaroid contains enough circuitry to produce a mobility aid for the blind at a much lower cost than ever expected. Small typewriter-like memo units can often be used by the disabled as communication aids, replacing small typing devices manufactured only for the disabled. Home microcomputers are now capable of being programmed to serve as teaching machines, communicators, word processors, and environmental controls. Their mass market appeal has made this type of hardware available at department store prices.

Beyond this type of change, I do not predict that the rehabilitation device field will see tremendous price decreases. Quite possibly the idea of seeking lower costs should be replaced by a different set of values. We may consider

accepting the relatively high costs. We should understand that there are no major rip-offs, but there's a very different market which by its nature increases cost.

If we do accept the cost of the devices, we should also look to the benefit they bring. A powered wheelchair may not be an easily affordable commodity. Yet, if a person who required independent mobility were to be denied that wheelchair, the cost to provide a human aide to assist in mobility would easily cost more. Simply stated, custom invention cannot be offered at department store prices.

Spending money on a device today may make a significant contribution to reducing medical and personal care costs in the future. The result of the provision of a device may even result in placement in the work force, which would bring a measurable return in tax dollars.

Very possibly there may not be an actual payback in direct monetary terms. The device that is provided may be associated with quality of life. During my first week of employment as a rehabilitation engineer I came across a quote by Dr. Frank Krusen, the noted physiatrist. He said, speaking of the practice of medicine and rehabilitation, "We have given more years to life, now we must give more life to years." This may be something to think about in relation to the cost of devices in rehabilitation.

Lex Frieden

Delivery Systems Abroad

Earlier this year, my wife, Joyce, and I had the opportunity to study rehabilitation programs in Sweden and the Netherlands. Accompanied by my attendant, Malcolm Brodie, we spent 6 weeks in Sweden and 3 weeks in the Netherlands visiting facilities and talking with a wide variety of people about policies and programs designed to benefit disabled people in those countries. Our study was sponsored by the World Rehabilitation Fund, Incorporated.

This was a novel opportunity because both of us are in wheelchairs. As a result, we were able to approach our study from a little bit different perspective than nondisabled rehabilitation professionals. We tried to live as much like ordinary consumers as possible during our trip. We stayed in a service house for disabled people in Gothenburg, Sweden; in a student flat in Stockholm; and in a newly constructed apartment unit near the center of Nijmegen, Holland. We shopped for ourselves, did our own cooking on many occasions, and used public transportation as much as possible.

Although we talked with many government representatives, organization leaders, and facility administrators, much of what we learned came from discussions with consumers. We talked with disabled people we met living in the places where we stayed, eating in the restaurants where we ate, and riding the specially adapted transportation vehicles in which we rode.

We discovered that, generally speaking, there are more services and benefits for disabled people in both Sweden and the Netherlands than there are in the United States. In particular, income benefits and cash subsidies for disabled people are comparatively high in those countries. In fact, their benefits are not unlike those we reserve exclusively for service-connected disabled veterans.

In spite of liberal benefits and extensive service networks, many of the disabled people we talked to were dissatisfied. They pointed out that many of the benefits they received discouraged independence and threatened motivation. Some of the people we talked to said they would like to go to work, but they couldn't afford to risk losing their benefits. Others said they had applied for jobs and been turned down because employers wanted to hire nondisabled people who needed the work because they did not have high pensions.

Needless to say, we were surprised and somewhat disappointed to find that our European friends had not solved all the problems related to integrating disabled people and helping them reach goals of independence. Nevertheless,

we did discover a number of exciting programs, and we got a lot of new ideas that may be useful to us in the future.

Perhaps the most impressive program we found, and the one I would like to describe to you today, is the Nation-wide Technical Aid program. Both Sweden and the Netherlands have a program for the centralized provision of and payment for technical aids and devices. These comprehensive systems not only provide aids, they prescribe, repair, evaluate, and replace those aids and devices as needed.

The aids are usually supplied free of charge by the government and may include wheelchairs, elevators, remote control devices, automobiles, and so forth. Being economically destitute or poor is not a requirement for receiving assistance in these countries. In reality, standard minimum or guaranteed minimum incomes prevent anybody from being really poor. In any case, people do not have to spend what income or savings they do have to purchase aids and devices they need. With exception of the automobiles, the upper cost allowed for purchase of aids is extremely liberal. We saw people using government-purchased wheelchairs which cost as much as $7,000 or $8,000. Additionally, the fewest number of wheelchairs that we found anyone having in Sweden was seven. We don't know what they did with them, but some people had as many as 20 wheelchairs that had been purchased for them by the government.

With respect to automobiles, Sweden pays only a portion of the cost of the vehicle, and all costs for adaptations. Most of the disabled people whom we met there used public transportation instead of private vehicles anyway. We were astonished to find that the only van adapted for driving from a wheelchair was at the Handicap Institute in Stockholm. It was a Ford van that was adapted in the United States, licensed as an experimental vehicle in Sweden.

In Sweden they are very safety conscious, and strict in that regard. They do not believe that it is safe for someone to drive from a wheelchair, and until they develop some effective restraining devices and other safety features, it is unlikely that people who cannot transfer themselves in and out of their own automobile will be driving themselves in Sweden.

The government of the Netherlands has purchased about 16,000 automobiles for use by disabled people in that country. These are small mini-vans made in France. They are all set up for nondisabled people to drive and for wheelchair users to ride in their wheelchairs in the back. They are very small, and could only accommodate one wheelchair, a driver, and perhaps one other nondisabled passenger. The government pays the entire cost of these vehicles, and they are more selective about who receives them than they are about who receives other types of aids and devices. A committee of representatives from the rehabilitation sector, the labor unions, and government reviews each application for such a vehicle, and decides whether or not the person shall receive one. The decision is generally based on what each person's needs are. We were told that someone who is working or going to school is much more likely to get a car than someone who is not.

In Sweden, each county is responsible for purchasing the aids and devices needed by disabled people in their own county. The counties refer people to one of several aid centers located in various parts of the country. People go there to look at and try out the aids that are available, and they consult with therapists and rehabilitation engineers about which devices would be useful and best suited for them. They may also have an opportunity to take sample aids or devices home from the center and try them out. We were told that certain more expensive aids may be lent to people on an extended basis rather than purchased for them.

If a person needs a particular aid or device that is not available commercially, then it is possible to develop and build a prototype or experimental model for that person to use. This is usually done at the Handicap Institute in Stockholm. The Handicap Institute is like a national technical assistance unit for all of these regional and county centers. This national institute, with a staff of more than 100, tests and compares all commercially available aids and devices for handicapped people. They develop product standards and consult with manufacturers on how best to meet those standards. They also advise the county centers and individuals about which aids are best for certain purposes. Additionally, they publish and distribute product guides related to all sorts of different equipment for disabled people.

Besides advising, evaluating, disseminating information, and developing some aids themselves, the Handicap Institute does nationwide need analyses to determine unmet equipment needs of disabled people. This helps them to stimulate production of needed devices by the private sector. In effect, they do the market research needed to justify investment by private manufacturers. They also have a fund that they may use to subsidize or share the cost of production for some limited market products.

The system in the Netherlands is not quite as well developed as that in Sweden, but it follows the same general idea. The government, through an agency called the General Medical Services (GMD), prescribes and purchases aids and devices for disabled people. The GMD has offices in almost every community, where people may go to make application for equipment they need. They may consult with a rehabilitation counselor at these offices, or they may get advice from therapists or specialists at other rehabilitation facilities. Each application must be approved by the GMD, and, as mentioned before, automobiles are the most difficult aid to be approved. Disabled people told us that low-cost, commercially available equipment was easiest to get approved. The more exotic or more expensive a device is, the more justification is required by the GMD.

Even though a person must be able to demonstrate some kind of real need before he or she receives approval for getting some equipment, the GMD is considerably more liberal with their judgments and expenditures than most rehabilitation agencies in the United States. Additionally, the GMD imposes no work requirements on disabled people who request equipment that may be useful to them in their everyday lives. We visited the apartment of a young man who had a modified kitchen, a modified bathroom (including roll-in shower), remote control automatic doors both front and back, remote control appliances, and ramped doors both front and back, all courtesy of the government. Another interesting aspect of the Netherlands system is that it is possible for the disabled person to shop for and choose a device, pay for it, and be reimbursed by the government. In most such cases, the GMD sends a counselor to inspect the equipment after it has been installed before payment to the individual is approved. We think this practice is good because it gives the handicapped individual more responsibility and thus more independence.

In summary, I believe, and I think Joyce would agree with me, that the nationwide system of evaluation, prescription, provision, repair, and replacement of technical aids and devices for disabled people in Sweden and the Netherlands should be modeled by the United States. The centralized provision of and payment for equipment should be both cost effective and cost beneficial. It seems like this would speed both the development and delivery of new devices to disabled people. On the whole, it would probably decrease the cost of such aids and devices to the government over a period of time. Finally, there is no doubt that disabled people could be more independent if an effective system were available to help them find and select equipment, pay for equipment, repair equipment, and replace equipment. I hope this presentation gives you some ideas that we may build upon to propose such a system here in the United States. Thank you.

Harriet G. Kopp

Technology and Access to Education for the Hearing Impaired

The wide range of degree of hearing impairment, age of onset of hearing loss, nature of loss, and socioeconomic conditions makes it impossible to generalize with respect to either the impact of hearing loss or the feasibility of technological compensation. Deafness may not be considered solely as a physical disability. Our cultural emphasis on spoken language is reflected in the social isolation of many profoundly deaf individuals. Unless an early, special effort is made to provide intensive language input to those born deaf, not only is there a delay in language development but, because of the intrinsic relationship between language and cognition, cognitive processing does not proceed on normal developmental schedules, resulting in learning and behavioral difficulties. As a consequence, reading and writing may be retarded, adversely affecting educational advancement. The problems tend to become cumulative, despite special schooling.

Hearing loss prior to development of linguistic competency has a profound effect upon the acquisition of receptive and expressive language. Different individuals may compensate for a similar hearing loss, occurring at a similar age, with varying degrees of success, dependent upon: home/family conditions; educational opportunities; presence of other disabilities; use of residual hearing, including early identification, diagnosis, and treatment; and as yet unidentified personality factors. In general, however, it may be presumed that a profound hearing loss sustained at an early age will have a greater effect on linguistic and cognitive competencies than a lesser loss, or than an equally profound loss occurring after these competencies have been acquired.

When the hearing loss is mild and there are neither cortical complications to impair the processing of auditory input nor visual disabilities to reduce the opportunity for visual compensation, the use of hearing aids may provide the wearer with sufficient acoustic information to permit him or her to function without other assistance. Speech, language, and cognitive skills probably will develop within normal expectation. However, the complexity and sophistication of hearing aid technology fall far short of providing full compensation. Amplification is comfortable only within a limited range of loudness and becomes painful when tolerance levels are exceeded. Quality is often distorted.

Hearing Aid Effectiveness

The hearing aid is still designed to provide amplification at frequencies at which there is residual hearing, frequency areas that I have termed "Auditory Asset Areas." Thus the wearer receives only partial acoustic information

from which to interpret a message. For example, spectrographic analysis of speech reveals that acoustic informational cues are available to the hearing individual throughout a wide frequency range and that maximal intelligibility is derived from transitional information which occurs as we articulate vowels and consonants in succession at normal speaking rates. Most human languages are designed chiefly for direct acoustic transmission. Much significant information lies in the frequencies above 2000 cycles. Unfortunately, most present day hearing loss occurs at those frequencies. Since hearing aid amplification usually is designed to compensate by increasing the sound level gain at frequencies accessible to the individual, auditory information must be derived from partial and often inadequate cues. Although we possess the requisite technology, only sporadic experimental attempts have been made to develop a hearing aid which transforms information input by providing high frequency transitional cues at the low frequencies accessible to the listener. This would take second formant information occurring in auditory deficit areas, where residual hearing is least effective, and transform it so it is accessible to the auditory asset areas.

Presently, the burden is upon the individual to process information from limited auditory cues. This requires significant dependency upon contextual data with supplementation from visual speech cues such as lip-reading, when they are available, and from environmental information. It demands considerable intellectual agility and most often succeeds when the individual has had normal hearing prior to the loss or has a mild or moderate level of loss, or has developed high linguistic competency. For example, the sentence "John is coming because he's thirsty" has an optional interpretation if hearing is distorted, "John is coming because it's Thursday." The listener may need situational cues to know whether it's Thursday or John wants a drink. We are reminded of the old joke about the indignant, elderly gentleman who complained to the ophthalmologist that he couldn't read with his new glasses. Only after long questioning, he revealed that he never learned to read and had thought that the glasses would enable him to do so. That joke, unfortunately, has analogies in hearing impairment. Although a hearing aid will make it possible for the hearing-impaired individual to receive auditory input which he may process, his ability to process the information cognitively will be related to whether he has learned to hear and interpret partial auditory cues. He can't process what he can't perceive, but just increasing the amplitude of the signal won't improve his ability to understand.

Hearing individuals learn to interpret minimal auditory cues most successfully when the information is familiar and spoken in one's native language. Rapidly spoken language by a familiar speaker, even in the presence of noise, causes few problems. To be understandable, speech in an unfamiliar language or dialect must be slower, louder, and free of ambient noise. Hearing-impaired listeners also must understand even minimal and distorted cues. Understanding is less difficult if the language, the context and the speaker are known, if the sound environment does not cause confusion, and if the visual environment provides supportive, supplemental information. The earlier age the processing begins in the individual's developmental growth, the more apt it is to be successful. Although present hearing aids are responsive to requirements of those with mild to moderate hearing losses and are useful for those with moderate to severe losses, they are not engineered to the specifications of those with severe to profound hearing impairment, nor do they serve those with additional disability areas which diminish visual supplementation of the acoustic signal.

Supplementing the Sound

The feasibility of tactile conversion and supplementation of the auditory signal has been explored periodically without success. As indicated by a Bell Telephone Lab research project on tactile perception of speech stimuli in 1944, the complexities of such research are painfully clear. The problem of code transformation resides, to some extent, in the ability to transform an

acoustic code designed to be perceived by auditory receptors into a signal system that may be decoded by receptors (visual or tactile) programmed for other highly specialized sensory systems. Direct tactile transmission of speech signals in continuous speech, if achieved, would permit visual attention to be focused elsewhere during reception of acoustic input. The hearing-impaired individual using vision to supplement aided audition is not free to read, to take notes, or to attend to incidental environmental input while listening.

Those hearing-impaired individuals who make effective use of their hearing aids may use the telephone and enjoy television and films provided the acoustic signal is clear and relatively undistorted by noise. For others, visual supplementation is needed for direct transmission. This may run the gamut from lipreading and natural gesture to the use of an interpreter providing a simultaneous translation of the message in sign and/or finger spelling. The use of oral or manual interpreters in education, business, medical, legal, and social situations is essential for many profoundly deaf individuals as is the employment of note takers. Although interpreters provide a much needed service and are governed by accepted rules of ethical conduct, they interpose a third presence in many situations which interferes with the spontaneity of dialogue, as in a medical or psychiatric setting. The problems are familiar to normal hearing individuals who have used a foreign language interpreter. It is especially difficult to find interpreters for the deaf who are familiar with highly specialized vocabularies. At the post-secondary level, a variety of innovative and ingenious strategies are used to permit the deaf student access to instruction in the field of his or her choice. Unless the student attends one of the special post-secondary institutions for the deaf, faculty members require considerable assistance in understanding the problems of the deaf student in the classroom and laboratory and in adapting both instructional and examination methods.

One approach to direct transmission of speech has been to transform the spoken message to print before transmission, as in the TTY and its analogous teleprinters, or to transmit handwritten messages. This requires special equipment at the terminals and limits accessibility to direct communication with the population at large. It has the effect of reducing spontaneity of conversation and certainly of requiring basic spelling competency.

Since speech production is controlled by auditory feedback monitoring and learned through extensive trial-and-error imitation of acoustic models, the speech of hearing-impaired individuals reflects the degree and kind of hearing loss and its time of onset, as well as the effectiveness of the hearing aid. Even when speech has been established for many years, a progressive or sudden hearing loss in late adulthood results in progressive deteriorations of speech. The speech problems will mirror the frequencies lost in hearing unless they can be fully compensated by a hearing aid. Disturbances in pitch and loudness control are common. Where deafness is congenital, the acquisition of speech is a long and tedious process requiring individualized tutoring. The effectiveness of auditory feedback is affected by many variables including the provision of very early use of well-fitted and maintained hearing aids. Too often, speech is not intelligible except to those very familiar with the deaf speaker. Much effort has been expended through the years in devising teaching strategies and visual supplementation devices for providing feedback.

Research since 1943

From 1943 to 1946, I participated in the Bell Telephone Laboratory development of the sound spectrograph and its analogue, the direct cathode ray translator. In the research process, it was necessary to define the parameters requisite to analyzing speech so that they might be visibly portrayed in a form which would be instantly intelligible visually, would retain individual differences and variability while providing recognizable/identifiable features to characterize each phoneme, and would permit knowledgeable viewers to associate

the physiological movement and physical factors basic to articulation, phonation, and resonation with the visual display. After the project was released from its wartime top-secret status, the sound spectrograph and the direct translator provided several generations of phoneticians and speech scientists with the chief research tool for speech analysis and synthesis. Such technical spinoffs as "voiceprint identification" of individual speakers and voice-operated typewriters and telephone switching devices saw their genesis and basic development by that same research team. It was apparent that these visible displays could provide a systematic approach to the acquisition of speech by the hearing impaired; a means of monitoring speech with instant feedback; a potential display system to permit the use of the telephone by the deaf; and a means of acquiring fluency in speaking foreign languages.

From 1944 through 1955, these potential applications were tested on experimental groups, and some are still in research stages today.

In 1945-46, one profoundly deaf chemist employed at the Bell Telephone Laboratories learned to use the real-time speech translator to receive and send telephone messages, and 15 hearing individuals learned to read real-time speech spectrograms at slow normal speech rates as spoken by a variety of speakers in several dialects and languages.

From 1946 through 1955, seven young deaf children and eight congenitally deaf, non speaking adults acquired speech using the real-time visual-feedback display system. All developed intelligible speech, and, using the Richards Basic 800 word English vocabulary, were able to use the telephone with familiar speakers at somewhat slow speech rates.

From 1959 through 1970, a miniaturized real-time translator was used at the Detroit Day School for the Deaf as part of the speech training of upper elementary and intermediate age profoundly deaf students. There, the display provided immediate feedback for monitoring speech and permitted students to practice alone, using printed spectrograms for pattern watching. Since 1970, the display has been in use in the speech clinic at San Diego State University, and commercial models have been provided for some experimental use in other clinics.

Children and Spectrographic Display

Only limited spectrographic research has been carried out on the speech of young children, either hearing or deaf. There is no significant spectrographic documentation of the developmental growth patterns of normal articulation, phonation and resonation from infancy through adulthood which could provide a pattern-matching basis for using visual feedback monitoring for acquisition of speech. Research analysis of the speech of the deaf, both intelligible and unintelligible, is limited to a few investigators with too few samples.

Use of the real-time translator with young deaf children has provided evidence that by age seven, they can understand the relationships of the patterns to physiologic movement and physical characteristics of speech. Younger children are able to associate production of vowel and consonant features with patterns. The ability to monitor acoustic feedback visually significantly improves the use by both children and adults of kinesthetic feedback and residual hearing in monitoring continuous speech. It is apparent, also, that a major advantage of the visual display is in the motivation derived from the deaf individual's ability to experiment with his own speech and to control it by trial and error with immediate reinforcement. Instead of depending upon teacher/tutor/family evaluation, the deaf individual can function with relative independence. He is able to monitor the supra-segmental features important to speech communication: stress, loudness, pitch, syllabication, and breath support. If instruction is carefully paced, he can practice independently.

The primary problems with real-time spectrographic display are the high cost of the equipment, the need for maintenance, and the lack of qualified instructors with preparation in applied physiologic phonetics. The technology is available, and the requisite parameters have been defined. Only the provision of low-cost equipment will make its effective use feasible. The NSF funding of the Integrated Sciences Corporation "Visual Feedback" project, the Childers "Laryngeal Vibration" research, and the Linville and Dobelle projects encourage expectation for the future. SRI had a proposal in the works, and there are probably others that will surface in the near future.

There are many visual displays available, commercially and in research laboratories, that provide partial information: pitch patterns; volume indicators; vowel resonance positions; voicing indicators. These are useful in correcting specific speech problems but not for the visual monitoring of the coordination of articulation, phonation, and resonation essential for the production of intelligible, continuous speech. A prime virtue is that they are available, require no specialized preparation of instructors, and are relatively inexpensive to buy and maintain.

Language Competency Problems

Problems in development of language competency related to delayed or inadequate input often stem from faulty diagnosis or failure to identify the loss. There has been no simple resolution to the educational and social problems generated by the long history of disagreement, both within the deaf community and among educators of the deaf, as to the most effective method of providing early language acquisition. The large number of variables makes the use of control and experimental populations extremely difficult. Proponents of either the oral/aural or manual (sign language/finger spelling) approaches to early language input can point to some individuals who succeed and others who fail. Actual research results are sparse and often plagued by uncontrolled variables. Since it is impossible to provide sufficient substantive school subject information either orally or through manual communication, it is essential that the hearing-impaired student develop high-level competencies in reading and writing. Normal speech rates are about 150 to 200 words per minute, but signing and finger spelling are difficult at that rate. A good reader can read 1000 words per minute.

Despite the acknowledged need for reading/writing skills, the average severely hearing-impaired student is retarded from two to three years in reading at the elementary level, and many post-secondary students have not achieved skills above the sixth grade. The effect of delayed language development and reading on cognitive processing is predictable and has been responsible for many of the socio-educational-vocational-psychological problems faced by the hearing impaired. Small pockets of success have been attributed to selected student populations, using particular long-term applications of structured, systematic approaches coupled with small class size and massive teacher/administrator effort. It seems essential that cognitive skills and language be acquired through a systematic controlled approach, and that reading be developed as early as possible. From 1959 through 1970, at the Detroit Day School for the Deaf (a large, heterogeneous, urban school), I was privileged to experiment with a methodologic application of a philosophic position integrating language, reading, writing, and speech through a focus on the teaching of science from pre-school through high school. The application of scientific problem-solving methods stimulates the student's curiosity, provides strong motivation for independent and divergent thinking, and offers an impetus for language (reading and writing) competencies required for logging data, report writing, and reading related research. This can occur and has occurred at all educational levels and appears to have the effect of maximizing cognitive growth opportunities, resulting in significant acceleration in mastery of school subjects, measurable on standard achievement tests. These results were reported in the Annuals of the Deaf in the 1960's.

Computer-Assisted Instruction

It appears logical to develop computer-assisted instruction (CAI) using programmed learning techniques to facilitate language learning and to teach reading and writing skills, mathematics, and other school subjects. A few agencies, institutions, and commercial organizations have begun to show an interest in CAI, but the major funding focus, in the past, has been on mediated instruction using filmstrips, overhead projectors, videotape, and "special-idea teaching machines" to expedite learning of specific concepts and skills. Interactive computer technology has not been applied effectively in a systematic fashion. The trend has been to develop software centered on a single concept or some other rigid, structured approach to cognition, rather than to initiate programs mindful of cognitive processing constraints and generalized from a cognitively based learning model, resulting in individualized and group-coordinated programs on longitudinal continuums.

There is, of course, another point of view. If technology continues to move forward with respect to the artificial ear or to implantation of acoustic receptors bypassing the cochlea, thus providing the ultimate in hearing aids, the problem of hearing impairment will be diminished for a large part of the severely deafened population. While the research at Stanford, in Los Angeles, and in several European countries appears to indicate great potential, there is no immediate relief seen. Certainly this is the ultimate hope in hearing aids.

The Bell Telephone Labs and IBM, among the large corporate research entities, are continuing efforts to use spectrographic analysis and synthesis technology to develop computers able to recognize spoken English, albeit with limited vocabulary at this time. Such linguistic/speech coding and decoding has been the subject of many research projects since 1945. Improvements in the basic technology being developed for commercial applications in telephones, dictating machines, coding systems, translation devices, typewriters, and printing may result in application to communication and instruction of the profoundly deaf. Scientific liaison between the educational community and industry is essential to ensure adoption and adaptation of such advances.

Much improvement in the lifestyle of the deaf would be possible if present technology could be applied to needs of daily living, including devices for communicating within the home; for transmitting infants' cries or children's calls throughout the house and outdoor play areas; for improving alarm clocks; for making news and emergency broadcasts accessible on television or with provision of special radio transmission converters; and for providing theater, film, educational, and religious assemblies with inexpensive modes of permitting access by the deaf to real-time translation of ongoing programs at several levels, taking into account those able to benefit from amplification and those requiring other forms of visual/tactile supplementation.

In the best of all possible worlds, deafness will be overcome by medical and technological advances. In the real world, it is possible to use present-day technology to enrich the lives of those who are born with or acquire hearing loss if we can excite the interest of the scientific community.

Rehabilitation Technology Linkages:

The Device

Maurice A. LeBlanc

Rehabilitation Engineering is the provision of assistive devices for people with disabilities. Children's Hospital at Stanford has a Rehabilitation Engineering Center (REC) which provides services in five primary areas: orthotics, seating and mobility aids, prosthetics, communication aids and controls, and prevention of tissue trauma.

A follow-up study was recently completed of clients seen at the REC. Of 196 clients contacted, 138 responded and 49 were interviewed in their homes. Results, documented in the report "Team Assessment of Device Effectiveness" (available from the Center) showed that

- About 80 percent of the devices provided were functionally reliable and effective.
- About 50 percent of the devices provided were being used an average of nine hours per day.
- Average cost of the devices per day of use was $1.50.
- Reasons for non-use were that devices were outgrown; that devices had mechanical malfunction; or that there were associated psychosocial problems.
- There was a correlation between successful use of devices and an active, participating consumer, and between non-use or failure of devices and a passive, non-participating consumer.
- Consumer participation is integral and essential for successful provision of assistive devices.

Perhaps the most important conclusion for the future provision of rehabilitation engineering services is that the initial evaluation and assessment with the consumer must cover not only functional needs but also personal/psychosocial needs and the environment in which the device will be used. The physical device itself is only one link in the process of rehabilitation.

The Person

John Preston, Jr.

Many physical, social, emotional, and environmental factors should be considered in the design and manufacturing of devices to be utilized in the rehabilitation or adjustment process of the disabled.

The task becomes one of balancing the disabled person's environmental, physical, and personal strengths against the debilitating forces of the physical impairment. This is especially true in the provision of an assistive device where there is a real need to reduce complications that tend to exacerbate those unusual problems created by the physical disability.

For the disabled and able-bodied alike, a lifestyle of homeostatic balance is maintained unless stress is overwhelming. Part of the adjustment process of the disabled person involves learning to live in satisfying equilibrium with one's surroundings.

Providers of service are not always aware of the extent to which these psychosocial needs of disabled persons and their families may impinge on successful use of an assistive device. These psychosocial needs must be considered for optimum benefit to occur. A measure of psychosocial benefits may be evident in lifestyle changes for the person using the device and for the entire family.

Lifestyle as a concept encompasses participation in daily activities, social interaction within the environment, perception of life tasks, aspirations and values, and one's self-concept of success or failure in these areas. Much of our understanding regarding the rehabilitation of the disabled has been seen as a medical problem. However, more emphasis is now being placed on the role of an individual's lifestyle in relation to disease and the rehabilitation process. Thus, the emphasis on intervention is not aimed at the emotional response to the disability per se, but on the adaptive response to the stress involved in the adjustment process. It is my opinion that there is a significant amount of stress involved with the introduction of an assistive device into the person's lifestyle. The following data tend to support this impression.

In our follow-up study we looked at certain lifestyle changes of 49 individuals who had received devices at the REC between May 1975 and May 1978, to determine if in fact individuals or families did perceive certain lifestyle changes after receiving an assistive device.

Responses to the questionnaire indicated that 21 percent perceived no change in lifestyle after receiving an assistive device. These same persons had devices scoring 0 or 1, denoting minimal or no effectiveness in achieving the objective of the device. For those 79 percent of respondents who perceived significant changes in lifestyle, the device score was 2 or 3, indicating moderate to optimal effectiveness.

The Environment

Sandra Enders

This is an exciting time and place. The Bay Area is a trend-setting community. We are at the cutting edge, both of technology and of the grassroots independent living movement. We live in a resource-rich environment. There are several major Rehabilitation Engineering Centers and at least seven independent living programs. Working relationships have been established.

The people and the equipment are ready. To use Professor Leifer's earlier pickup truck analogy--we now have many places to go. What we need is better roads to drive on. We are now at the dirt and gravel level, but

we need freeways to transport these increasingly sophisticated people and devices. And in places like the Bay Area, we also need bridges. It's this environment we need to address, as well as the technical and lifestyle aspects of equipment performance.

This road network that is needed is all aspects of service delivery--it's how we get from here to there.

When we discuss research priorities it is vital to include emphasis on the often overlooked area of delivery systems. We can create the most sophisticated equipment and become a responsible consumer body--but if the assessment, funding, delivery, and repair functions aren't simultaneously addressed, technology cannot be applied, and needs will remain unmet.

Service delivery mechanisms have been unable to keep pace with the rapid advances in technology and the newly evolving lifestyles of many disabled people. Research can help provide the objective data that are necessary to facilitate change in legislative and other policy-making processes.

Until these mechanisms adjust to these new realities, it is our responsibility to document evidence of the effectiveness and impact of technology, and to educate the people who are in decision-making roles about the things most of us take for granted about our lives, our work, and our assistive devices.

If priorities need to be set within this area, let us focus on the transitional periods for a person-- the times when a new system for controlling one's environment must be learned--the times when a disabled child becomes a disabled adult; when an able-bodied person becomes disabled; or when one becomes elderly and disabled. These are all times when mastery of one's environment must be redefined--all times when equipment is most often proposed as a solution. And, unfortunately, all are times when the service delivery mechanisms are most likely to fail.

Robert W. Mann

From Concept to Commercial Use: A History of Aids for the Visually Impaired

The 1960's and 1970's have brought spectacular improvements in the communication, mobility, vocational and recreational opportunities of blind, severely visually handicapped and multiply handicapped blind persons. I hope to convey, by specific example in my remarks here, the very substantial accomplishments forged by a small, modestly financed group of scientists, engineers, and entrepreneurs. While I will emphasize currently available technology, I want to impress upon you the process and the timespan involved from the first nascent emergence of an idea through the research, prototype development, evaluation, marketing, finance, manufacturing, promotion, sales, and distribution of devices.

First, however, I want to take advantage of this particular forum to pay tribute to John Kenneth Dupress, a person who is very special to many scientists and engineers involved with the problems of the blind. My first-hand knowledge of John Dupress has had a direct influence on my life. In fact, I would not be here today if John, who in 1958 had just joined the American Foundation for the Blind as Director of Technological Research, had not included MIT among the organizations he persuaded to apply science and technology to the needs of blind persons. Until his unexpected and untimely death in December 1967, he was THE worldwide provocateur for blindness-oriented research and development. John achieved his substantial personal accomplishments, including his post-World War II Princeton degree and his high-fidelity recording avocation and business, despite his Battle of the Bulge war injury and military captivity, which left him maimed and totally blind. I therefore dedicate these remarks to the loving memory of John Kenneth Dupress.

In the case of technology for the blind, a nonexistent field 20 years ago, we have lived through the lengthy and painful development of an industry. So in addition to giving you an overview of contemporary technology for selected items, I want to apprise you of the timeline involved. I'm going to look at the commercialization process that a device must go through. After research and development, the device must be exemplified in a prototype. That prototype and reproductions of it must be tested and evaluated. Only then can the developers go into preproduction commercial manufacture and address such marketing problems as distribution; selling; training of people who will sell it, people who will use it, and people who will train the users; maintenance and repair; and getting the device to the proper target group.

The ideas and the concrete examples of the ideas are bounced back and forth and changed many times between the first articulation of the goal and its

realization. The result comes about progressively, and only after this process can one move into manufacture, distribution, and consumption.

Let's look at some tangible examples. In 1966, at MIT, two of my undergraduate students looked at the large-print problem. Commercial television cameras were just becoming economical; you could buy them then for a thousand dollars apiece. It seemed to us you could arrange a commercial television camera in such a way that it would look at a copy and put it on a television monitor in the appropriate magnified or reversed black-to-white form, whichever the visually impaired person required. To us, the idea was novel. Similar ideas probably were emerging in other places, tied to technology that was just becoming commercially available. Since the technology was pretty straightforward, the only special things to be built were the manipulators of the copy relative to the camera. Then it was quite easy to move rapidly into the commercial exploitation of this idea. In 1971, Visualtek and Apollo Lasers both initiated a technology that very rapidly became available to a subject patient population. Figure 1 shows an early version of MIT's closed-circuit TV system for the severely visually impaired.

The problem of computerization of braille for the blind has been surprisingly refractory, considering that it seems simple on the surface. The origins of this situation go back to 1959, at MIT. Several of us including Dwight Bauman, Russ Farrell, Tom Sheridan, and I asked ourselves, "What are all the ways to get the remarkable capacity of computers involved in the production and utilization of braille?"

One of our schemes concerned the cassette, just then coming on the horizon of audio recording. We said, "Wouldn't it be great if there was a machine, like a magnetic cassette tape recorder, where blind persons could store notes (as well as in audio form), and then when they wanted the information back, this machine would spit it back in braille. It would be a marvelous device."

So there were a number of modes in which to have a system that exploited growing computer capability--new printing or embossing devices, or display devices. What was the feasibility of getting on with that? Optical character recognition machines could look at existing ink print and generate the material in computer code to be translated into braille. The computer might generate spoken words. So we were thinking of a computer system for enhancing the availability of braille: ease, scope, volume, access time, automation, and cost.

By 1964, both MIT and the American Printing House for the Blind, had their own quite different braille translation programs.

Let me talk a little bit more at length about the MIT System. The system that we call DOTSYS was developed to be systems oriented and accept various kinds of input. For example, by 1966 we had demonstrated receiving the *Wall Street Journal* on teletypwriter tape. The *Wall Street Journal* is edited in New York City and published in six or eight locations nationally, with the edited copy going over the telephone lines to teletypewriters. We used that teletypewriter tape in 1966 to demonstrate that you could go from the computer copy format into braille and have braille copy available to the blind reader of the *Journal* at the same time that the sighted reader had access to it, on the day it was printed.

By 1968 we had used compositor's tape, and, working with the American Printing House, who published the book, we did the translation and they did the publishing. In March 1968, *The East Indian Men*, a new novel, was published in braille a week or two after the ink print version hit the stands. And then around 1969, a serious fire burned out the Atlanta braille library, and we engaged in a cooperative project with the Atlanta public school system and the

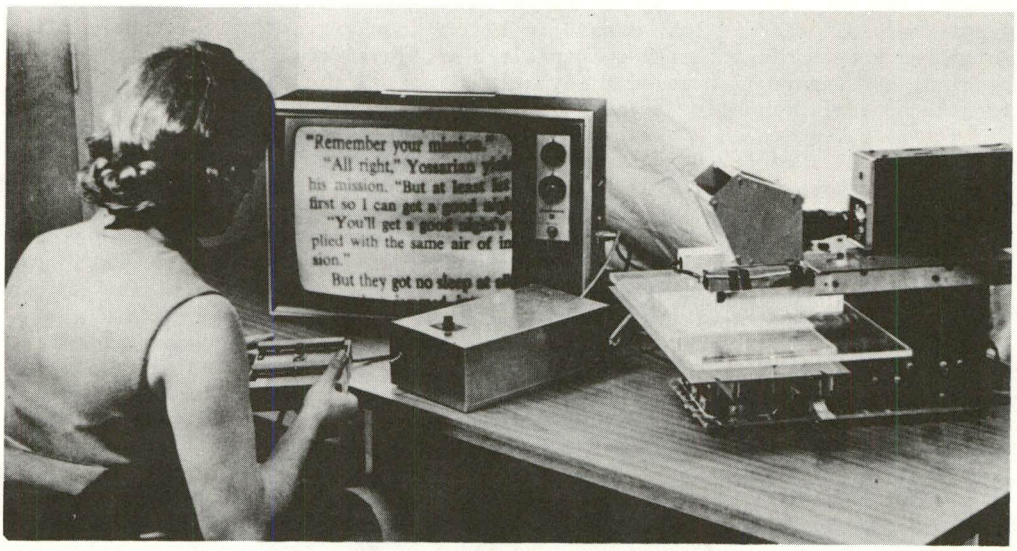


Figure 1. MIT Closed-Circuit Television System for Severely Visually Impaired.

Mitre Corporation here in Bedford, Massachusetts, to develop an appropriate computer translation system for the Atlanta public school system.

Since then, braille translation programs have become widespread and commercially available. It was easy to make the computer programs transferable, because the large computer companies like IBM were happy to encourage their distribution. All that is involved is copying a magnetic tape. Organizations like Mitre became involved, and now small commercial firms like Dutchberry, here and there, plus others, are offering commercially available translation programs.

You can translate the braille automatically by computer, but you have to get it into some palpable form. After all, braille is embossed dots on paper or some other medium, and there has to be an output device to produce those dots. For the production of press braille, American Printing House has used its own in-house electrically operated computer card reading coupled stereographers. Computer input tape cassettes of braille code materials are now available to help "take off" your computer translation program. Among the electrically operated automatic metal plate manufacturing is one made in Germany by Marburg; it is commercially available and it completes the linkage from the input to the braille translation program to the output in press braille. So one of the loops of that scheme that we dreamed about in 1959 has become available; and what I hear, both informally and formally, about current progress in computer translation in access to braille in hard copy is encouraging.

Going back to the MIT scene, remember we said, "But blind students and professionals will want to get copies immediately. They will not want to wait for press braille to come out and read it, they want to operate interactively--after all, learning and doing constitute an interactive process. I write and I see, I type into the computer and I see the output. The blind person should not be denied that kind of rapid interactive access with an ongoing problem." And so we tackled the problem of some kind of typewriter-like device that would produce braille and called it the MIT Braillemboss.

The original design study was done in an undergraduate project in 1960. In 1963 Dan Kennedy's master's thesis introduced the MIT Braillemboss in a workable form, producing braille cells at 15 cells per second. Then in a progression of projects demonstrating the application of this device, we put the system into Perkins in 1968, and it was used through at least 1973 both in mathematics instruction and for general literary purposes. We got the system, and we learned a lot about the system by using it with our own students at MIT. Then in 1965 we got another of our devices going into a system that we demonstrated at the (then) NASA Electronics Research Center.

In 1972, when we had not only the Braillemboss but also an interactive braille translation program, I participated in a demonstration at the National Braille Press. An administrative assistant typed straight English on a standard typewriter and the copy went out on a telephone line to remote computers in Waltham where the translation took place. The copy would come back over the telephone lines and be spit out of an MIT Braillemboss. So a service bureau could get immediate turnaround in braille translation.

Figures 2 and 3 show typical applications of the MIT Braillemboss.

Just 2 weeks ago there began again what I hope will be a mutually beneficial connection between ourselves and the National Braille Press, who apparently are now very much back into the computerized braille business. The point I want to stress in terms of these concrete examples, the moral I am conveying over and over again, is that these things take time. The process is essentially interactive; this process is involved in both the development of the devices themselves and in the demonstration, through the user populations, that they are in fact useful.

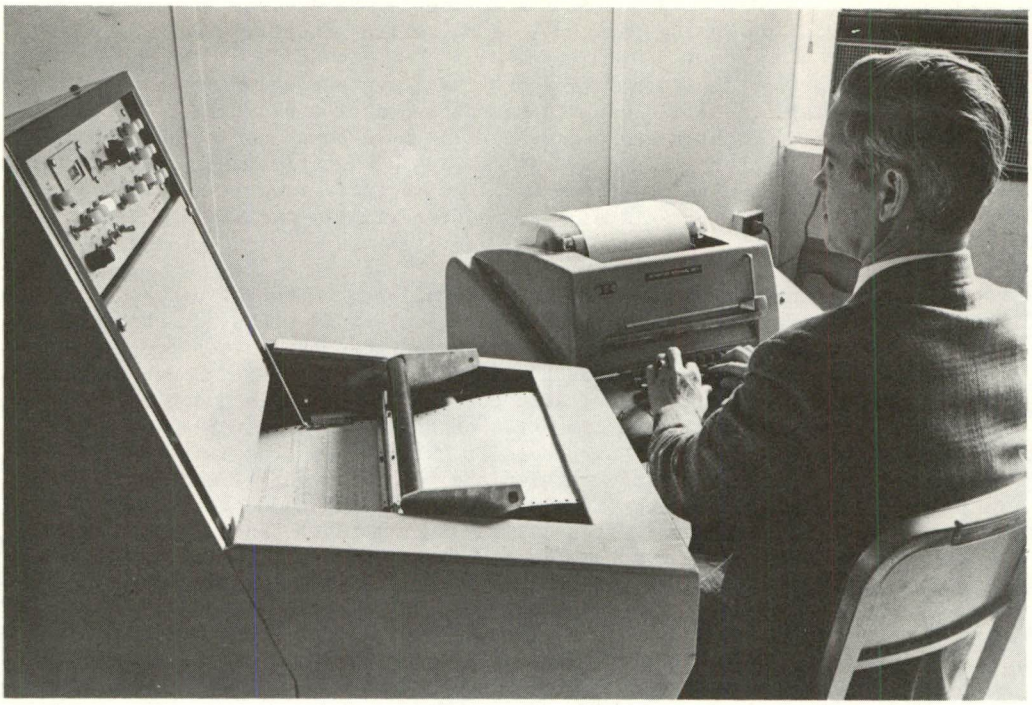


Figure 2. MIT Braillemboss in Use.

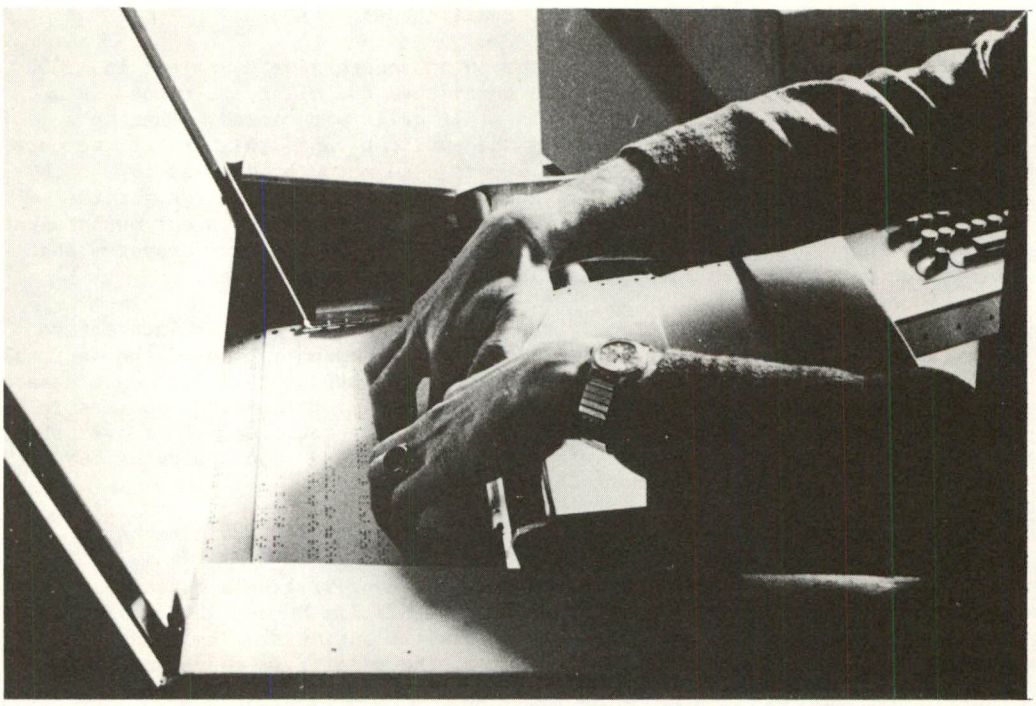


Figure 3. Close-Up of Analyst Reading Copy from MIT Braillemboss.

Very fortunately, in 1969 an organization called Triformation was organized. Progressively over the years they have developed first a portable braille terminal that puts out braille on a tape, and then more ambitious machines, the most rapid and effective of which is the Triformation LED 120, which produces embossed paper braille at 120 characters per second.

I have now given you several illustrations of how the ideas are developed, how they are demonstrated, and how they are transferred into the commercial market. They become viable products for profit-oriented companies who can make available to the user population practical devices that the companies can stand behind and maintain.

Let's pick up another thread. Back in 1969 we said, "It would be great to have something resembling a tape recorder that the blind person could carry into a meeting like this and quietly and unobtrusively operate a braille keyboard to take notes that would be stored on a magnetic tape. Then, later, the person could play the tape and get a braille register on some kind of a refreshable or movable braille display. The person could recapture the notes that had been taken during a conference, interview, or meeting."

We had a progression of projects of that sort, including several master's theses in the 1960's. One example was a refreshable braille display belt system the size of an attache case. This device, demonstrated by one of my students, was one of a kind; it worked but not very reliably. For various reasons, in 1966 we dropped that line of investigation. We felt we were too far ahead of technical capability at the time, and also Dr. Grunwald at Argonne National Laboratory was just beginning an ambitious project in this area that he carried through to about 1972 or 1973.

Well, some of you here know that there is now commercially available, from France, the device that we dreamed about: The Elfina portable braille recorder. It is a 12- or a 20-braille-cell display, a braille keyboard, and a magnetic tape cassette. There are probably just under a hundred of these around the United States. This device is getting a very thorough evaluation, I am happy to note. It is such an important part of this whole development and evaluation process that devices be thoroughly evaluated and thoroughly debugged, that users have the opportunity to interface during the process and indicate what they like and what they don't like about the product. But I think we are launched through the Elfina and through Versa Braille, which Telesensory Systems, Inc. has announced.

So, again, the development period spans two decades. The original work was done in 1962, and now, in the late 1970's and early 1980's, we begin to see concrete practical devices getting into the hands of users.

Remember I said back in 1969 that it would be nice if speech could be generated as the output of such a system. Well, speech generation has been an ambition of people in the computer business since the computer business has been around. In 1975, I think, the first practical device for a blind user that had a speech output was Speech Plus. This calculating machine, developed by Telesensory Systems, contains an audio device that enunciates the number you punch and the operation you ask for and then gives you a verbal output of the result.

In 1976 Ray Kurzweil founded the Kurzweil Computer Company. By 1976 he had a prototype of a reading machine with optical character recognition that looked at books and converted what it read into a form that generated speech. By 1978 the *New York Times* reported that there were 30 units of this type in the field, and by June 1980 there were 200 Kurzweil Reading Machines in the field.

As many of you know, Telesensory Systems has been vigorously developing a speech output system. They will announce sometime in 1980 or 1981 a device

comparable and competitive to the Kurzweil Reading Machine. The Telesensory Systems reading machine, however, is based on another development that goes back into the same two-decade developmental period. I am now shifting from these devices that require some significant interfacing apparatus between the material the blind person wants and the braille or spoken output, to what became known in the 1950's and 1960's as direct reading aids.

A portable camera of some sort is needed to look at ink prints and somehow generate an appropriate code, interpretable to either auditory or cutaneous tactile senses, to provide direct access to print. The idea is actually a very old one. Aub, in 1914, demonstrated what he called the Optaphone; this device has a camera that looks at print and generates a musical tone peculiar to the print being scanned. This idea has recurred over and over again over the years. The Veterans Administration calls them Visitoners and Stereotoners.

On the more tactile output side, John Linville, who was strongly motivated by the blindness of his very charming daughter Candy, in 1966 proposed a portable reading machine that would have a camera look at the ink print and generate a morphologically similar (that is to say, same shape, but much larger) tactile version of the letter that the camera is seeing and imprint it on the finger of the blind person. That was the origin of what has become known as the Optacon--Optical to Tactile Converter. There's a very interesting history associated with this particular device--after Linville invented it, he recruited Jim Bliss. Linville and Bliss joined forces and had the courage to form a company, Telesensory Systems, Inc., decidated to devices for the handicapped. They focused primarily on the problems of blindness originally, although they are diversifying now. In the Optacon, a lipstick-sized camera is used. As the right hand scans the ink print to be interpreted, the fingers of the left hand are inserted into a magnetic recorder-like device. Peizoelectric crystals, the things that you find in the read arm of your phonograph, now play a tactile tune, if you will, on your fingers that replicates the ink print that the camera is seeing. Devices have been added to the Optacon that make it possible to read the output of an oscilloscope mounted on a typewriter.

The Optacon, at least in my opinion, has to be considered the most successful device so far. It promoted the formation of Telesensory Systems, and by 1978 there were 5,000 Optacons in use, worldwide. The Optacon will be the input, the optical character recognition part, of the speech generating system that Telesensory Systems has announced.

I've concentrated so far on communications problems, reading problems. Let's look at one particular vocational device for blind persons. I picked this as a prototypical example of the process and the time involved in going from an idea to its practical realization. The work that we had done in the 1960's on these continuous braille belt displays, continued at a modest level through the late 1960's and early 1970's, had very little direct support. It was kept alive by a modest grant from the Ziegler Foundation. By the early 1970's we had a practical, electromagnetically operated single-cell braille display. It changed the electrical information into the braille display and it gave you a different cell configuration output. In 1974, my colleague George Dalrymple, who was responsible for this work, connected that refreshable braille display to the output meter of a radio station and made it possible for a blind radio engineer to pass the FCC examination that requires a radio engineer to monitor the signal level of the station he's responsible for. With this radio meter connected to the braille output display, the blind radio engineer monitored the signal level and met the requirements of the FCC.

We searched around for other ways to use the device, and out of a meeting in 1974 we talked with an engineer from the New England Telephone Company. We asked, "Isn't there some way we can use this refreshable braille display to create more opportunities for blind telephone operators?" In the telephone business, the operator was becoming more and more dependent on visual displays;

there were buttons with lights on them, flashing lights, light emitting diode (LED) displays, and illuminated numbers and letters the operator needed to have access to in addition to hearing and speaking. Blind telephone operators were no longer competitive for many of the positions that the telephone companies were generating. The telephone company was moving in the direction of what they called the TSPS--the traffic supervisory position switchboard--of which there are now 35,000, as well as 35,000 operators.

And we said, "You know, it should be possible for the New England Tel and Tel people to take the coded visual material that is coming in on electrical lines (it has to be coded to operate those flashing lights and alphanumeric displays), translate it, and present it as braille information. Then a blind operator could be competitive with a sighted operator." We then worked with the Vice President of Engineering at New England Tel and Tel, and things were looking very good until he decided to change jobs. All that nice developmental work, the possibility of a supported project, and a lot of cooperation--all disappeared!

I must make it clear that all through the programs that I have been describing, we have been supported most heavily by what is now the National Institute for Handicapped Research and its precursors, the Rehabilitation Services Administration, Social Rehabilitation Services, the Vocational Rehabilitation Administration, and the Office of Vocational Rehabilitation.

Historically, we've had a connection with the Arkansas Enterprises for the Blind (AEB) in Little Rock. We explored the same possibility with AEB and Southwestern Bell in Little Rock, and they responded by saying it was an interesting idea and they'd be happy to get involved in it.

Through this collaborative program between AEB and Southwestern Bell, George Dalrymple and Derek Raoul looked at the feasibility of providing a braille output for the TSPS switchboard. This is a mockup in our laboratory. It exemplifies the use of buttons and flashing lights--you can't hear the alphanumeric display that the sighted person can see and the blind person needs access to. Derek and George worked out a way of taking the same electrical information that comes into the switchboard and capturing it in a microprocessor.

When the blind person operating at one of these switchboards needs information, here at his or her fingertips is a refreshable braille display, just like that on the Elfina or the Versa Braille. The blind person can store information with braille input, and the information goes into the microprocessor and is stored there in digital form. When the person wants it back, it can be called up and presented in braille.

We started discussions with Southwestern Bell in 1975, and we had one device installed in 1977 and the second in 1978. We had enormously good fortune, but I think this success is representative of blind persons in general. The blind operators who used this system were shown to be competitive with sighted operators, by telephone system standards, and also more productive than the sighted operators. This discovery got not only Southwestern Bell but also American Telephone and Telegraph (AT&T) excited about the prospects of this system.

Independently of our operation, Telesensory Systems had been experimenting, along with Pacific Bell, with a system that generated a speech output rather than a braille output. So we decided to join forces, and MIT and Telesensory Systems proposed to AT&T a system that would combine the best features of both systems into a product that Telesensory Systems would either produce or purchase from the various operating companies of AT&T. The development process has been completed, and this is the new version of the AT&T switchboard. This is the Telesensory Systems module, which has the braille display and a keyboard and also has a supplementary audio output. Several of these are now under evaluation at various locations of the telephone company. They are expected to pass muster, and I think the telephone company will encourage its operating companies to

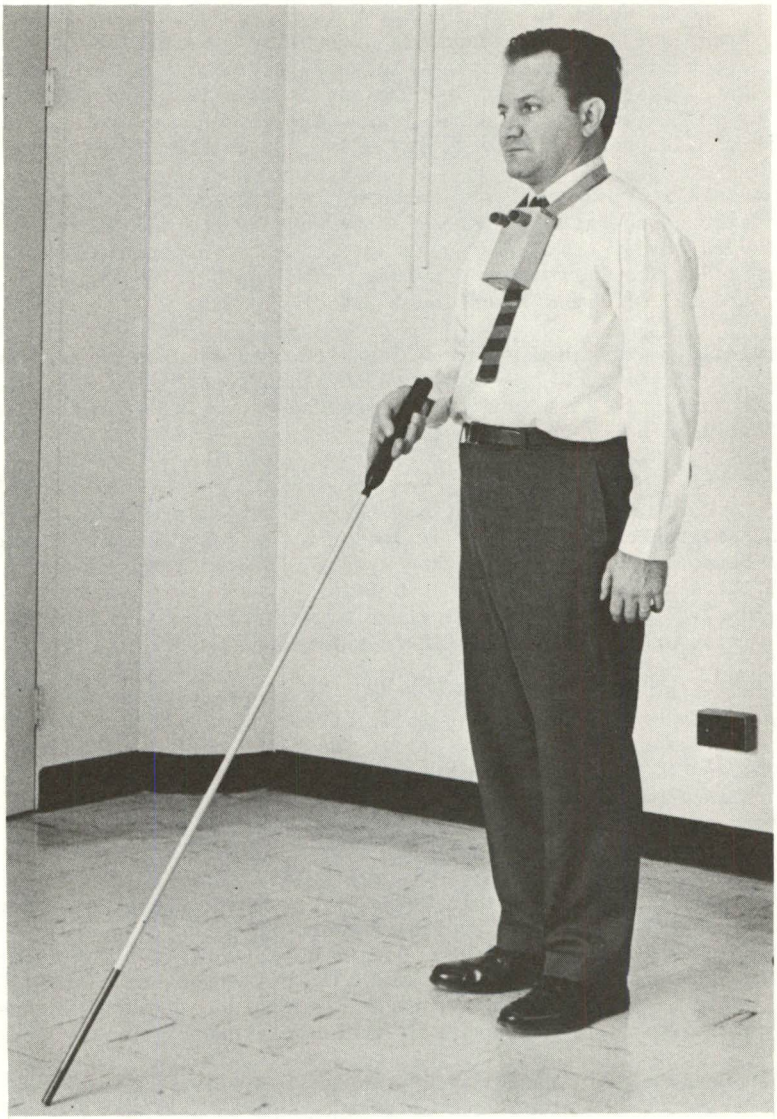


Figure 4. MIT Cable Cane and Pathsounder.

purchase these telephones from Telesensory Systems. If even 1 percent of the telephone supervisory position switchboard operators in the United States are blind, that would be a new vocation for 350 blind persons.

I want to switch now from communication in general to the problem of the mobility of the blind. Back when John Dupress was alive and we were actively involved in the early braille translation work, I can remember that many of the blind people who were participating with us would say, "Hey, why don't you guys work on some really nuts and bolts type problems. We have these long canes that we depend on, but they are the damndest awkwardest things in a VW." (Volkswagens were little in those days.) "In an auditorium we're afraid we might trip people. Can't somebody build a better collapsible cane?"

That sounded like the kind of project our students ought to attack, and between 1962 and 1964 we introduced as student projects in regular mechanical engineering laboratory courses an idea for a good collapsible cane. Some of the better ideas were refined in our laboratory, primarily by George Dalrymple. We got samples of one version, the *MIT cable cane,* into the field. It was deemed attractive to blind users if we could make it for $12. We couldn't make it for $120. So, we turned to a small company. Vito Proscia, who had replaced John Dupress as director of the center, was also blind. Vito worried about this problem of technology transfer with our MIT cable cane. He struck up a relationship with a small company called High Core. They said they could make that cane and sell it for $12. They needed $25,000 to pay for a swaging machine and they couldn't find that much capital. So Vito and I, with the help of MIT, found $25,000 from a foundation in Seattle, and we sent it out to High Core, and put High Core into business. The MIT cable cane thus became the High Core cane. I don't know how widely it's used now, but for a while it was certainly popular. Figure 4 shows the MIT Cable Cane being used by Vito Proscia. In this photograph, Mr. Proscia is also wearing around his neck the Pathsounder device described later.

You know, NASA makes the case (with considerable success) that the hundreds of billions of dollars that we put into the space program has had an impact on consumer goods. They call that spinoff. Well, here is an example of reverse spinoff. The $10,000 or so that the Rehabilitation Services Administration put into development of the cable cane has made it possible for High Core to produce collapsible ski poles, orthopedic canes, and window scrapers that you can put into your glove compartment. I call that reverse spinoff.

Among electronic travel aids is one called the *Pathsounder* (see Figure 4), which was developed by John Dupress and Lindsay Russell. It has a modest circulation of perhaps 100 to 150 in the field, and those who have it seem to like it very much. It is a quite simple device that floods the space in front of the blind traveler with inaudible sound. An echo from any obstacle, even one as small as a washline, in the path of the traveler will generate either an audio or a tactile cue, so it's useful for both blind and deaf-blind persons. An ambitious travel aid, one that has seen wide circulation, had is beginnings in 1960, when its originator, Leslie Kay, was at the University of Birmingham. At a conference in 1966, Leslie was talking about the binaural sensory aid. Later on, Derek Raoul did his doctoral thesis with Leslie Kay on the audio display of what is now known as the sonic glasses, produced by Wormwald in New Zealand.

In sonic glasses an ultrasonic beam, if interfered with by any kind of an obstacle, generates a reflection that is not heard but presented to the wearer's ear as a pure musical tone whose frequency corresponds to the distance to the reflecting obstacle. A very important beauty of the sonic glasses is the use of two ultrasonic receivers that play the respective echoes from the right and left field of the traveler into the right and left ears. As we know, if we hear a sound, we turn toward the direction it comes from. We identify it by binaural audio localization. So sonic glasses, also known as the sonic guide,

have range information in the primary tone by binaural localization, as the full localization in the relative intensity of the two presentations.

Derek Raoul just had a conversation with people from Wormwald, and they said that they are currently selling them at the encouragingly high rate of 30 or 40 a month.

I think it was Curie who said, "Chance favors the prepared mind." The sonic guide is an example of chance favoring the prepared mind, because it very quickly became clear that there was range and azimuth information and that the nature of the reflection surface was evident in overtones on the primary tone. The blind person could be trained to distinguish between a plate glass window and a bush or a fence or a hedgerow.

Of course there are problems with surrogate sensory display devices. The single toughest problem in all kinds of sensory substitution devices, both for the blind and for the deaf, is how to code information so that it can be presented to a sense not usually used to acquire information and interpreted as information by the central nervous system. For the blind it has to be the ears and the skin. For the deaf it has to be vision--sign language or the skin.

Well, any mobility assistance device, cane or sonic glasses, only tells you what is out there maybe as far as 20 feet. It really doesn't tell you how to navigate. An area that is seriously underplayed and deserves a great deal of attention is the development of appropriate tactile maps. We developed, along with others, tactile maps of the Boston area; this is a tactile map of MIT.

I want to end with a few glimpses into the future and, particularly to stress the things that you should be sensitive to.

To begin with, you are going to be bombarded with hardware. As a practical matter, there was no hardware in the early 1960's. The curve began to show a little upward slope in the late 1960's, showed some growth in the 1970's, and the 1980's are going to see more and more hardware. It is going to be very smart hardware. It is already, some of it, very smart hardware, because it is built around the microprocessor--the computer on a chip. This is an exciting period for computing and for making computing accessible to everybody. You are going to have to play a role in influencing what gets developed, how it gets evaluated, and how it gets introduced into the delivery system. There is a crying need for some consolidation and organization of the service delivery aspects of some of this flood of technology that is coming upon you.

For example, take computer translation standardization. A number of organizations are getting involved in computer translation. It would be highly desirable if that process were reasonably standardized so that information in computer coded form, on magnetic tapes and discs, could be transferred from organization to organization and be used by a larger body of blind persons depending on braille, as in Elfina or Versa Braille. A whole new storage format is developing. Braille is appearing on small magnetic tape cassettes. There has to be a technical standard for the form in which that information will be recorded. Don't let's get into the situation where, if you have a Versa Braille machine, you can't read an important piece of information in braille that is stored on an Elfina cassette--that's crazy. We have got to get some standardization in that system, and I appeal to the American Printing House for the Blind, the Library of Congress, the association of organizations that deal with blind communications--Please do something to get this system reasonably standardized. We don't want to get back to the Tower of Babel.

I would also like very much to encourage standardization for tactile maps. I was invited to an introductory session at Harvard University, because they

were going to present their tactile map of the Harvard campus. So I went up with great anticipation, and I learned that Harvard uses an entirely different set of tactile codes. This means that a blind student who is cross-registered between MIT and Harvard has to learn one tactile code for the map to get around Harvard, and yet another tactile code to get around MIT.

The fascinating and complex problems of the future are ones I characterize as person-machine. How do you organize and present information to the "wrong" sense, so that it is logical to the blind person or the deaf-blind person? How do you organize and present tactile information, or audio information, or both? How do you operate a sort of mechanical organ player so that it modulates sensations on the skin and in the ear and projects a sense of what this room looks like and how to negotiate it?

Also, there is a whole new area that is barely being scratched. A long-term horizon in my view is the one that is invasive in the medical sense, directly stimulating the nervous system, or even the brain, so as to better achieve a substitute for a lost peripheral capacity: an optic nerve directly impacting the occipital cortex in the brain, or a lost audio channel directly exciting the 8th nerve or area 18 in the brain. Somehow we want to fool the central nervous system into perceiving new stimuli as being representative of what the lost extraperipheral sensor would have been presenting to the brain, if the person had normal sensory function.

I think there are many things happening that are very exciting, that need your attention. I implore you to get involved in the process. You need to participate in identifying these goals. There have been times when it has been a very bleak area to operate in; it is now a very exciting area, in large measure because practical things are getting into the hands of blind persons, are being used, and are being improved upon. The cornucopia is, if anything, more full and flowing more copiously. 1984, 1990, and 2000 will see even greater advances.

This paper is based on a transcript of Dr. Mann's remarks made at the Helen Keller Centennial Congress, which was held in Boston, June 23, 1980.

Jeffrey Rubin

An Economic Perspective on Delivery Systems and Their Impact on Research and Development for the Handicapped

To explore more fully the links between delivery systems and research and development of technology for the handicapped, it is essential that the concept of a delivery system be precisely defined. In my view, an appropriate conception of a delivery system must begin with supply, demand, and their interaction in a market. It is this interaction that offers signals to producers about the potential economic gain from the research, development and marketing of new technologies. As long as the majority of the investments in research and development are made by profit-oriented individuals and corporations, the markets in which the products of research and development are exchanged will influence the amount and types of investments that are made.

The Demand for Technology

The demand by the handicapped for technology stems from the need to compensate for the consequences of their disabling condition. Both the handicapped and the nonhandicapped demand other technologies, but it is the demand for technologies to surmount the barriers caused by the disabling condition which is of concern to us.

To better understand the nature of this demand, several observations should be made. First, because the barriers are different for persons with different conditions, a variety of different technologies will be demanded. The size of that demand depends on the size of the population and on their desire and willingness to pay.

There is, of course, an alternative view one can take toward the demand for technology. In the view of some, the issue of monetary payment is irrelevant and concern should be focused on the difference between what a person can now do and what he would be capable of if the technology were made available. Thus, one hears of the "need" for more technology for more people.

One problem with the need-based approach is the arbitrary nature of determining need. More important for the analyst concerned with explaining research and development in technology is that need offers the firm no monetary signal as to how profitable a research and development investment might be. If we wished to assess the gap between what is and what might be, then the "need" approach should be pursued. Furthermore, if government support of research and development were based on need, there would be a further reason to approach the problem this way.

For the moment, we will focus our attention on economic demand and not need. But the demand for technology is not the best starting point. Instead, we should view technology as one of several ways to overcome the barriers cited earlier. For example, an individual with a hearing deficit wants to solve a communication problem. Several methods, some of which involve technology, are available for improving his communication skills. In this framework, it is possible to better understand some decisions regarding the purchase of technology.

One area where this distinction becomes important is the selection of a high- versus low-technology solution. In some cases, the barrier to be overcome requires minor adjustments in the existing environment. In other instances, the particular characteristic of the barrier requires more sophisticated technology. In light of this distinction, it is reasonable to find both a demand for high and low technology and to expect that these demands will vary in accordance with the nature of the barrier to be overcome.

Another issue regarding demand for technology is the restrictions imposed on demand when the individual does not have full use of resources. When reimbursement is restricted to certain purchases and when the ultimate consumer must rely on professional advice as to the adequacy of technology, we weaken the link between the wishes of the consumer and the suppliers in the market.

One approach that would recognize the "needs" view and the link between willingness and ability to pay and technology development involves providing handicapped consumers with vouchers to purchase either technology or the services of individuals. The size of the vouchers could depend on the estimate of need. An unrestricted voucher is not likely, and there would probably be limitations on which technology and services could be purchased.

Some reasons exist to expect the demand for technology to increase through more standard market mechanisms. As schools and businesses are forced to accept affirmative action, nondiscrimination and other rights of the handicapped, they will be searching for methods and technology to facilitate the employment and education of the handicapped. Furthermore, direct demand by the handicapped may increase as a result of recent amendments to the Social Security Act. The law affecting the treatment of work expenses under the Disability Insurance and Supplemental Security Income programs has been changed to allow the handicapped to deduct additional expenses. This will enable the handicapped to earn more income before benefits are lost. As a result, there will be greater demand for technology, especially those aids that are needed for employment.

In closing, two other observations about demand are worth noting. First, the demand for much of the technology we have referred to includes both a handicapped and nonhandicapped market. Of course, the broader the potential market, the greater the expected returns to investment in research and development. As a result, more technological developments will be encouraged. A second observation is that, because resources are limited, even the voucher approach cannot get all the potentially beneficial technology to all the handicapped. More thought needs to be devoted to the matter of defining the "correct" amount of technology available and in use.

The Supply of Technology

The decision by firms and individuals to do research, produce a product, and offer it at a given price most often relies on monetary considerations. While nonprofit organizations exist and are potential sources of technology, little work has been done to improve our understanding of decision making in nonprofit firms.

Even in the area of for-profit firms, there is a great deal of conflicting evidence on the factors influencing development of new technologies. It has been argued that firms having monopoly power have more incentive to develop new

technologies than firms faced with an extensive array of competitors. Monopoly power guarantees the firms the potential benefit from new developments, whereas in a competitive market the practices of the competition diminish the likely yield from new technology. Monopolists also may have a base of profits to draw on as a source of funds to conduct the necessary research and development. In sum, it would appear that these hypotheses are worthy of closer examination in such industries as wheelchair production and hearing aids.

At the Houston workshop, we saw another aspect of the supply of technology. The individual entrepreneur, motivated by personal experience and economic goals, was seen to be an important source of some significant developments. Although personal experience is a weak foundation on which to build a national policy of technology development and distribution, it deserves more study and possibly new forms of support.

While a case study of technology development is limited, there would appear to be value in more precisely identifying why individuals succeed or fail in this area. I think more investigation of those who have tried and failed would be helpful. Perhaps, some more general conclusions could be derived, with an eye toward changes in patent laws and liability rules that would better balance the goals of inventor and consumer protection with the needs for more widespread use of technology for the handicapped.

The linkages between individual research and the behavior of existing firms need further study. For example, existing firms may find it more profitable to let individuals take the risks associated with developing, testing and marketing an idea, and they buy the individual out. Generally, there is a need to better understand decisions firms make that affect the handicapped. Are these decisions the result of incompetence, lack of knowledge, or profitability considerations?

The Interaction of Supply and Demand-- The Market for Technology

When markets work well, they provide signals (excess supply and inventories build up an excess demand and people offer higher prices) to firms regarding appropriate decisions. Even if the handicapped had sufficient income, there is still the possibility that inadequate or malfunctioning markets might restrict distribution and use of technology. For example, knowledge about available methods, devices and services might not be widely available. Since the handicapped often rely on others (physicians and physical therapists) as well as on the usual advertising mechanisms, it would be interesting to know exactly how information is obtained and used to make decisions. The newly handicapped are in the unique position of going into a market they have never considered before. How are decisions affected by this situation and how different is this from what happens in other markets? More importantly, how can markets be made to function better?

Summary

The development and dissemination of technology for the handicapped is influenced in many ways by economic variables. Some of these effects are no different from what the nonhandicapped face in the market. Yet, the consequences may be very different. My failure to pick the best television for my purposes may affect my enjoyment of certain programs, but the purchase of an inadequate wheelchair may mean reduced mobility for a handicapped person. If the consequences of a wrong choice are more severe, we would expect more time to be devoted to the selection of the product. Does this occur?

In other instances, the market faced by the handicapped may differ significantly from other markets. The size of the market, the variety of needs requiring customizing of devices, and the need for available maintenance services all point to some special problems. The response of private and public markets

to these circumstances has been to develop a number of different approaches. Attention ought to be focused on these and other models to identify more precisely the reasons for their flaws and advantages. The resulting information could serve as the basis to improve on past performance.

Nonetheless, I am not optimistic that all the problems raised during the Houston workshop can be resolved. Both resources and knowledge have their limits.

It is not likely all the barriers raised by a disabling condition can be overcome. Yet, there is sufficient evidence to suggest that we can and should be doing better. I think these improvements will more likely be achieved when the goals in the area of technology are more precisely specified.

A. Bennett Wilson, Jr.

A Service Delivery System Model

I believe that there is at least one category of the physically (neuro-musculoskeletal) disabled who find for the most part little to complain about with respect to the delivery of services. That group is the amputee population, and it is my intention here to relate the history of the steps that resulted in the present system, and suggest that the model be applied in the case of some other categories of the physically disabled, if not at all.

When the Surgeon General of the Army, in 1944, was faced with the responsibility of rehabilitating an enormous number of amputees, many of whom protested vigorously about the antiquated devices being provided, he turned to the National Academy of Sciences-National Research Council (NAS-NRC) for advice. A meeting of scientists, surgeons, and prosthetists assembled by the NAS-NRC early in 1945 revealed that little or no scientific effort, at least in the United States between the two world wars, had been devoted to the problem, that there existed no organized body of knowledge in the field, and the knowledge that did exist was passed along from one generation to the next by informal apprenticeships.

Improved Artificial Limbs

The result of this meeting was a recommendation for a crash program for the development of new and improved artificial limbs by the application of advanced technology and engineering. The NAS-NRC was requested to initiate such a program with funds provided by the wartime agency, the Office of Scientific Research and Development, and a program was begun by engaging several industrial laboratories and coordinating their work with that being carried on in laboratories operated by the Army and Navy within their respective Medical Services. Originally it was felt that the medical profession would provide the engineering profession with criteria for the design of artificial limbs, and the engineer would dutifully retire to his drawing board and reappear in a few weeks with a useful design. This approach failed because there was not available sufficient fundamental data concerning the biomechanics and other characteristics of the functions of human limbs, and laboratories to conduct fundamental studies were established at the University of California, Berkeley (for lower limbs), and at the University of California at Los Angeles (for upper limbs). Both of these research projects brought together orthopedic surgeons and engineers in an environment that permitted close cooperation between the two disciplines, and a great deal of progress was made in a relatively short time. Simultaneously, engineers working with orthopedic surgeons

and amputees made considerable progress by substituting new materials for the old, applying new fabrication methods, and exploring the feasibility of designs that had been based on best guesses.

Both types of studies showed that while the design of mechanical devices was important, the useful function of devices depends almost completely upon meticulous fitting of the prosthesis to the patient and careful alignment of the components with respect to each other and with respect to the amputee. The basic principles of fitting and alignment were developed slowly along with the development of new devices, and by 1952, it was felt that a sufficient body of knowledge had been developed in upper limb prosthetics to warrant a concerted effort to get the devices that resulted from research onto patients who needed them. A comprehensive textbook was prepared, and after a successful pilot program late in 1952, a formal education program was initiated at UCLA in 1953 to train prosthetists, therapists, and physicians to apply this new body of knowledge as a team. Approximately 10 teams were admitted on a regional basis for each of nine courses held over a period of 18 months. Prosthetists received training in fitting and fabrication for the first four weeks, at which point the therapists arrived to learn fundamentals of upper limb prosthetics and how to train amputees to use the new prostheses. The physicians arrived a week later and the final week was spent in learning prescription principles and team operation. Although some of the leading prosthetists were quite skeptical of the value of this program, it proved to be a huge success, and the education project became a permanent fixture at UCLA. Prior to this period it had been accepted practice for the amputating surgeon to refer the amputee at the time of discharge to a list of local "limb-fitters" for an artificial leg or arm. With the new program, the amputee clinic team was created.

Prosthetics Education

By 1955, a sufficient body of knowledge in above-knee prosthetics had been developed mainly by the research group at UC-Berkeley, and UCLA initiated a series of courses in this subject in 1956. It soon became obvious that one institution could not handle the demand, and similar education programs were established within two medical schools, at New York University in 1956 and at Northwestern University in 1958.

Until the opening of the Prosthetics and Orthotics Education Program at Northwestern University, support of the educational programs had been provided solely by the VA, but as Congress provided DHEW with funds for education in the health sciences this responsibility was assumed by the Vocational Rehabilitation Unit of DHEW (the name of which has been changed from time to time).

The success with the short-term continuing education programs led to the establishment of preparatory courses for individuals desiring to enter the field of prosthetics and orthotics, and the American Board for Certification in Prosthetics and Orthotics has geared its requirements for certification to the preparatory courses given at UCLA, NU, NYU, and the University of Washington.

Concurrently with the development of the education program, the NAS-NRC established a logical system for the orderly progression of a new device or technique from the idea stage to widespread use on patients. This system was known as the Transition Procedure and is diagrammed in Figure 1.

Transition Procedure

All elements in the transition procedure obviously are important, but the clinical evaluation step is probably the most difficult to carry out efficiently and effectively. Early attempts to carry out evaluations on a strictly scientific basis proved to be futile because there are so many factors that enter into acceptability of a new device or technique. Any one of these

TRANSITION PROCEDURE

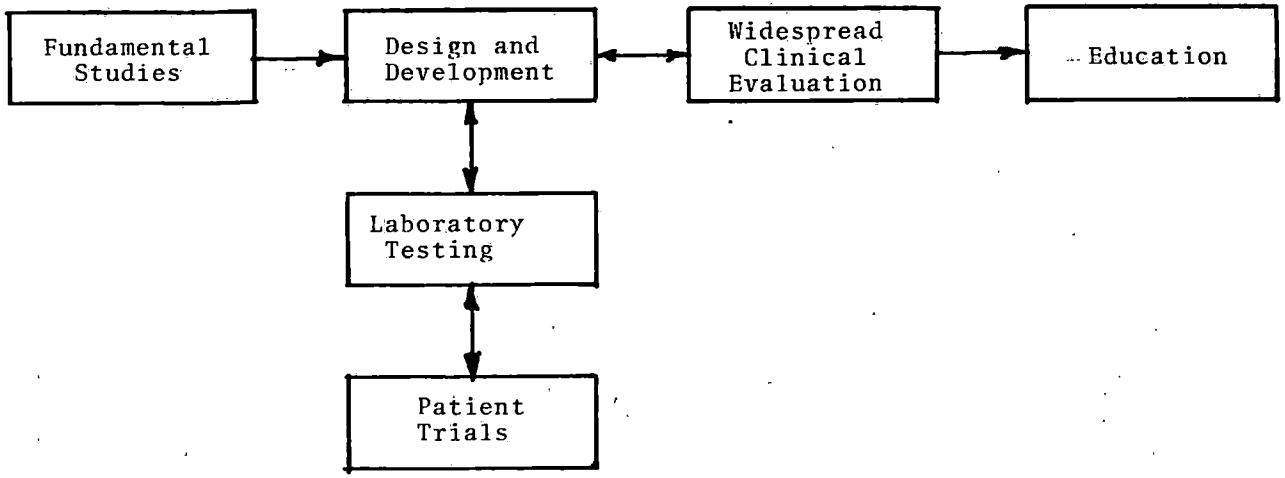


Figure 1

factors can result in rejection, and it is impractical to carry out a study in which all of the variables but one are eliminated. A good compromise system was developed, however, and the faculties of the schools were involved in the clinical evaluation program, decreasing the time between development and introduction into the education process.

About 1962, the field of orthotics was added to the prosthetics program and the same system was followed in advancing this field. Today, most artificial limbs and orthopedic bracing are prescribed by trained clinical teams and delivered by well-trained prosthetists and orthotists. The continuing education function is now being carried out by the American Academy of Orthotists and Prosthetists, while the universities continue to be responsible for preparatory education.

The end result is an efficient service delivery system that is improving continually through the introduction of new devices and methods of treatment into the field by means of organized education programs.

For reasons that I don't understand, this technique has not been applied to the Rehabilitation Engineering Program that has developed somewhat as an extension of the Prosthetics and Orthotics Program. Nearly ten years after the creation of the Rehabilitation Engineering Centers there is no evaluation program, nor is there an education program. Yet there are a great number of products of research and development that could benefit from a carefully planned and executed clinical evaluation program, and there is certainly a lot of useful information that needs to be compiled and disseminated through texts, movies, sound-slide presentations, and formal courses.

Without a formal clinical evaluation program and a formal education program, I am afraid progress in rehabilitation engineering will continue to be slow with respect to improvement in patient (and client) care on a widespread basis.

2 Co-Invention

Elmer C. Bartels

Rehabilitation Engineering through Marketing: Getting from Here to There

It is my pleasure to be here with you tonight to discuss some of my perceptions with respect to rehabilitation engineering. In initiating my remarks I would first like to read a recent magazine article that, for me, raises some concerns. Let me first read the magazine article.

Talking Wheelchair

> Victims of cerebral palsy or stroke and other disabled persons who cannot speak clearly, if at all, now have a helpful new gadget: a talking wheelchair. Developed at Stanford University's Children's Hospital and funded by the NASA Ames Research Center, both in California, the device features a computer word processor and a speech synthesizer mounted on a wheelchair.
>
> Users tug a switch or shift a joystick or peck at a typewriter keyboard--depending on how well they can move--to string together words and sentences on a video screen. Then they activate a mechanical voice to deliver the digital message in a monotone like the computer HAL's in the movie *2001*.
>
> The device could confer artificial speech on the 1.5 million Americans--such as deaf-mutes--who cannot speak understandably. The computer stores 925 widely used words; follows 600 grammatical rules; talks at varying speeds, pitches, and volumes; and can even be programmed to stockpile complete sentences and phrases for later use. An expert operator can turn out, impromptu, as many as 30 words a minute.
>
> Six patients tested the device for a week. An elderly stroke victim, who otherwise wrote what she wanted to say on note pads, talked over the telephone--via the prosthesis--with her family. A young woman with a neurological disease, contracted three months after bearing a son, was able to speak to that son, now five, for the first time. Her first words: "Kevin, put your pajamas on right now!" [by Robert Brody]

Many worthwhile projects are developed by rehabilitation engineers in such federally funded programs as Rehabilitation Engineering Centers, Research and Training Centers, NASA-funded projects, NSF-funded contracts, and projects by private entrepreneurs and personal friends of disabled individuals. Devices have been developed since year one to help disabled people

mitigate their functional limitations. The most rudimentary of these may have been a stick to assist someone with a nonfunctional leg, and some of the more exotic equipment of today includes the puff and sip wheelchair.

Let us examine some of the reality with respect to rehabilitation engineering and engineered equipment. First of all, think of the top three marketers and manufacturers of rehabilitation engineered devices.

Now that you have thought about these engineered devices--What were your top four or five manufacturers? Let me offer my assessment of the top three. Everest and Jennings provides mass-produced wheelchairs of a vast variety. Surgical supply houses provide a wide variety of urinal appliances for people with incontinence problems. The van conversion companies are providing equipment for an emerging market in van conversion for mobility-impaired individuals utilizing wheelchairs. IBM was, I believe, the first company to initiate the braille typewriter, which has become a mainstay among communication devices for blind individuals. And finally, one must recognize the hearing aid market.

It is interesting to note that the equipment developed by the manufacturers came out of the private entrepreneur's need to produce a product that met the needs of the marketplace at a profit. They have done so, and they have done so successfully, for the mass market.

The question that must be asked here is whether the rehabilitation engineers, under federal funding, including Rehabilitation Engineering Centers, Research and Training Centers, and NASA and NSF funding, are actually producing equipment that gets into the manufacturing environment to meet the needs of individuals on a mass basis. In order to examine that question, let's look at the process by which a rehab engineering idea becomes a marketed product.

Process of Development

In the idea stage, disabled individuals, the rehab engineer, or a friend must often define a functional limitation. The engineering solution needed may be as simple as adding a lever to a doorknob or as complex as the Tufts communicator that has been developed here in Boston. The engineering solution then may be very simple or it may be as complex as the electromyographical technology that is used on the Boston arm; or it may be computer technology that is used for an environmental control system; or it may be the lightweight tubular alloy that is used for most modern wheelchairs; or it may be new chip circuity that could be used in operating the variable speed wheelchair. Thus, the combination of a functional limitation and the technology of the day come together to develop an engineering solution to a functional limitation for a specific individual with a specific kind of disability.

In determining the viability of an engineered device, one of the most important considerations is, Does it work? Does it work in the first instance, or are several iterations needed to overcome its particular functional limitation? That is to say, it does meet the need. After having engineered a specific device, the next question one might ask is, Does it meet the needs of others with similar functional limitations? Very often this is where the device comes to an end. The options available are either to drop it as being a one off developed device, hold it for use by a few more people, or go into a manufacturing and marketing operation. The capacity of the developing individual then comes into play with respect to manufacturing and marketing a specific device for a mass market. Most often that capacity to do so is just not available, and the device sits on the shelf to be reinvented by someone else at a later time, and possibly reinvented again and again, until ultimately it reaches the attention of an entrepreneur who takes the device into a manufactured status.

Considerations for manufacturing a device would include some of the following issues:

- Is there a mass market for this product, and if so, how big is it?
- Are models to be developed in order to assess its marketability in the mass market?
- Is there a profit to be made?
- What is the manufacturability of this particular device, on a cost per unit basis?
- Is the technology available to develop it on a mass market basis?
- Can it be developed so that its reliability is high when it is used by a disabled individual in a certain set of circumstances?
- Is the device maintainable in the community by a disabled individual or by someone who would be available?
- Is it usable over a large geographic area where geography, temperature, and humidity vary widely?
- Is the product easy to use?
- How much time does it take to prepare to use the item in order to mitigate the functional limitation?
- What are the alternatives if this product is not available?
- Does the product fit into a range of available products on the marketplace? (For example, the fact that a platform lift is available and the price of vans on the open marketplace is exceedingly high may affect the marketability of platform lifts.)

It is at this point, again, that many of the idea people walk out. The questions raised above cannot be answered well enough to meet the financial criteria of the day and bring the product into the marketplace.

Marketing Products

In marketing any product there must be a mass market of some size in order to make production financially viable. This is a factor in the marketplace which cannot be overlooked. Just because disabled individuals have a need does not mean that the mass market is there. Some of the factors that affect whether a mass market is available are the following:

- The mass market must be generally available in large enough numbers to ensure an open marketplace either in this country or worldwide. This would be either a limited market or an unlimited one.
- The need of an individual or group of individuals is only the first step in developing that mass market.

- Disabled individuals not only must need the device, but they must also think they need it and be willing and able to use it satisfactorily.

- There must be an ability to pay for the item in that either the individual is willing to purchase it with available funds or a third party is available to do so.

- And finally, the cost of the item must be within reach of the individual or the third party payers to make the mass market viable.

Conclusion

Many of the considerations that I have proposed here tonight are nothing new. As you think about the rehab engineering through the marketing process that I have outlined briefly, you can see that it makes no difference whether you are talking about soap, automobiles, motorized wheelchairs, or the Kurzweil Reading Machine. I would propose that we in the rehabilitation field and those in the private sector address some of these engineering and marketing issues together. I suggest the following four points:

- There must be a closer link between the academicians and the manufacturers of what can be classed as rehab engineered items. The private sector is the group that will bring these products to the individuals who need them. The academicians will only affect the very few people who have the benefit of a specifically engineered device.

- In order to proceed in developing of devices, we must diminish the "this is mine" syndrome and the "not invented here" syndrome. Many devices are developed with a protection attitude, and other devices are viewed as being not invented by the manufacturer and therefore of no interest. The only people who suffer from this lack of communication are the disabled individuals who need the product.

- There must be a close working relationship among the consumers who will use this specific product. This relationship ensures the relevancy of the engineering and manufacturing environment to the needs of handicapped people and also helps to ensure quality in the developed equipment.

- I would suggest that the people in the rehabilitation field and in the marketing field keep on dreaming with respect to innovative solutions for handicapped individuals today. The rapidly advancing technology is making things that were not possible yesterday mundane today and obsolete tomorrow. We must keep moving with the ideas and keep on dreaming of how to do things better.

Michael Hingson

The Consumer Testing Project for the Kurzweil Reading Machine for the Blind

In discussing a consumer testing project such as the National Federation of the Blind (NFB) reading machine testing project, let me discuss briefly the significance of employing consumer evaluations. When asking consumers to test a project, it is assumed that the product is at a stage where it works well enough to be tested in a meaningful way. In the case of the reading machine, that means that the machine reads printed material and outputs what it reads in an understandable voice.

Also, the company whose product is being tested must have enough faith in the product to allow it out of the laboratory for relevant testing. It is one thing to test a product inside a company, and quite another to do so in the field.

Finally, it must be assumed that those doing the testing can provide meaningful feedback to the company. In the case of the National Federation of the Blind, the organization is large enough to represent a broad cross-section of the population. As a result, the federation was able to draw the members of the project staff from within its own ranks. Those selected to conduct the project were chosen because of their research qualifications and their abilities to perform the tasks necessary to successfully complete the project once it was begun.

A corollary to the last assumption is that the company will act on the recommendations provided by the testing project staff. The job of the staff is to study the use of the device being tested under actual conditions. The staff then makes up a set of recommendations to be submitted to the manufacturer and the evaluator, and then the recommendations of the evaluator should likewise be trusted and therefore followed.

The NFB testing project used five reading machine prototypes. The prototypes were placed in a variety of actual working settings where people were expected to use them. One machine was placed in an agency for the blind early in 1977. The second machine was also placed at an agency for the blind in Maryland. Machines were subsequently placed in libraries and universities. Machine placements were made on the basis of exposure to possible users and on the basis of proper in-house staff to manage the day-to-day activities of the project at that site.

In all, over 150 persons used the five machines, each for at least ten hours. An ongoing dialogue was kept up between the project staff and the staff

of Kurzweil Computer Products. Over 100 different recommendations were made from the beginning of the project to its end, a period of some 18 months. The recommendations served to clarify the impact of the project.

Soon after the beginning of the project, a user pointed out that the reading machines could not handle Xerox copies. It was recommended that some sort of adjustment be put on the machine which would allow the user to compensate for the lighter Xerox copies. Within a week a contrast control was installed mitted the reading of many Xerox copies. The recommendation did not serve to create a new idea, that is, the need to read Xerox copies, but it did establish the contrast control as a higher priority than it had been.

Other recommendations included the improvement in the speed of the reading machine speech as well as a redesign of the keyboard. Many recommendations were followed in a new design of the reading machine, while others are still being implemented even today, two years after the end of the project.

I believe that there are several lessons to be learned from the consumer testing project of the National Federation of the Blind. First, there is a definite need for consumer evaluations of products. The Kurzweil Reading Machine is certainly a much more usable device for having been evaluated by consumers.

Second, consumer testing projects should be conducted as independently as possible from the manufacturer. The NFB project was certainly ideal, since the machines were purchased, placed, and operated by the National Federation of the Blind. The NFB project staff collected feedback and relayed this feedback to Kurzweil Computer Products in the form of substantive recommendations. If companies do not permit true independent testing, then they will not obtain the real consumer-oriented feedback that can most benefit their products.

Third, a well-run independent project can have many benefits for all parties. Machines will oftentimes receive a great deal of public exposure, which is always helpful when products are performing well. Manufacturers also gain revenues from the sale of the prototypes to be tested. Finally, all parties gain from having a properly designed, meaningful product.

The Consumer and Basic Engineering Research:

Problems in Co-Invention

Deborah Kaplan

In order to stimulate thought about rehabilitation engineering and independent living, I would like to begin, in this introductory panel, by addressing some common biases and perspectives that I believe have acted to prevent those in the field from benefiting from the ideas and experiences of disabled people. The concept of independent living, as we know it today in California, has come to mean disabled people exerting a great deal of control over their lives. Because earlier models that emphasized services to disabled people, with disabled people in a more passive role, are being challenged, it is no longer satisfactory to disabled people to have decisions made for them; they are insisting that they be involved at all levels in the decision-making processes.

In the area of rehabilitation technology, we already have quite an established group of centers and active groups that have been working on devices and equipment for disabled people for several years. Many of these Rehabilitation Engineering Centers are closely attached to, or affiliated with, rehabilitation hospitals or medical centers. Because of this, a perspective has developed which views disabled people according to a rather strict and limited medical model. Disabled people are referred to as "patients" rather than people. They are usually dealt with when they are at their most dependent, either just beginning to cope with a new disability or dealing with a medical condition that requires hospitalization. Because they are not seen in their own environment, at home or work or whatever, they are rarely viewed as people who are in control of their lives, with a wide range of choices regarding how they will relate to their environment. Without this perspective, of disabled people taking advantage of the services of Independent Living Centers and similar groups, of disabled people going into new and unexpected areas of endeavor, the rehabilitation engineer cannot adequately grasp the needs of the people being served. The needs of a person in a hospital setting are not the same as the needs of someone who hasn't been to a hospital in years and is successfully living in the community.

Another problem that interferes with the rehabilitation engineer's ability to develop a realistic picture of the needs of disabled people and the best way to solve those needs, is that the field of technology for disabled people is rather insulated from much serious criticism. This is because of

what I call the aura of "do-gooderism" that pervades the entire area of providing services to people with disabilities. In our society, "helping the handicapped" is viewed as inherently good, selfless work. Although some people in the field may deserve such unrestrained praise, it's not a very helpful thing for a professional to only receive positive feedback all the time. In fact, it's rather patronizing; disabled people run into that all the time. People are afraid to criticize us for fear we'll fall to pieces before their very eyes. This field, I feel, needs more hard and cold criticism. That kind of feedback is not always easy to take, but it can be extremely helpful if it can be taken without overriding defensiveness. We need to take a much closer look at what is being done, how closely it is related to actual needs, and how useful it is likely to be, given how people will probably use it.

Because of these problems, we have not involved disabled people enough in developing research and technological priorities. The coming decade, more than ever before, will present us with the problems of ever-growing needs and expectations coupled with not enough financial resources. Given that we can't do all the things we would like to, and even if we could, disabled people must be involved in making the decisions affecting what is going to be developed and how. There are too many ideas that sound appealing to those who have never actually experienced the day-to-day problems of dealing with a disability, but that simply are not practical. There are many other ideas that sound good in the abstract but don't fit in with the already exixting priorities disabled people have for their future. Disabled people have too many real needs, especially now that the independent living movement is broadening the possibilities for all aspects of our lives, that we don't want to see limited resources put into inappropriate projects. Of course, everyone in the field feels the same way; nobody wants to see resources wasted. One way to increase the odds that resources will not be wasted is to involve disabled people who are familiar with the technical field in all aspects of the rehabilitation process, from germination of ideas to product evaluation.

Of course, disabled people need not always be viewed as outsiders coming into the process to give their input. One way to avoid the extra headache of researchers and technologists having to also become experts in outreach is for current professionals to actively bring people with disabilities into the field as technicians, professionals, and program managers. Every profession has its own unique responsibilities, and I feel that it is incumbent upon those working in the rehabilitation engineering field to put pressure on the schools to accept disabled students and to create internships and summer jobs specifically targeted for people with disabilities who are trying to get into the field. Of course, many members of the profession are already engaging in such activities. We ought to be hearing from them and reading about how they have accomplished these objectives. Then, others can duplicate their efforts and perhaps change can occur at a meaningful level.

An Experience in Problem Solving

Ralf Hotchkiss

I first began working on solving problems for disabled people using technology when I was in high school. At that time, I recall vividly, I received my first lesson in how our society tends not to be very critical in developing products for people with disabilities. I started out working on equipment for blind people. I researched what had been done very diligently in the library, and I became very interested in electronic devices for blind people, such as curb-sensing devices. Much research had already been conducted on this problem, and I found quite a few papers on it. My research indicated that the devices that had been developed all had problems; they were too expensive, too heavy, or required too much maintenance. The papers concluded that more research money was required to refine the basic idea of developing a device that a blind person could use to sense from a few feet away when a curb was approaching.

I began work on my own curb-sensing device, and after two years of work I developed a gadget that could be clipped onto the end of any cane, with rechargeable batteries, costing about $5 to make. With it, a blind person with a good ear could hear a curb coming up ahead. According to the literature on previous research, some blind people who tested previous devices after they had been built commented that they missed the tapping sound of their canes when they substituted the curb-sensing devices. So, I had my device make an automatic tapping noise.

With great pride, I took my curb-sensing device to my mother's piano tuner, a blind man who clearly had a good ear. He and a blind friend of his tried it out, and it did tell them when a curb was coming up. But they didn't really approve of the basic idea behind the device; even though it successfully sensed upcoming curbs, they could not use it as a substitute for their tapping with their canes. They pointed out that they still needed to use the cane in the traditional way to find out many other things than when they were approaching a curb, such as whether the surface of the curb or road is slippery, whether there's gravel, and many other characteristics of the surface.

It took a few years for all of the lessons of that experience to sink in. All of the researchers I had read about had only used blind people for final evaluations, in a non-technical way. They didn't involve them throughout their work. Ever since that time, I've made sure that I involved at least one disabled person in my work with experience in the particular problem I'm working on. Luckily, I work on wheelchairs and also happen to use one. But I've also made a point of seeking input from a variety of wheelchair riders, people with a wide range of disabilities. And when I begin to get involved in other areas, I'll be sure to find people with the requisite experiences who are technically oriented, as well.

Raymond Kurzweil

The Development of the Kurzweil Reading Machine

In discussing the development of the Kurzweil Reading Machine I would like to take a slightly different approach than has been taken before. When Martha Redden asked me to speak today, she asked that I talk about how we funded the project. The challenge of funding was probably the greatest challenge we faced. The difficulties in funding what was to be a very expensive project proved to be our major worry. The challenge was made all the more difficult because of the difficult economic times during which we sought funds. Although I will talk more about the subject of funding later, let me say that our approach was to use a variety of funding sources, some of which were unique.

The Kurzweil Reading Machine

Before talking about the funding of the project, let me briefly describe the reading machine. Many of you may already be familiar with the Kurzweil Reading Machine in one way or another. However, I believe that a review will be helpful.

The Kurzweil Reading Machine combines two different technologies. The reading machine can scan any printed or typed material prepared in virtually any format, produced in any type style and type size, and convert that material into speech. The machine automatically scans the printed page, finds the text, and then scans the page in a line by line fashion.

The first technology employed was omnifont character recognition, a system that can recognize characters of any type style without prior knowledge of the type styles involved. Since there are hundreds of different type faces in existence, we could not possibly depend on the user to identify the particular type face he or she would be reading. Using specially designed hardware and software, we developed a mechanism that could automatically perform this task for the user.

The second technology required was unlimited-vocabulary synthetic speech. This second technology was more developed when we began our project. Several approaches to the problem of unlimited vocabulary-speech had been worked on by different people.

When we began our project, we felt that the principal challenge lay in the development of the first technology. There was no system that could handle the omnifont requirement we needed. There were several recognition systems that could recognize particular fonts. Such machines were and are being used to digitize commercial documents prepared with the particular

specifications of the given Optical Character Recognition (OCR) system in mind. Of course, most material is not prepared in one given OCR type style. Since blind people want to read material prepared in a variety of type faces, limited font OCR systems were not practical. Today we still have the only omnifont character recognizer on the market.

Let me show you a brief film which can better illustrate the capabilities of the machine. This film shows the reading machine in a library setting, an ideal place to read material prepared in many different type styles.

Let me now take you through the steps that enabled the project to get to its present stage. I hope to give you a view of the variety of sources of funding we used, and then I will try to draw a few lessons for anyone else in the audience who might be planning to start a development project.

Funding Sources

We started out by funding the project ourselves. We first wanted to construct a working model in order to demonstrate the true potential of the reading machine. We began in 1974 by approaching some private investors, but it was a particularly hard time to start a company. In 1969, studies show, there was $500,000,000 in venture capital for developing new technologies, while in 1973 the figure dropped 99 percent to $5,000,000. Our initial investors were friends and families of the founders of the company. Each person invested a small amount in the project, probably because it was an exciting concept with a particular appeal that did not exist for many other projects.

Up to early 1975, when we completed the first prototype of the machine, we had only spent about $400,000. With the completion of the first model, more significant funding was needed in order to continue. The next step was to refine the machine by placing units out in the field in order to obtain consumer input.

The approach we used was to draw upon a variety of resources that would be likely to fund such a project. Since we had a working model, we approached standard venture capital sources, who were now more interested in funding our work than they had been before. We approached government agencies, and we began a consumer testing project with the National Federation of the Blind (NFB), who in turn approached private foundations for funds.

Over the next few years, all of these sources contributed in different ways to placing machines in the field for testing. The government was a difficult source to approach, because there is an excessive number of worthwhile projects needing assistance for the limited funds available. We were fortunate to gain the interest of the Bureau of Education for the Handicapped. This agency saw the significant possibilities offered by a true reading machine for the blind and eventually helped to place about 100 units of the machine in the field.

Access by a project such as ours to a variety of sources of support is necessary in order to obtain enough critical mass to make the project a success. It is particularly important to have some kind of government involvement, at least for purchasing and testing early models, as demonstrated by our experiences and those of the developers of the Optacon. The Optacon received significant support in its early stages of development and now is a viable product in its own right in the marketplace.

Consumer Testing

The consumer testing project of the National Federation of the Blind proved helpful in several ways. Not only did it provide sale of test models but it provided a good deal of visibility for the machine. When other

investors and the government saw that the machine was really being used in actual settings outside the laboratory, they became more interested in their own involvement. In addition, the consumer testing project provided us with invaluable feedback about the many user controls and the overall design of the machine. It is one thing to say that a machine will read any material, and it is quite another for the machine to do so in a useful way for the operator. The NFB testing project gave us many recommendations which have led to a much improved Kurzweil Reading Machine. This particular consumer testing project was set up in such a way so as to keep up an ongoing dialogue between users and the engineering staff. We feel that both Kurzweil and blind people benefited a great deal from the project.

Recently we have been acquired by Xerox Corporation. We now have access to funding which has heretofore been unavailable to us. We now have a very well funded research program. We intend to continue to keep our lines open to consumer input. We also have access to Xerox optical technologies and computerized circuit design, which should make the reading machine more efficient and less expensive in the long run.

We learned several valuable lessons from our experiences on this project. First, involve as many sources of support as possible. Second, choose a worthwhile project that will generate interest. Our particular project generated interest because it helped to meet an important need of a large group of people. In addition, the technologies involved had a wide range of possible applications not only for blind persons but for others as well. Third, it is difficult to put all these pieces together to make up a successful project. Each source of support has somewhat different goals. Skilled management is important in order to organize a project and achieve the results that everyone is really interested in--workable technology for the handicapped.

Hadi Madjid

Everything Transitory is Symbolic

There's a spirit of the time that conceives of the individual as reaching a peak between the ages of 20 and 35. It's only a mild exaggeration to say that before that, the person is thought of as being trained, educated, exercised and taught to be at that peak. After that, it is said, it's pretty much downhill.

This idea forms an implicit pattern of thinking for most of us. For example, a scientist may believe that the truly creative people do their work at age 20 or 25. Businesses don't like to hire people over 40. This view of man is quite prevalent, but it is a model that I think is quite antithetical to the truth and to work with the handicapped. This idea is embedded in almost everything we do. This kind of thinking also elevates fact to total supremacy. Our scientific technique is designed to generate facts, to value facts, to work with facts, to pick out facts, to be objective. That's what science is conceived of as doing, and it does it very well.

I see this "peak idea" in economics, my own field. Economics considers the perfect economy to be one which reaches an optimum, a peak. Just as the individual is considered to have a peak between 20 and 35, so, also, the properly run economy has a single peak, a maximum, where the factors of production and consumption all fit in very nicely as they reach that peak.

The same view holds in physics, where there has been a search for the fundamental particle for years. Physicists hold an implicit belief that there is such a thing, and that is nothing else but the same world view: a single fundamental particle is a single peak.

But that's not what man is. I ran across a quote from Goethe, in *Faust*, which to me expresses very much what man is and expresses a factor that needs to be included in scientific and technological work. Now, Goethe was a poet, but he was also a scientist. His science didn't fit very well into what science was doing at that time, but I think in some ways he was ahead of his time.

Now, what does Goethe say? "Everything transitory is symbolical only." And what is transitory? That's man. Everything that dies--lives and dies--is aware of time, is conscious of the passege of time. All of that is symbolical. And I think that men and women are essentially symbolical, also factual, but symbolical above all. And, that's what I think science has forgotten in its preoccupation with the facts. Man is not entirely factual.

A person who becomes handicapped has to deal with facts. He or she has to earn a living if possible and has to act in a practical way in the world. That's

absolutely necessary. But it's also necessary for a handicapped person to deal with himself as a symbol and not just as a fact. If he deals with himself only as a fact, that leads to all kinds of trouble.

I am going to try to illustrate two aspects of the symbol. One aspect is that a symbol is essentially a dualistic structure. It always comes in dual form--black and white, good and evil, handicapped and non-handicapped. A symbol is inherently dualistic, and I will try to deal with that issue. Another aspect of the symbol is that it is almost infinite in extent. It cannot be grasped by consciousness or by facts as an entirety. Fact rides on a symbol, like a little ship upon a sea, and a ship can never encompass the whole sea. It can never be everywhere. It can be here or there and remember where it was, but the sea is vast and it can never be everywhere at once, and that's a very crucial thing about the nature of a symbol and the nature of man.

A person who becomes handicapped is straightaway facing the dualistic structure of the symbol. If the person is in a traumatic accident, the situation is plain: the person is in a sense destroyed. What the person was no longer exists. There is a shattering of the whole structure--the physical and the psychological. It is a tragedy. It is a destruction. But out of that destruction comes a resurgence. I always think of this reaction in the image of the phoenix rising out of its own ashes. The traumatic accident is like the ashes--the burning of the phoenix. The phoenix rises again. In the midst of tragedy, in the midst of suffering, there are glimmerings of joy and love and hope and energy and drive and meaning.

I think that the failure of many handicapped people to make it, to be energetic, comes out of a wrong world view. If persons hold strongly to the belief that they are only a fact, what happens in the dissolution is that they think that they are the fact of their dissolution. They are clearly handicapped. The tragedy has really occurred. The destruction of their whole selves has occurred and they cannot allow themselves to feel the glimmer of the phoenix rising. The phoenix has an immense strength, but a person who thinks that there is only fact in the world, seeing a little glimmering of joy or hope, will squash it, because clearly that has no meaning in the context of one's own tragedy. The person thinks, "How can I feel joy when I am so destroyed?" There are some people, I think, who can never allow their feelings, their resurgence of energy, to rise again.

I think we've all seen the phoenix rising again in ourselves and in others. When it does, it's a tremendous force. I think that many who enter the field of science and technology for the handicapped do so as people who would like to solve the tragedy, would like to alleviate the suffering, would like to overcome the difficulties, for others. And, partly, that's for themselves. Because, when they face somebody who is handicapped, they say, "Wow, that could happen to me. And I would hate to have that happen to me. I will try to do what I can to overcome that possibility, and I think that my science, my technology, can do that." They think that science, the domain of the fact, can overcome, in essence, the domain of the symbol.

It can't do that, but that is the implicit belief, I think, of many scientists. The trouble with that belief is that the scientists really don't integrate the opposites that must be reconciled in order to do profoundly good work.

There's a play by Sophocles, *Oedipus at Colonus*, that follows *Oedipus Rex*. To me *Oedipus at Colonus* is a marvelous play about understanding what being handicapped is. Oedipus, blinded and about to die, goes to Athens. He calls on Theseus, the King of Athens. Theseus appears and says something quite marvelous: "I have come to listen to you." As I read these words, I thought "He's not afraid to face blindness."

Theseus says, "I have come here because I make no claim upon the future," meaning "I know that, in my own life, I might become blind. I might lose my kingdom, as you have, Oedipus, but in spite of that, I will come to you with energy, with love, with joy, with a positive attitude to life. I accept the possibility of tragedy. I do not try to overcome it. I do not try to deny it." And, out of that, something very good happens to Athens.

Now, in the field of blindness, whenever technology, at least in the past, has tried to deal with something that resembles the eye, scientists have gotten into trouble.

The scientist really gets into difficulty with mobility devices, where he thinks he can somehow replace the eye and do away with blindness.

The laser cane is the culmination of that kind of thinking. It's a bunch of lasers attached to a cane. And it's somehow supposed to solve the whole travel problem. You have a laser that is supposed to pick up stepdowns, another laser that goes above the head and picks up things above the head, and another one at midrange. And then there's the cane. Now, all of this hullabaloo is supposed to tell the person about everything that's in front of him. It's sheer nonsense. Why is it nonsense? Because the inventor wants to replace the eye. He does not really understand that that's not the problem. He's trying to deal with a symbol as if it were a fact.

A better invention is the sonic device Bob Mann talked about. It's worn on the chest and usually used with a cane. That box does not interfere with a cane, and it has its own limited function. It's only picking up things ahead of one; it doesn't disturb the cane. Now, that was invented by Bob DuPress, who was blind. I may have some question about how well that device functions, but it is better in terms of design and in its conception.

The Sonic Guide, a pair of sonar glasses, is probably the most advanced, fanciest instrument for mobility. It is a little bit like that box: It leaves the cane alone, which is fine, but it solves the problem only partially. At its core and depth, it's still that same old goal of trying to replace the eye. The problem is very subtle and invisible to most people. It's in the display of information.

The Sonic Guide produces a musical sound. It feeds information into the ears, and that tells a person what's ahead of him. That information is displayed in a spatial field, or a person is trained to think of it as a spatial field. There are beeps of different frequencies, and the higher the frequency, the more distant the object. So, here is information that tells one how far the object is. The sound is stereophonic so you can also tell the direction. Also, one can sometimes tell what the object is by the quality of the sound. So, what do the glasses do? They tell you how far away something is, at what angle, and maybe what it is. However, the Sonic Guide is a profoundly musical device. It is not seeing. It is hearing. And it is musical. When I've used it, I've found it very, very difficult to know how to deal with those two issues: they just merge. The inventor has never thought of the fact that this instrument is musical and not visual. He has forced it into a seeing spatial pattern, and that leads to trouble. The inventor is driven by the need to make the blind person whole, and he can't do it.

I think that the inventor has to face the duality of the symbol. He has to ask himself what an accident or a tragedy means, and he has to accept within himself the possibility that that could happen to him and still do the inventing and still live life well.

The second aspect of the symbol is that it is always greater that the fact. The definition of blindness and, I suspect, of all handicaps, is a definition,

oddly enough, based on a symbol. But, people don't understand that it is a symbol; they think of it as a fact. Now, the profound impact on an individual concerning blindness or any other handicap is, I think, a symbol. It has a meaning to the psyche. It transforms the psychological as well as the physical aspects of the person. It is a total shift in being, and that is always symbolic.

People understand this concept implicitly and unconsciously: when there is deep trauma, there is a transformation of the psyche of the whole person. That is what people mean when they define blindness, deafness, or some other handicap as something specific. But, it's a symbol. As far as the scientist is concerned, in his world of facts, that is not the way to define a handicapped person.

A handicapped person faces a field of gates. They are a little bit like obstacles, but they are gates that can be opened or closed. For example, if I go to a library and there is a Kurzweil machine there, the gate is opened. If there is not, it is closed. If I have a reader who comes, the gate is open. A person who uses a wheelchair has a step to overcome. What that means depends very much on where that step is and where the person is going. Each person has a whole domain of these gates, and he's surrounded by a vast field. That field of gates is like a symbol. It is dual in that the gate is either open or closed, and it is infinite in extent. The field of gates is never fully describable or known.

About six years after I became blind, I became interested in skiing. Now, I never thought of skiing in the first five years. So, in the first five years, that whole issue of skiing, that gate, was unknown to me. It was unconscious. It didn't exist. Then that gate appeared. Now, at first when I went skiing, I didn't do it very well, because I had the wrong technology. The gate was closed. I discovered the correct technology, a bell, and put it on my guide, and I skied very well. These gates, by the way, are not always open. Once a gate is open, it doesn't mean that it's going to stay open. Gates always have to be manipulated and handled.

If the person is viewed as facing a domain of gates, one begins to see what the technologist can do. The fact and the technology address a certain set of gates. If the technologist tries to deal with all of the gates at once, or with the whole person, he can't do it. It's like people trying to invent devices to replace the eye--you can't do it. It's trying to deal with symbols as facts.

One of the major advances in blindness technology is the Optacon. What does the Optacon do? It is a gate. It is not trying to replace the eye. Its purpose is to permit the blind person to go into a library and take a book and read it. The person carries a little device that allows him or her to access information freely. That's a gating problem, and it's a gating solution. The Kurzweil machine is similar, but it's a different kind of gate. These two are good examples of truly good machines. They solve a narrow gating problem, and they can do it.

At the leading edge of invention there has to be co-invention. The handicapped person and the technologist who is not handicapped have to work as a pair, as twins, as brothers. If that's not done, the process won't work. It's not just a matter of preference. It's not just a matter of political power. It's a matter of the structure of reality. It transcends preference. It's the fundamental heart of a relationship in reality that's composed of both symbol and fact. The only reason it's such a problem is that people think that all that exists is fact. The person who's not handicapped, but who is an inventor, cannot possibly have any intuitive grasp of that whole domain of gates. He can't do it. He's not in it. He's not a gate manipulator. Unless he works with somebody who is within that domain of gates, who is handicapped, he cannot do it. He has no information. He has no sense of what it is to be handicapped.

The gates an inventor tries to address are only local gates, partial gates. Which partial gates is he going to address? He has no notion of which ones to do until he deals with specific handicapped people. Each person and each class of handicap deals with a different domain, and he has no way of knowing what that domain is. It shifts all the time. He cannot do it without working as a co-inventor with a handicapped person.

I'm talking about the leading edge of invention, not about things that have been explored and are already on the market. The inventors never would have gotten anywhere with the Kurzweil machine if they had not involved the consumer so deeply. It's truly remarkable what happened there. I think the credit goes to Barry Unger. If it weren't for him, I don't think the Kurzweil machine could have flown very well.

I would like to quote C. G. Jung concerning successful treatment of psychological ailments: "Only the wounded physician heals." He himself did his most creative work, produced his greatest output, between the ages of 70 and 86. At age 70, he had a severe heart attack and almost died. And for the rest of his life, his heart was not well, and yet, in spite of that, he worked. I think there is quite an intimate relationship between truly profound and creative work, and an event that is in some way wounding.

Jacob wound up with a limp after wrestling with an angel. I think that any profoundly creative effort always involves the phoenix, always involves a stage in which there is destruction, a burning, and ashes, out of which the phoenix rises. That's where the very creative work occurs. And it's never easy. It's never risk-free. There's too little understanding about the nature of creativity and the nature of man in science today, I think because the fact is held supreme.

Grassroots Rehabilitation Technology and the Delivery System:

Getting Things Done at Independent Living Centers and Models in the Nonsystem

James Tobias

Independent Living Centers often look at rehabilitation technology from a services point of view, rather than from a research and development point of view. Three of them are the Design Department of Southern Illinois University, the Assistive Devices Center of California State University at Sacramento, and the Berkeley Center for Independent Living.

The work performed by these different centers shares many characteristics:

Client Orientation. The problem is brought to the center and stated by the client, not by a technologist or a clinician.

Functional Approach. The emphasis is placed on "How can I perform this function?" rather than, "What can you give me that will make me like 'everyone else'?" or an engineer saying, "I am competent in 'x'. How can I use 'x' to serve what I see to be the needs of disabled people?"

Interactive Design Approach. Often a team approach is used, including non-technologists, and the client acts as a designer.

Low Cost. The focus is on inexpensive items, because funding is often a problem.

Appropriate Technology. Much attention is given to the level of technology and its impact on original cost, maintenance, usability, and aesthetics.

Off-the-Shelf Items. Often the device is a simple modification of something readily available which is not produced expressly for rehabilitation purposes.

Over the course of the conference, much enthusiasm was expressed for the work these centers do. Cost comparisons to what might be called the "research and development model" indicated that grassroots technology could be very efficient in providing services, due to several factors, such as economical parts search (known as scrounging) and low labor costs (known as exploiting student helpers and volunteers). These economies should not be underestimated. They are permanently available, not just local flukes.

Key problems which presented themselves were:

Funding. Always number one. There is a gap between a full-blown R&D effort, requiring grant-writing and a long time-line, and immediate funding for commercially available equipment. Grassroots technology sits in this gap and is funded generally through loopholes, personal contacts, and luck.

Information. How many times have we heard the phrase "reinventing the wheel?" There is no consistent centralized way to share experiences and designs at the grassroots level. Australia has an organization called Technical Aids to the Disabled for this purpose.

Professionals. Clinicians and counselors in rehabilitation are unaware of the available products and services, and so are at the mercy of inertia and salespeople.

Consumer Involvement. Consistent oppression of disabled people has led to their exclusion from technical fields of work--they who can be the most useful in grassroots technology.

The key to the solution turned out, not unexpectedly, to be funding. Not that money solves anything, but diverting money to service-based rehabilitation technology will automatically expand the services provided, and this will have the effect of exposing more consumers and professionals to technology as a practice, not a catalog of products.

A Note on Mystification

Often nontechnologists look at the designer-technician as a wizard. It is important to deflate this myth. Everyont has excellent ideas for devices, but these ideas might never see the light of day due to a hardware inferiority complex (HIC). These designs at the grassroots level, by the way, have HIC's with respect to the even more wizard-like R&D programs!

If the idea is to provide functional services, then we must give up this socially enforced tendency to worship equipment and refocus on people. Here are some phrases to repeat before a mirror.

If you are not a technologist: "I don't care if it is 'state-of-the-art'!" "No, I'm not dumb, you just have to learn to express yourself so we can understand you." "Microprocessor, shmicroprocessor!"

If you are a technologist: "Sixty seconds of silence. (You may have to work up to this)." "That sounds like a good idea. Can I explain how we might be able to build it?" "Gee, I didn't know that."

A warning about the delivery system: In the effort to create order out of chaos, it is easy to declare a system where none exists. We can inflate figures, ignore important information, and distort data in an effort to squeeze cumbersome reality into a logical framework.

There is, in fact, no system. There is a patchwork of methods of getting technology into the hands and under the rears of disabled people. All these methods arose separately, from different "jurisdictions"; they were not designed to work together. In truth, where they touch, they are as likely to conflict as to cooperate.

So we have a Delivery Deck--a deck of cards that we as clients, case-workers, etc., try to shuffle around in order to piece together a good hand. We play one card or another in an effort to take the trick. The problem is that the deck has about 47 cards, 19 of which are jokers, some of which are spray-painted over, and some of which can only be read in a mirror.

To examine this non-system, it is possible to abstract our several "models" at work in the business of providing technology to disabled people. What is a model? Several things: an attitude or mind set, a way of perceiving problems, a methodology, and a set of success criteria. Models are pure forms and exist in mixtures at every site or institution where rehabilitation technology is done.

Of course, the aforementioned warning applies with full force to this "model" idea. The concept should only serve to throw light on how services are being provided now, and not claim to be an all inclusive framework.

Medical Model

Sites: Hospitals, Nursing Homes, Rehabilitation Centers.
Statement: "This is a patient. The patient is sick. I will cure the patient."

This model occurs because most disabled people have some disability-related truly medical situation. The line between illness and physical condition is blurred. For example, as a spinal cord injured person reaches medical stability, who can tell when a doctor is no longer needed? So medicine enters the field of technology, and a doctor's prescription is needed for a wheelchair.

Advantages:

- There is a great medical infrastructure, especially in cities, hospitals, clinics, journals, medical schools.
- Strong client-orientation, real intention to help.
- Few bureaucratic distractions.
- Integration of policy and practice: MD's both see clients and determine solutions. This integration is possible because of the power of the MD's social role.

Disadvantages:

- Like all benevolent dictatorships, there is condescension, arbitrariness, and a lack of recourse.
- Distortion of aesthetics: why chrome tubing for wheelchairs?
- Focused on physical maintenance, which loses sight of any possibility of increase in function and independence. To a doctor, a disabled person is always a patient.

Catalog Model

Sites: Used almost everywhere.
Statement: "Let's see, what page is that thing on? You'll love it!"

This model encourages us to collect all the catalogs of available equipment, ordering devices directly from distributors or through medical supply houses.

Advantages:

- This system can be operated by technically untrained people, such as caseworkers and clients.
- There is a large variety of aids available from one central location.

- Most of the aids have been tested or tried.

Disadvantages:

- Aims at a limited range of functions, leaving out sexuality and much of recreation, for example.
- Discourages new solutions, which may be cheaper or more effective.
- Seeks to adapt an individual client to pre-existing equipment.

Research and Engineering Model

Sites: Rehabilitation Engineering Centers, Universities.
Statement: "What an interesting problem! We will design and construct a solution."

This model grew from successes by engineering in other fields, such as communication and transportation; and by the success of single mission agencies, such as NASA. It is strengthened by the declared need of engineering departments for "socially relevant" work.

Advantages:

- Use of a scientific approach, including background research and detailed planning.
- Oriented to the "most difficult challenge", so it serves the most severely disabled.
- Many resources are pointed at one problem.

Disadvantages:

- Fixation with hardware and a corresponding lack of attention to psychosocial factors.
- What works in the lab may not work in the wide world.
- Massively concentrated effort means few clients; here the assumption is that one case represents thousands of disabled people. This is more false than true.
- Conflict between "interesting problem" and the needs of masses of clients.
- Aimed at manufacturing, but this is most often absent.

Vocational Model

Sites: Department of Rehabilitation, Veteran's Administration.
Statement: "Now what can we get you to make you job-ready?"

This model arose historically as an attempt to reintroduce injured workers into the job market. It then began absorbing cases of people who had never worked.

Advantages:

- Theoretically cost-effective, as the taxes paid by the re-employed clients should more than pay for the services rendered.

- Oriented toward integration of the client.

- Closure--once you're out of the system, you're really out and invisible to it.

Philanthropic Model

Sites: Disability-specific organizations, or philanthropic and fraternal organizations.
Statement: "How can we help these people?"

Advantages:

- Very client focused; often the fraternal organizations have particular people in mind for whom they raise money.

- Disability-specific organizations provide identification and continuity for their clients.

- Disability-specific organizations are well informed on that disability and may commission their own research.

Disadvantages:

- Reinforces dependent stereotypes by making the client a passive "charity case."

- Narrow focus by disability rules out other disabled people, regardless of the severity of the disability.

- Fraternal organizations often lose sight of alternative solutions in the thrill of fundraising for a particular expensive device for a particular person.

Grassroots Model

Sites: Independent Living Centers, hobbyists
Statement: "Nuts and bolts, rubber band and paperclip technology."

Advantages:

- Client oriented, as client originates problem statement and is involved in the design.

- Affordable.

- Leads to self-help.

- Unbureaucratic.

Disadvantages:

- Lacks technical sophistication; unaware of or biased against high-technology solutions.

- Maintenance and safety often questionable.

- Hit and miss; no easy management or organized outreach.

So we have all these models operating. It seems like a smooth combination; what you don't get from one, you get from another. So what's the problem? Maybe there isn't one.

Say you're a quadraplegic and you want to open your refrigerator door by yourself. You call up the local medical supply company. They don't have a refrigerator door opener, but their car door opener looks close and they can adapt it.

Six weeks later it arrives and they break it while bending it, but you have to pay for it anyway.

So you call up the university and they send over a couple of engineers who design a puff-and-sip activated microprocessor-based refrigerator door latch. Only one thing: it only works when nothing else in the house is plugged in. Your frozen chicken pot pies all melt.

So you call up the Center for Absolute Personal Sovereignty for People with Disabilities, and they say Sure, no problem. Two days later they drop off a piece of plywood with green dotted lines where you're supposed to cut out and glue together, but you don't have a saber saw. So you call them back and they say they're sorry, but the funding for their core services just got cut and everyone's at the state capital yelling at legislators, but they'll get back to you.

So there are some problems left; flaws in all of these models and cracks between them where people fall through. We need to take a look at these gaps.

Gaps in the Models

Barbara Nevins

Information Gap

Information comes from a bewildering multiplicity of sources; catalogs, data banks, conferences, sales literature, clients, magazines, reports, etc. As an information user, how do you make sense of it? As an information giver, how do you reach the right people?

Attempts to remedy this come in two forms: "clearinghouse" and "assigned responsibility."

A clearinghouse uses a data storage system to centralize and index the information. Many have been tried, with mixed success. Failures can be explained by insufficient funding or planning for one or more necessary parts; framework, accumulation, high visibility, and availability. "Assigned responsibility" uses one staffer to be an information broker. This task is time-consuming, and yields a contradiction. To the extent that this staff has other commitments, not enough broker time is freed up; but if it is a full-time job, the staffer can begin to lose touch with the concerns of the line staff.

Attitude Gap

Strange and negative attitudes toward technology are not specific to the field of disability; they pervate the whole society. We are ambivalent: on the one hand, we worship technology and try to apply it everywhere, and on the other, we seek to avoid it because it is overwhelming and unknown.

Many clients are subjected to massive doses of technology during their medical rehabilitation at the hands of well-intentioned staff members. Much of the equipment is ineffective, ugly, and unreliable. As a result of this overkill/oversell situation, we have seen anti-technology reactions. Clients identify hardware as another dependency.

Caseworkers, too, suffer from this. Few caseworkers have strong science backgrounds. Ignorance (as well as healthy doses of intimidation by the technically sophisticated!) reduces their ability to judge in technical areas, and they often err toward either anxiety-avoidance or hardware fixation.

Maintenance Gap

Obviously, equipment can't be used if it's not maintained. Very few locales have good wheelchair repair shops, and the situation is worse for more exotic equipment.

Here's a no-win situation for you:

If the device is manufactured, it probably comes from a small company far away, so repairs may be difficult to arrange, be costly, and take a long time.

If the device is a custom job, it probably comes from nearby, but it's a prototype and bound to be failure-prone. So repair costs and down-time may wind up high anyway.

Add to these the fact that funding for repairs may be difficult to find, and maintenance becomes a number one obstacle to greater use of technology.

Policy Gap

What is a consumer? A consumer is a person who buys a product and uses it. When the general public has a need, a demand is created and the product is made to fit that need. If they're not satisfied with the product, they return it, write the manufacturer, tell the retailer that it doesn't suit their needs, and get something else that's better or have something custom made.

In the case of the disabled consumer, the user and the buyer are two different people, i.e., the disabled person and the agency that pays. The user, who has no impact on the buying of the device, can only buy what's approved. There is no feedback system that listens to the user say "Does it meet my needs? If it doesn't, I'm not going to use it." Here we have a situation where the user has no impact on what needs to be purchased and the buyer has no impact on the use of the device. This situation is set up to produce a lot of waste.

I had a client who was a hemiplegic from encephalitis. I went to his home to do an initial evaluation. When I arrived I was ushered into the living room to wait for him. I took a look around the room to get an idea what this person was like, what his home environment was like. I noticed the fireplace, the plants, a comfortable chair and some family pictures. And then it struck me--I did a double take at the plants, realizing that the plant stand was a transfer tub bench. It had been ordered for him when he was in the hospital, and he had found that he couldn't use it. He worked out another method that was better for him. That's a waste. It didn't suit his needs. When he was in the hospital, someone decided that he should have it. It was purchased by Medicaid, and it's sitting there.

The same thing goes for another client who was a quadraplegic from a spinal cord injury. I went to this house to do an initial evaluation and the first question out of my mouth was, "Why don't you have a power door?" There was

a power wheelchair, virtually brand new; although it was purchased for him four years before, he had only used it for one week. I asked him why he didn't use it. He said, "I do fine in a manual chair," and he closed the door. That chair cost a couple of thousand dollars, and I tried to pursuade him to sell it or use it, but he had no desire to do either.

Since the medical model and the third party payers lack functional orientation to disability, they continue to use a list of pre-existing equipment that means custom aids are not covered. This, of course, contributes to the waste, because the consumers are often given inappropriate equipment.

Where is policy made? In some instances, when policy is made on an administrative level, it cannot truly reflect what disabled people need, because the administrators making the decisions are isolated. Then there's policy made on a lower level, by the counselors at the Department of Rehabilitation. They do receive the necessary input from the consumers, but the policy itself is random. The outcome is inconsistent, because policy is made by isolated counselors.

In one case, there was a problem obtaining a power wheelchair for a person who had both Medicare and Medicaid--dual coverage. The reimbursement method and rate prevented medical supply companies from selling power wheelchairs to people with dual coverage. When both insurances were involved, Medicare became the primary payer, and they did not reimburse in a lump sum for equipment over $600, and this included power wheelchairs. Their reimbursement schedule is based on data 18 months old that reflect the prices from that period. Also, their cumbersome coding system for power wheelchairs groups together indoor and outdoor power wheelchairs, a grouping that does not give an accurate price profile for either type of power chair.

In San Francisco, this problem kept cropping up, and I kept attempting to solve it. I found that helping someone get around funding barriers is not always a help. It appeared that many other therapists and consumers were encountering this problem. We at the Independent Living Project in San Francisco called a meeting, gathering together a rare combination of consumers, medical professionals, medical suppliers, and attorneys, and we found that everyone knew something about the problem but no one knew everything. As a group we were reticent about working with the medical suppliers at first, but then we found out that they had made many attempts at changing the system, so we began working with them.

Policy had been made on an administrative level with no contact with the users of the equipment, or with the people creating that equipment. We presented constructive suggestions to Phil Nathenson, the Regional Director of the Health Care Financing Administration in charge of these programs, and we opened up communication where there had been none in the past. Nathenson, his staff, their medical consultants, and those on the implementation level knew very little about power wheelchairs. We got them to waive the lump-sum rule so that any power wheelchair could be paid for all at once. The coding procedures were reorganized. The timetable for the reimbursement schedule needs to be more current, and legislation is necessary to change the schedule.

Some of these people who had never seen a power wheelchair before were making important decisions about who would get what equipment and when. Right there in the conference room we began to educate them about power wheelchairs, showing them what armrests and footrests were. We then created a set of wheelchair guidelines to educate the carriers, the medical suppliers, and the people at the Medicare bureau. (This will be used in Region IX and, we hope, throughout the nation in the coming year.) They welcomed the information and have since requested a sensitivity training for themselves and for the carriers.

One important thing we learned is that if one group approaches an administrative level to make a change, the input lacks perspective and strength. If you have consumers, researchers, and medical professionals, then you will get all the background you need and look at how the entire community will be affected. You must present solutions to the problem and work with the community on collaboration and cooperation to achieve communication with the policy makers. Policy is also made on a lower level, by the counselors at the Department of Rehabilitation. Equipment and services received by consumers with disabilities are inconsistent and depend to a large extent upon the whim of the counselor within a certain framework. For example, in California, electric door locks sometimes get funded for people with spinal cord injuries and sometimes don't. It could be the same counselor, and many clients with the same disability, but it will be approved for one person and not another.

Phony Overlap or Case Management Gap

There seem to be two problems here. One is that people enter the system willy-nilly and receive assistance depending on whom they contact. Let's say that the REC at Stanford tells the consumer to get a joystick modification that he needs. Since there's no central location where a disabled consumer can find everything he needs and get a reliable referral, he does not know who to turn to for his modification.

In an attempt to case-manage their specific client groups and to contain costs, disability-related associations such as the Multiple Sclerosis Society tell their clients that they will cover the needed equipment if the other agency doesn't. The consumer then must run from agency to agency to find out who will cover it. This false sense of security is currently being experienced by a man with a high-level spinal cord injury in California who needs an environmental control system. The Department of Rehabilitation has stated that they will pay for it if Medicaid will not. It is common knowledge that Medicaid will not cover such an expense, but nevertheless the phony overlap gap exists and the client, the medical supply company, the occupational therapist, and the engineer are sent on a wild goose chase in an attempt to pin down the funding source.

Coverage Gap

The problem is that coverage is often spotty from locale to locale and from model to model. Within one region, enormous sums of money may go to the Department of Rehabilitation and to one hospital and not to a university or the Independent Living Center (ILC). Or virtually no money might go to one region and lots of money to another. For example, there are three REC's in Northern California and only one in Southern California. There is no one body monitoring all the funds for hospitals, rehabilitation centers, REC's, the Department of Rehabilitation, and the ILC's, to see that money is equally distributed.

There is another level to this coverage problem: If the Department of Rehabilitation lacks funds, then people's needs are not being met because caseloads are too big. The department will not be able to case-manage effectively or give their clients the services that they require. What is the cause of this problem? There seems to be a lack of functional orientation on the part of the policy makers (those distributing funds). They are dazzled by technology, impressed with what technology can do, whereas so many consumers are looking for a simple, unobtrusive, and aesthetically pleasing solution. How many people will need, use, or be able to afford a robotic arm? Yet $700,000 is being used in researching and building this device. Money needs to be distributed to where it will do the most good in the long run and in the short run.

Training Gap

Doctors are not trained to think in terms of life beyond the acute phase and the cure. They're not trained to think in terms of functional ability. Dr. Judy Northrup of Ralph K. Davies Medical Center in San Francisco states that, "as we keep people alive longer and continue to eradicate acute medical problems, more people will survive with functional limitation." In the specialized fields of medicine, including occupational therapy and physical therapy, people are trained in dealing with a sick population and in doing everything they can for them while they're in the contrived hospital environment with the goal of sending them home. But few of these medical professionals know what the realities of home really are. An occupational therapist can show someone how to button a shirt with the aid of a simple device, but equally important to that individual is a home evaluation to determine access to the home and within it, including recommendations for modifications and a thorough discussion of accessible transportation within the community.

Doctors' lack of training is evidenced by the questions that they ask people with disabilities. For instance, they are curious about methods of transferring, sex lives, exercise, etc., all of which may be unrelated to the reason for the person's visit to the doctor.

Irving K. Zola

Involving the Consumer in the Rehabilitation Process: Easier Said than Done

Every rehabilitation conference I attend has at least one session devoted to consumer involvement. Right now I see that issue as being at the same level of discussion and implementation that the issue of physical accessibility was 10 years ago. Then the emphasis was on passing legislation to assure physical accessibility to the millions who had previously been excluded. It was, of course, but a first step. And while much of the effort has been stalled because of so-called "economic constraints," many of us, like the blacks realized in the 1960's, feel that the causes of such gradualism go deeper. So now here we are in the 1980's. And while the old battle goes on, new ones emerge. Now we spend our time legislating decision-making accessibility--trying to assure a representation, a role, a voice, and more important, a vote in areas where others make decisions about what is "best" for us--what we with handicaps need.

But this legislation can only do so much. The battle will not be over when people with handicaps serve on all the important committees. That will only solve the problem of the physical distancing. It is the conceptual gap that will then emerge as of most importance. And that is my task in this paper--to discuss some of the beliefs, values, and models that keep the rehab world and those they hope to serve--apart.

Independence: Whose View?

We can start with a strongly-held American value: our traditional emphasis on independence and self-reliance. Our political leaders need only mention our dependence on foreign energy sources and the public rises in indignation. Not surprisingly, the striving for independence is a similar hallmark of the rehabilitation literature. But I would claim that as unreal as complete independence is in the field of energy, so, too, is it in the life of many with a disability. The key seems to be who is defining what is independent. In my personal life space, the issue has most clearly surfaced in regard to wheelchair use. Most people with mobility problems have had to face the increased physical difficulty in doing things which once were easy. We had to overcome much reluctance, fear, and even pain to use our muscles while our arms, legs, and even heads rebelled. And once we could reach certain physical goals--take those steps, climb those stairs, scale that hill--we were told explicitly that we must always do them in order to maintain our strength and independence. The example is tried and true, but let's look also at what happened when it was left at this level. I was always told to push myself to the maximum of my physical capability. I was never given any advice as to what to do when my capability had reached its limits. In my case, this meant traveling just like everyone else. I would park my car where they parked and walk the full distance

to wherever it was that I wanted to go--even in winter on icy sidewalks. No matter that it took me five times as long to get there or that I arrived at my destination cramped and exhausted. The important thing was that I got there under my own steam--physically independent and mainstreamed. Was I really? The answer is a resounding "No!" After a while fewer and fewer people wanted to walk at my pace. Thus either through my embarrassment or theirs, I eventually went earlier, or alone, or not at all. In the middle period of my life (till my late 30's) this meant I omitted many activities which required considerable walking or where my slowness impeded the activity. Specifically, I stopped going on tours, visiting museums, or attending large public events. I occasionally mentioned this to my varying orthopedists and prosthetists. They, in turn, only shook their heads in sad acknowledgement. None of them ever suggested that I use a wheelchair! This only a change in consciousness permitted. And then very reluctantly and only in the last eight years!

My point is that in living in accord with someone else's definition of physical independence, I, for far too long, contributed to the demise of my own social and psychological independence.

The dilemma becomes even clearer with people who only use wheelchairs, particularly those who are forced to use physical means to propel themselves when electronic means are available. I would argue that there is literally no physical circumstance of which I am aware where the increased physical independence is worth the decreased social and psychological independence. In the rare circumstance where the physical exercise is essential, I am sure other forms can be created. And in the rare circumstance in which a substitute cannot be created, why not have at least two wheelchairs--one electric and one hand-propelled?

As you can see, I'm concerned with whose values define independence. In my more cynical moments, it seems a matter of whom we are dependent on. There seems to be a great fuss about paying for our dependence on personal care attendants, about letting the client control the money, and about the fact that fees may range from $3 to $10 per hour. But there seems little argument about our costly dependence on kidney dialysis machines. Could this, I occasionally ask myself, be in any way related to the fact that such dialysis treatments are medically dominated, technologically fascinating, and profit-making? Efforts to make us independent of this are greatly resisted. Thus attempts at self- and home-dialysis seem to vary more by geographic location than physical condition--ranging from under 15% here in the Northeast to over 50% in the Northwest![1]

The independent living movement crystallizes this issue well. Its very philosophy proclaims a new notion of independence. Independence, they claim, is not measured by the mundane physical tasks we can do but by the personal and economic decisions we can make. It is not the quantity of tasks we can perform unassisted but the quality of life we can live with help.[2] To retain the old physicalist criteria of independence can only ironically contribute to the very isolation and dependence we so clearly seek to avoid.

Assessment: A Question of Premature Closure

Sometimes operating assumptions are not so visible as in ideas about independence. Sometimes they are buried in more pragmatic matters such as the way rehabilitation programs assess an individual's physical and mental capabilities. That such assessments may be undüly influenced by time and space consideration was illustrated to me by an experience I had when living at Het Dorp.

For those of you unfamiliar with this place, suffice it to say that it is a village in the Netherlands, created specifically to house people with severe physical involvements. Aside from the medical criteria that residents had to

satisfy in order to live there, they were not admitted unless they had no other place to go. This was not a medical center. It was a village and no rehabilitation was done here. For all intents and purposes you were there because nothing more could be done for you. And yet, not only did many live a more viable existence there than otherwise possible, but some actually "improved" sufficiently to leave the village. Some critics have attributed this to a faulty selection policy. I don't think it was so simple. Many residents, uninhibited by external standards and timetables, were simply able to experiment with new ways of doing things with no cost to themselves. They were able to fail--and when they did, they could try again. And often they eventually succeeded. I am not talking about miracles of returned functioning but about, in rehab terms, improved functioning. A further observation was reported, almost embarrassingly, by an official--an observation of some interest. He noted that many inhabitants were living far longer than expected. In other words, as Dubos had noted in *The Mirage of Health*, a far more important factor in the better health of a population than improved medical techniques was improved living conditions.[3] And this social improvement knows no clearcut timetable as does the physical one--the so-called expected return of function within a given time period.

Thus, I would contend that many programs not only give up too early in the rehabilitation process but also have no systematic way of assessing our long-term progress and capability. In fact, most of us with disabilities are never given a chance to improve, a chance to be reassessed, or even a chance to learn about new devices. Let me be most concrete. You see before you an excellent example--a well-educated, rather informed individual, with excellent health insurance, interested in prevention, enrolled in quite a prestigious HMO, a staff member of several local hospitals, and a friend and colleague of many eminent physicians. Now let me add these facts. It has been 30 years since my polio and 26 since my accident--both incidents that left me with considerable right-side weakness. Thus I wear a long leg brace and a back support and I limp and use a cane. Now to my medical supervision. I have never, in the more than 25 years since my rehabilitation was "completed," been called in by any of my orthopedists or prosthetists for a check-up or to discuss new ways I could do things or new devices I could use. I do not mean, of course, that I have not seen these people, but rather that I only did so when something was awry or broken, and then quite naturally we all focused on the trouble. Anything new that I do or use today I learned from friends or read about. Now you might argue that that is the American way. I would argue that it is haphazard rehabilitation--a consigning of me and many like me to the "we have done all we could" category. I am not claiming callousness. I am claiming that there exists a system built on certain assumptions that prevents the rehab world from ever really knowing if they have done all they can.

The implications of this are, of course, more tragic when it affects children rather than adults. When the system operates on people who have no other resource or when it operates so very early, then the damage may be permanent and the results invisible. And this occurs in a more insidious way when we are referring to an individual's mental functioning. I have known for a long time that in many areas we are stuck in some single-minded concept of normality and development. As a sociologist, I was long aware of how time-bound and culture-bound were our notions of goodness and badness. Later it became apparent that this was true of what was thought crazy and sane and still later of what was healthy and ill. But it took some political events, such as the civil rights movement, to see how this was true of even things we thought were more biological givens--more genetically determined. I am referring to I.Q. Not only have we come to realize that some of the basic questions that are part of such I.Q. tests are biased against certain populations, but so, too, are the very dimensions that have traditionally been assumed to be the essence of intelligence.

Westerners grow up in a setting that demands and thereby stresses the acquisition of logical, analytic and especially verbal abilities. As McBroom has aptly noted,

> The minds that blossom in this environment are highly adept at categorizing the world into many discrete bits of information and organizing this material into abstract systems of knowledge. This kind of mind conceptualizes, theorizes, and explains, and in so doing it gains a high level of control over the physical environment. Such abilities yield high scores on I.Q. tests...[4]

Concretely this means that people not committed to the Western and urban style of living have no need to develop the cognitive style we so highly value. People who don't need these skills will simply not devote much effort to obtaining them. What is thus being measured on such tests may be, to a lesser extent, genetic givens and, to a large extent, cultural prerequisites. One can, of course, argue that to succeed in our world, one needs our abilities. But our world is not the only world people live in. At the very least, such reasoning means that we are not measuring a people's given, inevitable, or fixed ability to move in our world, but more their current inability to do so.

John Gleidman has recently claimed that the same difference in world views or, more mundanely, cognitive styles may also be seen in the appropriate standards by which handicapped children are assessed. During the 1960's, a professor of psychology at the University of Montreal, Thérèse Govin-Décarie, studied the children born with deformities whose mothers had taken thalidomide. In particular she was struck with how little light conventional psychological theories shed on the children's development.[5] A psychoanalyst, André Lussier, came to quite similar conclusions in his work with a child born with severe limb deformities. He continually found that behavior

> he first interpreted as pathological and harmful to the child's development frequently turned out to be an essential ingredient in the child's conquests of his physical limitations. For example, when the child boasted that he could learn to play the trumpet, Lussier interpreted it as unrealistic fantasy--until the boy actually succeeded in doing it. All manner of actions that seemed pathological when assessed by the norms of standard psychoanalytic theory turned out to have a different functional meaning in the disabled child's life.[6]

Such data led Gleidman to the following conclusion:

> Because of the stigmata of disability, for example, handicapped people often move through a different social world from the one the rest of us inhabit; many of them do so in bodies that place important constraints on the way they obtain information about the world around them. Researchers frequently appear to assume that the developmental theories proposed by Piaget and others, elaborated from observations of able-bodied children, will work for the handicapped. But it may be that the cognitive and emotional growth of handicapped children follows its own healthy logic. A disabled child who is physically dependent may be putting his most sophisticated cognitive skills into learning how to charm, manipulate, or otherwise enlist the help of others; to keep safe from harm; to deal with the split between his social worlds: the home, where he is loved and respected, and the street, where he is viewed as a biological fact. The able-bodied child of the same age may be spending the same energy on working free of his dependence on parents and building his sense of competence by developing skills.[7]

Since you have been patient with me so far, let me further extend this speculation. What I would contend is that those of us with profound physical involvements may not only be "deficient" in some cognitive abilities the rest of you possess but may also have some highly developed and underappreciated

abilities of our own.[8] I am thus willing to resurrect for closer examination some of the old truisms about the extraordinary development of other senses possessed by those who are visually impaired or hearing impaired. And I am beginning to suspect that the same phenomenon occurs more subtly for many of the rest of us. Immodestly, I have both a highly developed time-sense and an extraordinary ability to break things down into common elements. Both of these talents I think are very much related to the long periods of total confinement (of nearly a year apiece, once paralyzed and once in a body cast) where I became extraordinarily concerned with what time it was, how long it would be before..., as well as with how to keep myself busy and sane. I am not raising these observations to note the special blessings of being handicapped. I am arguing that as we physically learn to compensate one muscle for another, so too we may well engage in a similar compensatory process, both cognitively and psychologically. When we have little enough to be rewarded for, that reason alone may be sufficient for acknowledging such new traits. But, in addition, such abilities may well be essential to our rehabilitation--the essential building blocks of our new self.

Safety: At What Price?

With such global considerations as a context, I want to examine the effect of similar assumptions on the direct application of rehabilitation technology. An issue of great concern in the design of activities as well as devices for those with handicaps is safety, the protection of the individual from unnecessary harm. While the wish to protect vulnerable people from danger is a worthy goal, it is often achieved at too great a cost. Loring Mandel wrote of this in a play, "Do Not Go Gently Into This Good Night."[10] Melvyn Douglas portrayed a retired cabinet-maker who for "his own good" was placed in a nursing home. His breaking point occurred when the staff refused to allow him to use the available woodworking machinery because it was too dangerous. He rebelled; he claimed that he had the right as a human being to run the risk of injuring or losing his finger. Since they disagreed, he quit the home. Most of us are not so fortunate. We do not have the power to quit. They won't let us leave. And we have no place to go.

This is seen most dramatically in regard to people with mental handicaps, those labeled "retarded". The tone was set early in this century. I can do little better than quote it directly.

> ...self control and independent life are not for mental defectives, either in their own best interests, or in the best interests of the family, the community, and the nation. Common sense forbids it. In the nature of things it cannot be. Mental defectives may be nearly or quite self-supporting; they can never be self-controlling or self-directing except in a childish way, and they can never be the masters of their own fate except at the cost of disaster and ruin to themselves and others--disaster that affects future generations as well as the present generation, and that tends to undermine as far as it goes, the security of the homes and the nation concerned. Mental defectives are permanent children...[11]

It took over 60 years to begin to undo this perspective--to question what in this statement was social fact and what was self-fulfilling prophecy. Though many had speculated about what overprotection might do to such children[12], it was not until the early 1970's that someone gave empirical truth to this fear.

In a study of mildly retarded children, the investigators reported that the more overprotective and controlling the mother was, the more likely was the child intellectually to show a decrease in I.Q. score and physically to experience poorer muscle coordination.[13] In short, many became "permanent children" when they need not have.

There is a body of psychological literature that claims that risk-taking is essential to the growth and development of all individuals.[14] Aaron Wildavsky, the political scientist, has even claimed that it is essential to the growth and development of society itself. When it is absent, society stagnates and dies.[15] Robert Perske summed it up well when he concluded:

> The world in which we live is not always safe, secure, and predictable. It does not always say 'please' or 'excuse me.' Every day there is a possibility of being thrown up against a situation where we may have to risk everything, even our lives. This is the REAL world. We must work to develop every human resource within us in order to prepare for these days. To deny any retarded person his fair share of risk experiences is to further cripple him for healthy living.[16]

I spent yesterday with a para who races auto cars and the week before with a quad who was learning how to ski. Both of these are activities I would not have engaged in BEFORE I got polio! Without trying for a moment to denigrate the achievement and courage involved in their doing this, what else I think they are doing is putting some risk back into their lives where so much has been denied them. Hoping there are no police safety officials around, I realize my risk defiance comes from a continual neglect of seat belts and an almost congenital inability to keep to the 55 mile-an-hour speed limit. Given that I travel a lot, I think I'm on the way to collecting a speeding ticket in every state in the Union.

In short, if society does not let us have normal risk in our lives, many of us will go to extreme lengths to reestablish it. Thus to design an environment or device to prevent any kind of risk may go too far. It may not produce a real life but a mirage of one. There is human dignity in risk. There can be dehumanizing indignity in safety.

Doing Too Much Too Technically

Technology can also do too much for those of us with disabilities. The machines or devices that technology creates may become so complete that they rob us of our integrity by making us feel useless. I saw an example of this in a very different area, but I think it has relevance here. Many years ago when the convenience food business was in its most expansive phase, the manufacturers discovered that there were at least some areas in which they had gone too far. The one that I personally noticed was in the preparation of cake mixes. At one point, all the ingredients were included. All one needed to do was to add water, stir and then bake--the same formula that worked so successfully with soups. But there was resistance. Sales faltered. It seemed that cake-making contained some important elements that differed from soup preparation. Baking had more intimate connotations--it had associations with being "fresh" and even "special". As a result, the manufacturers quickly altered their strategy. They not only said one had to add fresh eggs but on the sides of the box, they gave hints on how to improve the recipe--how to make it more special, more one's own.

I think that I am seeing the same thing with device use, though for many reasons the resistance is not so visible. I mean that the physicians and the manufacturers are not hearing about it. We cannot refuse to buy your products--we have nowhere else to go. What I have noticed is that many disabled persons have invented an addition to their device or altered its use to suit their purposes. For years I thought this was merely our way of correcting the faults of our prostheses. But now I think something more is at stake. For 15 years, my own leg brace has not fit properly. No matter what they do, there seems to be one place where within 24 hours a pressure sore will be produced. It is, however, a problem I have solved by creating a special patch that I place over the spot every day. And I realize now that it is with a certain pride that I

note the dubious looks of my orthopedist or my prosthetist whenever he sees it. I have solved something they could not. But I've also done something else. I've made the brace more a part of me because I have given it my own unique stamp. Now again, I am not arguing that the rehab world should stop inventing devices that we need, particularly when we ask for them. But rather that whatever the device, it need not do everything. It may even be worthwhile to encourage us to invent or create things that not only help the device to serve us better but also make it more our own.

There are other even more subtle ways in which the use of technology has gone and is going too far, where our selfhood and very integrity are at stake. There is very little understanding of what happens when bodily parts and functions are replaced by equipment. Such replacement is not an unmixed blessing. It has been found, in regard to transplants and skin grafts, that the physiological body rejects parts which it feels are alien. So, too, the psychosocial person rejects parts that he or she feels are alien. No one who thinks of himself as independent wants to use even a cane or crutches. And when he does, he often tries to avoid using it in public or simply gets angry, as Barry Goldwater did in his speech in 1980 before the Republican National Convention. I for one am more subtle. I manage to misplace my cane at least once a day. The problems escalate the closer the appliance gets to the human body. Thus it is not at all clear what it means to have as part of one's daily routine the putting on of braces and the strapping on of prosthetic limbs. The problem becomes more serious, in the sense of unknowable anxiety, if not psychosis, when we become internally attached and thus dependent on machines, from the insertion of pacemakers to the attachment of the kidney dialysis machine. In each case, we have unwittingly become like the Frankenstein monster of some mad scientist's creation. A warning note on this was sounded nearly 30 years ago, when Francis MacGregor studied the effects of plastic surgery on people with major facial disfigurements. Unprepared for what the new "me" would look like, people showed, instead of relief and gratitude, profound reactions of distrust, anger, depression and even suicide.[17]

I am arguing, of course, not for the elimination of all such mechanical devices but merely that those who use them may neither be as proud nor as grateful as the inventors think they should be. For these machines and devices alter a sense of self so profoundly as to make the now livable life not worth living. I believe there is a similar problem in the over-technicalization of care. I am referring specifically to the invention of robots or the training of chimpanzees to service, dress, and feed high-level quadraplegics or others with similar high degrees of physical involvement. While it might well be cute when one's favorite pet brings in the newspaper or, in rare instances, one's slippers, it is less cute when these involve more intimate tasks. I realize that part of the appeal of machines and animals is because of the intimacy that, it may be perceived, is easier to share. But I draw your attention to the long-term loss of this short-term gain. I did not accidentally use the term "care" when I introduced these tasks. Let me read you some of the dictionary definitions of "care". According to Webster, care involves

> painstaking or watchful attention; regard coming from desire or esteem; a person who is an object of attention, anxiety or solicitude.

My point is a simple one, that care, as in the terms "medical care" or "personal care" is not merely a technical task. Quite the contrary--it involves very personal qualities. To objectify this care into a technical service, to replace the human element with a mechanical or animal one, can only lead to the further objectification of the individual receiving that service. I am not arguing that much of the traditional way that such care has been given is "healthy". Any time that it is patronizing or infantilizing, it cannot be a good thing. But as bad as such qualities are, they are at least human ones.

They reinforce the humanness of the individuals involved. To be handled by a machine or an animal, where once I was handled by a person, can only be invalidating of me as a person.

In Conclusion

What then do I conclude?

Unless the notion of independence is expanded from physical achievements to socio-psychological decision-making;

unless the idea of independent living ranges from the quantity of physical tasks we can do to the quality of life we can lead;

unless rehabilitation frees itself from some of its culture-bound and time-limited standards;

unless the idea of human integrity includes the idea of taking risks;

unless rehabilitation changes its service model from doing something to someone to planning and creating services with someone;

unless we do all these things the rehab world will find itself in the position of Walt Kelly's Pogo, who once exclaimed in despair, "We have met the enemy and he is us."

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3 From the Lab to the Consumer

James C. Bliss

Economics of Technology for the Handicapped: A Manufacturer's Viewpoint

In the handicapped community, there is a trend toward greater participation by consumers, teachers, counselors, therapists, and other workers in research and development decisions, especially in those projects funded by the U.S. Government. As a prerequisite to this participation, an understanding of the commercial product development process is essential to arriving at sound decisions. Unfortunately, this understanding is too often missing in proposal review teams, with the result that projects are sometimes funded with unrealistic goals and schedules and inappropriate applications of technology.

In this discussion, I will try to give some understanding of the high technology product development process as well as answer the following questions, which I am asked frequently.

- Why is product development so expensive?
- Why does product development take so long?
- Why are products for the handicapped so high-priced?
- Why aren't companies interested in my product idea?
- What goes wrong so that some apparently good product ideas never go into production?
- What role should government play in the process of developing high-technology products?

Products for handicapped people span the spectrum from low technology to high technology. They also span the spectrum from incorporation of readily available technology to a requirement for special technology. The more technology needed to solve a problem and the more this technology must be specially developed to solve this problem because readily available technology is inappropriate, the greater the cost and the longer the development process.

At this conference we have seen some very clever solutions to problems using low technology and readily available components. Unfortunately, not all problems of handicapped people lend themselves to solutions of this type. For example, components from which to make a reading aid for the blind, such

as the Optacon, can't be found at your local hardware or computer store. When the Optacon was developed around 10 years ago, about 20 Ph.D. theses were written on various aspects of the special technologies that went into the design. Yet the Optacon has been a successful product, which illustrates that, at least in some cases, the value of a solution merits the development and application of high technology.

In this discussion my remarks will be limited to high-technology products because this is where my experience has been and because I feel this is the area least understood by most people in the field. That is not to say that low-technology solutions shouldn't be used whenever possible, but rather to point out that many problems, particularly those in communicative disabilities involving vision, hearing, and speech, require high technology for an effective solution.

The Product Development Process

Our experience indicates that the high-technology product development process requires many formally defined steps and that attempts to bypass or shortcut these steps are likely to end in disaster. The major steps in the process as we've defined it are illustrated in Figure 1.

Initially, a product idea can come from anywhere--from consumers, workers in the field, outside inventors and investors, and from the staff from within any of our own departments. Our first step is to assign someone, or a team, to do a screening study in an attempt to evaluate whether the idea has merit and should be pursued further. This screening project can be set up relatively quickly. Screening projects usually last a couple of weeks to several months. The end result is either to determine that the idea is unworthy of our further consideration or to write an investigation proposal containing the information listed in Figure 2.

As a concrete example, I will relate this process to a hypothetical product called the Enabletron, which is completely fictional. This fictional product is sufficiently close to real life to accurately illustrate the product development process. However, any similarity between the Enabletron and real products is purely coincidental.

The initial idea for the Enabletron came from the field in 1976. Braille, the basic form of written communication used by blind people, was based on archaic technology which was rapidly becoming noncompetitive and too expensive in the world of electronic information processing. We heard of French research on a device that combined cassette tape memory storage with a piezoelectrically driven array of pins that formed braille cells. We initiated a market study and began to explore technical feasibility. Several months later the ensuing report gave somewhat inconclusive recommendations. The idea appeared promising but there were many doubts regarding market acceptability and economic viability.

We decided to apply for a research grant to investigate the feasibility of using our piezoelectric technology, developed for the Optacon, to build a refreshable braille display. The braille display was then viewed as the most difficult technical barrier to a product and thereby presented the greatest risk for product development. Without government support at this stage the project may not have been pursued. Fortunately, several months later we received a $75,000 grant for this study. An engineering team was formed which successfully completed the project about a year later with a working breadboard of a braille display.

In the meantime, more favorable marketing information was being received. We decided to write an investigation proposal for the next stage toward the development of a product. Since the investigation project would commit major

resources from the company, board of directors approval was sought and obtained. The components of the Investigation Project are shown in Figure 3.

Probably the most difficult objective of the Investigation Project of a high-technology product is achieving a completely functional breadboard. It is important to appreciate that this is an experimental unit whose purpose is to indicate that the technical problems can be solved within certain cost constraints. Many dollars and months may be needed to go from a prototype to a production product.

In the Investigation phase of our Enabletron Project we built several completely functional units. This effort involved a full-time team of six or seven engineers working together for over a year, at a cost of approximately $400,000.

First reactions to these breadboards were very encouraging. Market forecasts continued to improve so we wrote an Enabletron Development Project proposal with the components shown in Figure 4. A Development Project (see Figures 5 and 6) is typically much more expensive than an Investigation Project, which is much more expensive than a Screening Project. In our Enabletron case, board of directors approval was obtained for the Development Project and we initiated what turned out to be a two-year effort costing an additional $1.5 million (even though initial time and cost estimates weren't that high).

While we thought we had solved the major technical problems in the breadboard units, experience soon showed otherwise. It became apparent that the method of recording braille data on cassette tapes was not reliable and that the tapes could not be conveniently duplicated. This necessitated a return to an Investigation phase on this aspect of the project. Several inventions and many months later, we had a reliable data encoding system which enabled both digital and audio data to be recorded on cassette tapes in a form which could be conveniently duplicated (much to our surprise, this problem had not previously been solved in the field).

Having achieved a reliable tape system, we proceeded to the Prototype Development Phases shown in Figure 7. Prototype units were achieved which passed all of our internal testing. We began production.

To illustrate the risks and pitfalls in high-technology product development, a disastrous discovery was made in the first production units. A high number of braille displays were failing in the field. This was all the more surprising because this key component of the product had been designed two years previously and numerous prototypes had been operating without fault for months.

Production was halted. A massive scientific effort was mounted to solve the problem. Around the world, universities, experts, and companies were consulted as we tracked down every possible approach which could lead to a solution. After a four-month crash effort we had a new design which successfully passed all environmental tests. (The problem was discovered to be due to a combination of high humidity and high temperature--a rare condition for Palo Alto, California).

In this example I have shown how a high-technology product development can take over four years and $2 million before any sales are made. Several more years will be necessary before the break-even point is reached. All of this investment except for the $75,000 government grant came from company earnings and stockholders. During this development period, there was considerable risk in that the product could fail for any one of a myriad of factors. Especially because of this risk and the length of time capital is tied up, it is necessary to expect that a reasonable return will eventually be generated.

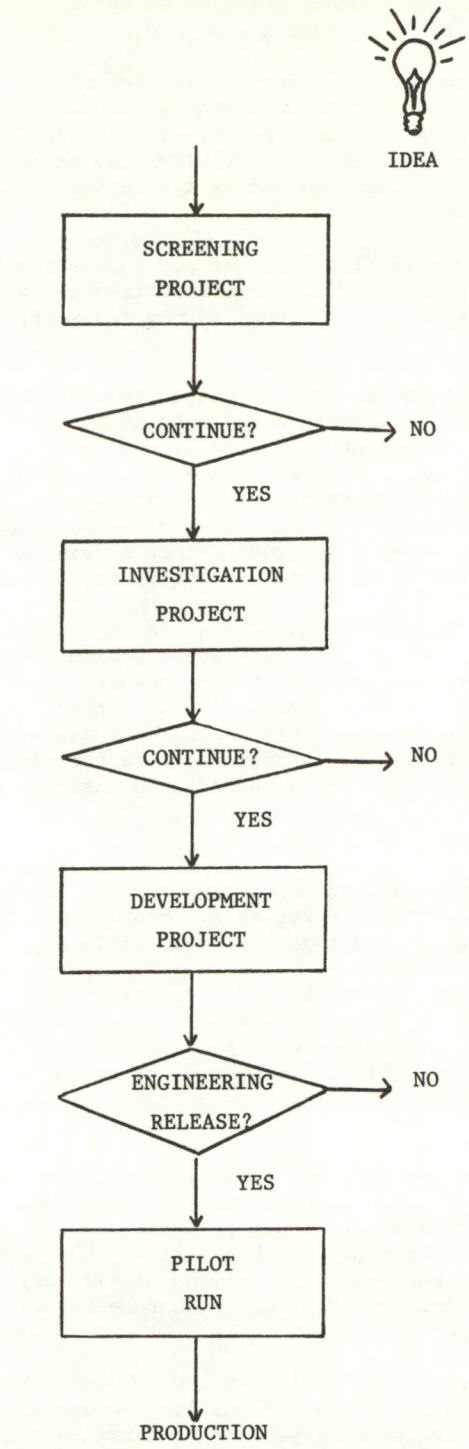

IDEA
SCREENING PROJECT
CONTINUE?
NO
YES
INVESTIGATION PROJECT
CONTINUE?
NO
YES
DEVELOPMENT PROJECT
ENGINEERING RELEASE?
NO
YES
PILOT RUN
PRODUCTION

Figure 1

INVESTIGATION PROPOSAL

1. Preliminary definition of the product to be investigated.

2. Explanation of how the new product will meet perceived customer needs.

3. Initial estimates and future projections of market potential and cost of goods.

4. Identification of technical problems to be solved as demonstrated by the breadboard.

5. Initial estimates and future projections of engineering resources required both for the investigation project and the development project (personnel plus capital equipment).

6. Review of schedule.

7. Standard TSI financial analysis and internal rate of return (IRR).

8. Effect of the proposed project on existing projects, especially any change in staffing needs.

9. Proposed duration for the investigation project along with a working schedule of goals.

10. Proposed total budget and funding sources for the investigation project.

Figure 2

INVESTIGATION PROJECT

Purpose:	To debug the idea/specification/technology and to develop the marketing plan. This requires a successful demonstration of in-house capability to meet product specifications, and a high degree of confidence that the specifications meet the needs of the customer.
Budget:	Formal
Schedule:	Working schedule of goals Periodic reviews
Deliverable Items:	In-house expertise required to solve all known technical problems Completely functional breadboard Refined market estimates Report/Recommendation Development proposal

Figure 3

DEVELOPMENT PROPOSAL

1. Final Report of the Investigation Project

2. Detailed technical and functional specifications of the product

3. Detailed analysis of market segments, strategies, forecasts, and schedule of product introduction and product life

4. Analysis of competition relative to our position

5. Staff requirements

6. Itemized cost breakdown and estimated cost of goods at various production levels

7. Itemized budget of development costs by all departments, indicating personnel, general equipment, tooling, capital equipment, in-house test equipment, burn-in equipment, outside services, etc.

8. A work breakdown schedule and accompanying PERT chart with explicit milestones and review points

9. A program schedule, indicating how the engineering schedule will mesh with project activities of other departments and specified review dates

10. Detailed financial analysis, including an internal rate of return calculation

11. Evaluation of the engineering breadboard

12. Impact of the proposed project on the company

Figure 4

DEVELOPMENT PROJECT

Purpose: To apply proven technology to produce a successful product.

Before undertaking, must be able to answer following questions in the affirmative:

Have we demonstrated solutions to the major technical problems?

Is there a market for the product?

Can we make the required return on investment?

A Development Project will involve every department in the company.

Figure 5

ELEMENTS OF DEVELOPMENT PROJECT SCHEDULE

1. Engineering design program
2. Reliability test program (thermal, shock, etc.)
3. Product safety program (UL, CSA, etc.)
4. Field evaluation program
5. Documentation
6. Manufacturing phase-in program
7. Engineering test program
8. Internal information
9. Realistic milestones based on experience gained from previous project (achievement, date)
10. Properly timed review points and time allotted to address action items
11. Milestones for an engineering design prototype, production prototype and a production pilot run
12. Service program, including manual
13. Marketing program, including owner's manual, brochures, etc.
14. Training program

Figure 6

PROTOTYPE DEVELOPMENT PHASES

1. Design Prototype

   Purpose: To debug the engineering design

2. Production Prototype

   Purpose: To debug the design and manufacturing tooling for the product

   Units used for evaluation and test by Marketing, Service, Quality Assurance, Reliability, Engineering Test, and Manufacturing Engineering

3. Production Pilot Run

   Purpose: To debug the production process (Process Instructions, Inspection Instructions, Test Methodology, Documentation, etc.)

Figure 7

Discussion

While the application of high technology to aid disabled people can be a long, costly, and risky process, the payoffs can be great. In purely economic terms, an investment of a few thousand dollars in equipment which enables a disabled person to become employed, be more self-sufficient, and realize a greater potential, can result in a many-faceted reward to society. This potential value needs to be fully appreciated, especially by participants in the evaluation and decision-making process. True value to society should be the yardstick by which programs are measured, not what a consumer product should cost, or what a disabled individual can afford to pay.

To make intelligent decisions with respect to research, development, evaluation, and dissemination of technological aids for the disabled, the new-product development process needs to be fully understood. Often a government role in funding the initial stages of the product is crucial and makes economic sense to both government and industry. Even more important, government must play a strong role in creating a market for appropriately applied technology.

In the past decade we have seen great progress toward providing disabled people with aids and tools that enable them to better realize their potential and to be more effectively integrated into the mainstream of society. Today, some of these gains are being threatened in the name of saving money, or "we can't afford it." We need to get the true economic story out and show people why "we can't afford *not* to do it." Instead, we need to expand our programs and build upon the beginnings achieved in the past decade. Much more can be done. This requires us all to be alert to threatened setbacks, to be knowledgeable and ready to defend our programs with solid facts, and to be creative and imaginative in devising and promoting new possibilities.

W. Larry Busch

Grassroots Rehabilitation Technology: A Need for Encouragement and Information Transfer

A half-century ago, Hubert Everest, a paraplegic, and Henry Jennings, a mechanical engineer, bolted together the first of their many wheelchairs. This initial effort, by amateurs working outside the mainstream, grew up to become the mainstream itself--remarkably successful example of grass roots rehabilitation technology. Today such so-called "amateurs" working on the fringes of the health care field are still likely to develop devices that make significant contributions and may even redefine the state of the art. This basic source of innovation should be carefully encouraged to augment the increasingly technical and specialized field of rehabilitation engineering.

The very success and sophistication of the health care industry seems to have hindered some grass roots rehabilitation designers from contributing as much as they might. Some imaginary barriers are discussed below.

You always get what you pay for; therefore the most expensive equipment is the best. This is only occasionally true. Is what one is paying for what one really needs? Is the most costly device costing so much that one foregoes other significant items that could be of greater benefit? For example, a top-quality wheelchair that does not provide a proper position for its occupant is simply not a good device for that individual at any price.

Two well-known therapists, Karel Bobatt and Berta Bobatt, have shown that "...the postural control inhibition of pathological reflex activity and the normalizing of muscle tone have been found to be the prerequisite for the development of normal motor patterns."

For many individuals, a custom-fitted seating insert is thus the single most important aid, for it is a prerequisite of most educational and training programs. Therefore, if funds are limited (and when aren't they?), an economy chair with a custom insert may be a vastly better investment. In the rehabilitation engineering field, cost and desirability are not synonymous. The rule should be to make the highest and best use of funds in terms of the user's comfort, safety, and function.

The professional always knows best. Definitely yes. And yet just who are the professionals in this field? Any telephone book may list pages of health care professionals but is unlikely to include a single rehabilitation engineer. Physical therapists, orthepedic therapists, and physicians do not commonly focus their expertise directly on rehabilitation equipment. Therefore, the "professionals" are likely to be a team: consumer, designer/engineer, and medical specialist, rather than a single individual.

Participants in design and engineering programs at universities, members of service organizations, and interested volunteers can all become valuable human resources to enlist in a grass roots rehabilitation design program. These people, aided by established professional and medical advice, can create an effective rehabilitation design team. Such ad hoc teams have created unique products that manufacturers have put into production and many others that are well worth sharing for duplication by other groups. What is needed is for more multidisciplinary teams to be formed and for greater information flow among these groups.

Neither the consumer nor the nonspecialist knows enough about adaptive equipment to really contribute anything significant. Mr. Jennings wasn't an expert when he built the wheelchairs with Mr. Everest, but the idea obviously had considerable merit. The consumers live with their needs and desires for a superior way of coping for 24 hours a day; the health care specialists, for only 8.

There seems to be too little formal effort devoted to insuring the continued success of the grass roots effort. Several hundred companies market at least some products specifically designed for the handicapped. However, most of these devices were adapted from outside the health care field or were modified versions of equipment originally devised by consumers or nonspecialists. Relatively few were initiated and developed purely for use as adaptive devices.

The grass roots design team can also develop lower cost alternatives to commercially available devices. For example, a set of walking parallel bars can be made from readily available automobile muffler pipe. One uses concentric diameter pipes, custom cut and bent at any muffler shop, and assembles them with removable pins to allow for adjustment or storage. The system can look quite elegant, is ridiculously simple, and (best of all) is inexpensive.

So why spend $250.00 or more for a commercially built set of bars if $50.00 worth of custom fabricated muffler pipe can be assembled to serve the same function? If users both knew of it and could use the grass roots muffler pipe solution as well as a commercial version, they could have $200.00 left to spend for other needed equipment. Unfortunately, most buyers don't know of many practical alternatives to the way it's always been done--spend all one has, hope it's right, and wish for more. The result is that the usually fixed or shrinking equipment budget goes further and, most importantly, more of the consumer's needs can be met. Surely there are scores of other grass root solutions to adaptive devices now in use waiting to be identified and popularized. The muffler pipe parallel system works particularly well when scaled for children.

Countless consumer products can be of unexpected benefit to the handicapped with very little or no modification. For example, if one were to describe an ideal mixing or feeding bowl for use by someone with poor motor skills, it would likely be a deep dish with an extremely stable base, would be unbreakable, etc. The description bears an astonishing resemblance to that of a dog feeding bowl. Obviously, some would find a "dog bowl" unacceptable for purely social reasons. If there are simply no other alternatives, especially for the price, the objection seems misplaced.

There is a continual flood of new consumer products. Rarely do any of them have simple provisions that could make them useful to the handicapped, the elderly, or anyone else not in the core of the mass market. By looking through any large department store catalog with an eye for creative uses of the products one is bound to find numerous possibilities well worth experimenting with.

Grass roots technology legitimately gives rise to the concerns of medical soundness, ethics, and safety of "amateur" devices. Wheelchair seating inserts, braces, and the like are not truly appropriate items for any purely grass roots operation. Communication systems, self-help aids, etc., generally do not have a medical impact; if they can be made to work safely, their appropriateness is easily established. The more people with experience who can be consulted on

any given project, the safer and more effective it is likely to be. If there is any doubt whatsoever, the physician in charge should be consulted. It is tempting to copy patented products whose price generally reflects not only a profit margin, but also research and development, liability insurance, and a service network. However, a healthy (profitable) commercial sector benefits the consumer and professional alike. Their territory should be respected, but not assumed to be without appropriate alternatives.

We can hope that the rehabilitation engineering profession will accept the responsibility of identifying and improving grass-roots-designed devices created outside of their ranks and then take a lesson from retailers in disseminating the information. This task is most applicable to custom or low-volume devices that are understandably of little interest to commercial suppliers. The need for more and better adaptive equipment is so great that there is room for competent efforts, including grass roots. The possibilities are enormous. Let's get on with it.

David J. Fylstra

Product Development for the Handicapped Community: A Dual-Purpose Telephone Terminal for the Deaf

Acknowledgements

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Introduction

Rehabilitation engineering has traditionally been beset by the difficulty of bringing a successful prototype to the commercial marketplace at an affordable price. This has been especially true when the target consumer is a private individual with limited financial resources. Rehabilitative products often appeal to limited markets that cannot provide sufficient volume to interest many manufacturers or to provide the economies of scale and hence the benefits of low price.

A solution to this predicament is to search for creative ways to "piggyback" the rehabilitative product upon an existing large-volume commercial market. It is something of an art to combine two perhaps conflicting target consumer focuses into a single product, and this strategy certainly is not applicable to every rehabilitative need. In some areas, though, a successful if compromising marriage of two markets can make the crucial difference in entering a rehabilitative product into the market at an affordable price.

The hand-held terminal, developed at SRI International (formerly the Stanford Research Institute) under a grant from the National Institute of Handicapped Research, exemplifies this strategy. The need for an ultraportable teletypewriter device (TDD) for deaf persons is consonant with the need for a portable data terminal in the data communications marketplace, if only certain

coding incompatibilities can be overcome. Moreover, advances in microelectronic technology make it possible to share, economically in a single device, the function needed by these two markets.

Background

The ability to communicate is surely becoming increasingly vital to successful independent living for the handicapped person, especially as he or she attempts to gain employment. Our society depends on ever more sophisticated ways to store, index, and communicate information, and many of them are inaccessible to the deaf individual. Probably the most frustrating aspect of this predicament is the stark uselessness of that ubiquitous instrument, the telephone. This places the deaf person in a role of dependence, for he must rely upon his relatives and friends to communicate over the telephone on his behalf, and then at an enormous sacrifice of privacy. Sometimes the only alternative is to journey across town just to communicate. His inability to call for aid renders him helpless in emergencies. In a society that takes the telephone skill for granted, 1.8 million deaf Americans[1] have until recently been unable to achieve their potential for education and employment.

Deaf telecommunications began in the early 1960's by building on the already well-advanced foundation of data communications developed for commercial purposes. A pioneering deaf engineer, Robert Weitbrecht, realized this technology's great potential for providing visual communication via the telephone medium. In 1964 Weitbrecht developed a modem (modulator-demodulator) and acoustic coupler[2] that could be used to transmit and receive digital signals through the direct-dial telephone network. By using surplus (hence very inexpensive) Baudot-coded teletypewriters in conjunction with this modem, deaf people could communicate with one another and with hearing people. A deaf person could hold a telephone conversation with a friend by typing messages on a teletypewriter, attached with an acoustic coupler to the telephone network, to another similarly equipped teletypewriter located in the friend's home or office. H. Latham Breunig and Jess M. Smith soon organized Teletypewriters for the Deaf, Inc. (TDI) for the purpose of acquiring and distributing teletypewriters among deaf persons, and the Deaf Teletypewriter Network quickly grew.[3]

For the network to grow it was essential that the signaling characteristics of the machines remain stable. But, because of that commitment, the Deaf Network began to deviate from the international standards of data telecommunications, which were already scrapping the older Baudot code in favor of the more flexible (but incompatible) American Standard Code for Information Interchange (ASCII).[4] The Deaf Network departed even further from the former norm in 1967 when the Bell 103 modem became a standard.[5] This more flexible format, designed specifically for data communications, enabled simultaneous transmission in both directions (full-duplex) by assigning two frequencies to the originator of a call and two other frequencies to the answerer of a call. In contrast, the modem developed by Weitbrecht was designed for half-duplex communications, in which the two parties take turns talking. This latter modem had already established its own standard among the deaf, whereby both parties shared the same pair of tones, using frequencies that were different from, and therefore incompatible with, the new Bell standard.

Thus the two communication systems became mutually unintelligible. The deaf system was using the obsolete Baudot character set with the Weitbrecht modem, while the standard U.S. system used the ASCII code with the Bell 103 modem. Deaf persons consequently became isolated from the rapidly growing world of computer communications, a situation that effectively precluded them from making use of new low-cost terminals, couplers, and automatic answering devices; it denied them access to computer systems and prevented them from interacting with many of the approximately four million ASCII terminals in use throughout the world today. Furthermore, this incompatibility made it

much more difficult to access such new and exciting personal communication media as electronic mail.

While the Teletype Models 15 and 28 were popular among deaf persons during the early years of the Deaf Network, their disadvantages were soon recognized. Several small manufacturers began to market semiportable teletypewriter devices based on modern solid-state technology, typified by the Micon MCM, the Krown Research Porta-Printer, and the Specialized Systems Inc. Porta-Tel. However, none of these devices could be carried on the person on an incidental basis. The deaf traveler still found the telephone system to be inaccessible.

To answer this need, SRI International in January 1976 began the development of an ultraportable hand-held terminal expressly designed for personal communication by deaf persons. First formulated as a conceptual sketch in July 1974, this device was envisioned as being small enough to fit into a pocket or purse and attachable to the handset of any standard Model 500 telephone. In September 1977 SRI was awarded a grant by the Rehabilitation Services Administration (RSA) of the U.S. Department of Health, Education, and Welfare (HEW) for development of a prototype terminal to demonstrate its practicability and evaluate its suitability as a telecommunication device for deaf persons.

This ultraportable terminal was to have all the essential ingredients for personal communications: a full alphanumeric keyboard consisting of calculator-style keys; a liquid-crystal display or a small printer; a modem and acoustic coupler for connection to the telephone network; and a line signal indicator to enable the caller to determine when his call has been answered. It was to be operable from virtually any telephone encountered in travel situations, such as coin and motel room phones, and hence would have to be battery-operated and self-contained. In conception this terminal was not meant to replace the Model 15 TTY or other nonportable terminals in common use, but rather to supplement them in travel and emergency situations.

A principal emphasis of this development was to design and construct a low-cost terminal that was fully compatible with the existing system of deaf communications, as well as with the international standards of data communications. We believed that both capabilities are needed to help bridge the gap during the inevitable transition of deaf communications from the Baudot to the ASCII system. But, more importantly, we foresaw the tremendous market potential of such a terminal in the area of data communications per se. It was our conviction that, by designing a terminal with standard capabilities, we could enable deaf persons to benefit from the substantial price reduction that would inevitably result from increasing utilization of a pocket-sized computer terminal in general data communications.

Development of the Terminal

Surely effective evaluation of a product by the ultimate user is vital to its success. It is difficult to ask a consumer his preference for a new product when he has never experienced one before, so the product has to exist in some form before it can be tested. Thus, the designer has to formulate and construct a prototype of the intended device based on interviews with users and an examination of existing products. Once the device has been constructed in breadboard or prototype form, it can be subjected to evaluation.

Ideally, the development of devices and systems for the handicapped is an interactive process of designing and testing. As a practical matter it is difficult to involve the end user at every design step. We thus adopted a three-stage plan for the development of the hand-held terminal. First, a flexible experimental prototype terminal would be designed and constructed; second, a variety of methods would be employed to evaluate the design; and third, a final design would synthesize the results of the technical and user evaluations.

First-generation Terminal

Our initial conception of the terminal was to reduce the parts cost through the use of standard, high-volume calculator technology. The result was a design approach that actually resembled a calculator mounted on the telephone handset. The user would hold the telephone handset and attached terminal with one hand while typing with the other hand. He would read the response on a liquid-crystal display or thermal printer. By using a small permanent magnet speaker the terminal could be coupled acoustically to the mouthpiece, while an inductive pickup could couple magnetically to the telephone earpiece. This packaging approach appeared to represent an ideal solution because it simplified manufacturing through the use of a single container and printed circuit board; it was completely self-contained; and it eliminated the environmental noises that often plague acoustically coupled modems.

Our design goals of battery operation, dual ASCII/Baudot as well as Bell 103/Weitbrecht compatibility, and easy modification of functions clearly mandated the use of a microprocessor-based system. A low-power Complementary Metal-Oxide Semiconductor (CMOS) microprocessor family by Intersil Corporation was selected, and software-intensive techniques were employed to provide many functions that would normally be performed by hardware circuits, thus reducing cost, volume, and total power consumption. The use of the microprocessor also made it simple to modify the terminal's behavior on an experimental basis.

Ten months of intensive effort culminated in the successful construction of four prototype hand-held terminals. Two made use of a 3-line, 36-character liquid-crystal display, while the other two terminals employed a 16-character-wide thermal printer. A switch-selectable Bell 103/Weitbrecht modem was constructed on a 4-inch-square printed circuit board and standard ASCII and Baudot transmission formats were provided in software. While the resulting device was somewhat bulky (approximately 4 by 7 by 1.5 inches, weighing 24 ounces), it nonetheless demonstrated unequivocally the practicality of the hand-held terminal.

Evaluation

A key to successful evaluation of a new product like the hand-held terminal is to search for ways to increase the audience of evaluators. The best evaluation is one based on an in-depth, personal interaction between the designer and the experienced user of the new product, but this is a costly process. While we relied most heavily on the comments of seven deaf individuals, each of whom used the terminal daily for several weeks, we employed a variety of other methods to expand the evaluation.

A detailed user's manual, with numerous illustrations and instructions, was written and distributed widely. This enabled us to seek the advice of experienced deaf teletypewriter users without regard for geographic limitations. Several people responded with handwritten critical appraisals based on what they had read in the manual.

Demonstrations also enabled us to expose the terminal to a much wider audience. In all, perhaps a thousand people in the U.S. and Europe have seen the terminal, and quite a few have used it personally, if only briefly. While this kind of feedback is admittedly based on first impressions, it offers the opportunity to observe the naive user during his first critical moments in learning to use a new tool.

The results of this evaluation were surprising. Probably the most critical design problem was that the packaging approach forced the user to support the terminal and telephone handset in one hand for the duration of a phone call, causing a significant fatiguing in the person's arm. Furthermore, the small

keyboard represented a severe bottleneck by slowing the user's typing rate. Finally, a technical problem with the magnetic pickup caused the terminal to be incompatible with certain low-leakage telephone handsets.

On the other hand, a number of design features proved to be very popular. For example, the decision to combine all functions (except the battery recharger) into a single, self-contained device made it impossible to lose any vital components. Likewise, the printer was found to be useful for recording important details and easing the strain of following a conversation, although the more technically astute among the evaluators suggested that it be sacrificed in order to gain a longer battery life between overnight rechargings.

Second-generation Terminal

Clearly a new design of the terminal was needed to solve the fundamental packaging problems while preserving the successes in the electronics and software. We expended a significant effort during the second year in exploring several possible packaging approaches. A valuable evaluating technique during this stage was to rough-cut a block of wood into the shape of a candidate case and elicit reactions from people.

Ultimately a new approach was adopted that resembled a hand-held language translator. The package became table-top operable, thus freeing the supporting hand and doubling the typing speed at the same time. This was made possible by mounting the telephone handset on the rear surface of the case; the magnetic coupling technique was eliminated in favor of a hearing-aid microphone, thus solving the compatibility problem with certain telephones. It is interesting to note that the use of gracefully curving edges and pastel colors in the case seems to make such a device much more attractive and delicate to the user.

With this new approach, a second design effort was undertaken. We placed heavy emphasis on eliminating parts and reducing the total manufacturing cost. In addition, we constructed molds to cast a two-piece epoxy plastic case which closely resembles the final case a manufacturer might employ. The final phase of hand-held terminal development culminated in the construction of five prototype terminals.

During the last several months these second-generation terminals have undergone an in-depth evaluation by hearing-, speech-, and mobility-impaired employees and clients of the Community Services Department in San Bernardino, California, with positive results. Most of the problems that have arisen represent the difference between an experimental prototype and a commercially manufactured product.

Conclusions

In retrospect it seems clear that product development for the handicapped must be an interactive process, and that the ultimate user must be involved as early in the initial design as possible. It is not unreasonable to ask that handicapped persons themselves participate in the design process. The art of evaluation relies upon a creative search for ways to make a candidate solution real, if only in mock-up form, so that it can be tested immediately.

If the ultimate user should be involved at an early stage, it is equally vital that the manufacturer be involved as well. The step from a prototype to mass production is indeed a long one. The manufacturer must interactively advise the designer on issues such as parts supply and selection, the limits of tolerances in product line tooling, and methods for ensuring high reliability.

The hand-held terminal project is now in the final stage of seeking a firm agreement with a manufacturer to mass-produce the terminal. We anticipate that it will enjoy a significant market because of its potential usefulness to the

data communications industry, as described earlier. It is our hope that the deaf consumer will be the ultimate beneficiary of this process, by virtue of having access to telephones everywhere at a low cost.

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Larry Leifer

High Technology, by Design, for the Handicapped

The typical consumer of assistive technology is illustrated as one who is affected by the output of a research and development process over which he or she has no influence. The individual does not participate in the specification of goals or in the allocation of resources to attain objectives. Available expertise as a consumer is not utilized. This lack of influence is not unique in our society. It is, however, a particularly wasteful procedure where resources are severely limited relative to the magnitude of the problem. Metaphorically, the consumer in this case is like a passenger in the back of a moving pickup truck, who does not know where the vehicle is going and cannot communicate any desires regarding the goal or the way to get there.

Consumer Involvement

The input-process-output model illustrated in Figure 1 does have self-correcting feedback loops that can and should involve disabled consumers. The most accessible control path is supervisory (Figure 2). Here the individual need not understand the details of a technology or research methodology to participate in the setting and monitoring of objectives. It is important that people in the supervisory control loop understand the research and development process itself. Not understanding would be equivalent to giving directions to the driver of a vehicle without knowing anything about the characteristics and capabilities of that vehicle.

It is possible and desirable for disabled individuals to become members of the technical research and development professions. In such roles they become part of the inner control loop illustrated in Figure 3. Here their expertise and experience with physical disability may become an intimate part of the assistive device development process. As members of a design development team, their experience and example can provide other team members with daily exposure to the issues that will ultimately determine the technical and market success of their product. The disabled individual can be in the driver's seat.

Not every disabled person need or should endeavor to labor directly on behalf of disabled colleagues. This can no more be the case than that all of us should formally train to be doctors, plumbers, engineers, and musicians. My point is simply that it is possible and desirable that those members of the disabled community who have a taste and talent for science and technology should be encouraged to pursue a productive role in this area. And, all of us should endeavor to understand the process that develops our assistive devices.

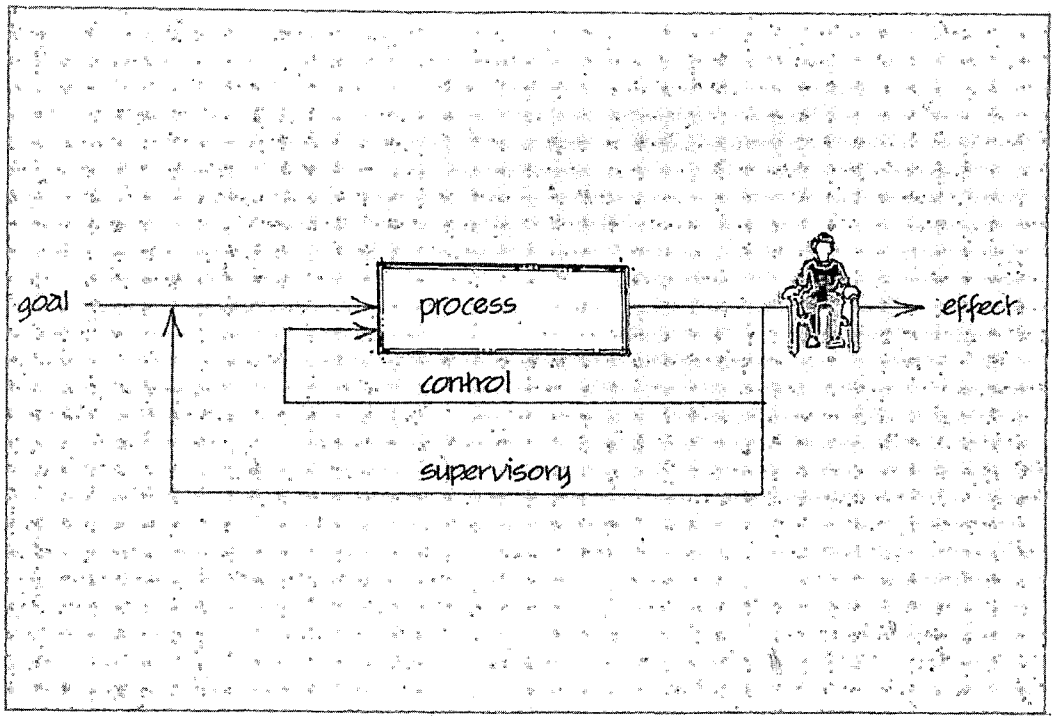


Figure 1. The disabled consumer is pictured here as the passive recipient of a rehabilitative device development process over which he or she has no control. There are three input channels to the design/development process. The first specifies the GOAL and allocates resources to achieve it. A second, SUPERVISORY feedback, channel compares the output of the process with the intended goal. The third channel, direct feedback CONTROL, provides corrective technical feedback to make the output match the objective.

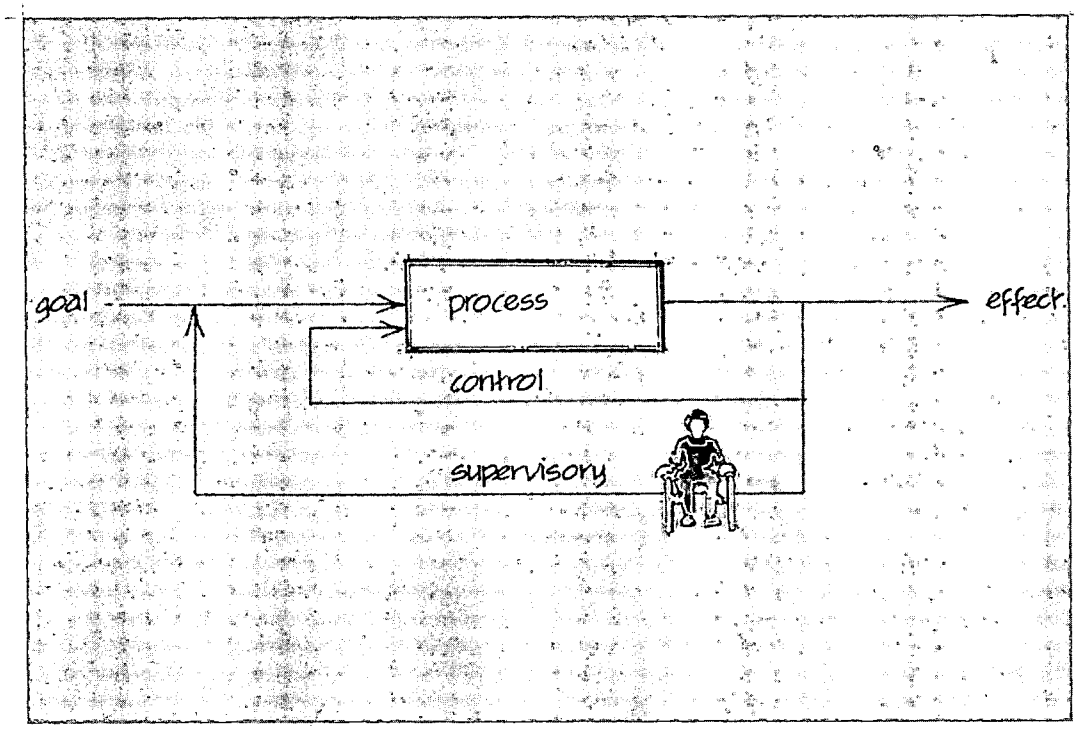


Figure 2. Through familiarity with research, design, and development processes, the disabled user can constructively participate in the SUPERVISORY control loop. Detailed knowledge of the technology being applied is not essential. Experience with the disability being addressed is highly desirable.

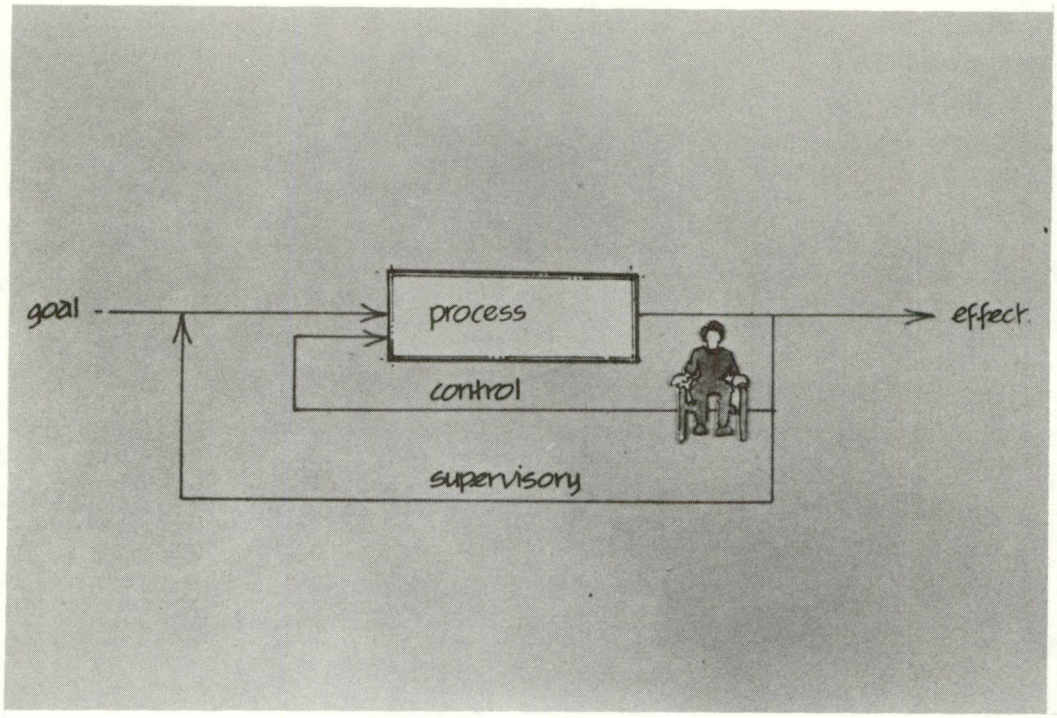


Figure 3. The user is in direct technical CONTROL when he or she is a member of the design/development team and a member of the disability group addressed by the assistive device.

Understanding Research and Development

The research and development process may be likened to an onion in which the fundamental studies lie at the center. Applied research, design, development, production, marketing, and maintenance lie in succeeding layers, which are usually differentiable in terms of their input, output, and manner of operation. Information should always flow between and through adjacent layers. Outer layers of the onion occupy more space, require more energy, and take longer to develop than do central layers. Ideas are the essence of inner ring activity. Time is the essence of outer ring activity. The closer one comes to having a complete, tested, and marketable product, the more it costs. Because research and development are inexpensive relative to production, it is wise to invest realistically in the idea phase of product development. A bad product brought to market is surely the worst case. Though a rehabilitative device may be conceived at any level in the hierarchy, project costs will generally be minimized and understanding maximized when the project is undertaken and understood from the core.

Success is the right product at the right time and at the right price for the market. Wisdom lies in achieving this by design, not by luck.

Not all good ideas are good products. In fact, as few as 3 percent of the ideas that are prototyped will ever be produced commercially. This hard reality is due to many factors. Foremost among these factors is cost; not just the cost to manufacture, but the cost to market, distribute, and service. Costs other than manufacturing typically determine final product cost in the "medical specialties" market in which rehabilitation products are often categorized. This is especially the case when extensive product evaluation and safety testing must take place before sales income can be used to offset development costs. When product development must be paid for by capital investment, capitalization costs will drive final product cost further from the manufacturing cost baseline.

Increased production quantity is often the key to net product cost reduction. Accordingly, rehabilitation products should be conceived and designed to address the largest possible consumer constituency. To achieve this end, one must keep in mind that all of us came into the world with great potential and near total disability. There is a high probability that we shall experience a period of serious disability during our commercially productive life times. And it is virtually assured that as aging individuals we shall experience greatly reduced flexibility and reserve relative to our peak years. These alternate user populations can give the designer a larger market if they are willing to fully explore the opportunity. In this context we all have disability expertise and a vested interest in the development and commercial availability of the best possible assistive devices, which are, after all, tools.

Robotic Manipulation Aids

It has been hypothesized that electromechanical manipulators can be used by severely disabled individuals to regain functional control of their personal space. Functional control is meant to include the activities of daily living and one's own clerical and vocational tasks. Benefits are predicted in relation to self-esteem, and to personal and financial independence. This approach is based on the premise that a single general-purpose system will better serve the disabled individual than a collection of special-purpose devices.

Technical feasibility is predicated on the recent and rapid evolution of microcomputer-controlled manipulators for industry. Though initial development of such systems is too expensive for rehabilitative engineering resources, it is important to ensure that technology transfer into rehabilitation is done while the industrial development team is available for consultation. Then, the rehabilitation team will be free to focus upon the critical and difficult issue of human-machine integration.



Figure 4. Patients and staff from the Spinal Cord Injury Service at the Veterans Administration Medical Center in Palo Alto as seen during the pretesting demonstration of a laboratory model industrial manipulator.



Figure 5. The User-Robot-Environment triad illustrates that the robot (manipulative aid) is intended to give the user physical control over an environment which is otherwise only subject to wishful thinking. Direct user-environment interaction is replaced by a two-stage path. Through a command and control link the robot will manipulate the environment according to the user's wishes.

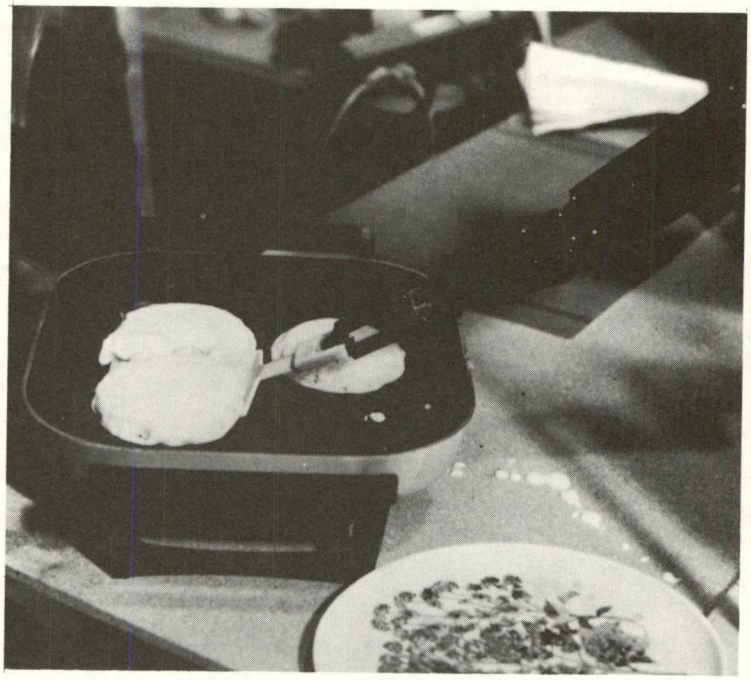


Figure 6. The "World's First One-Armed Robotic Cake Baking Contest" was held to assess the feasibility of using a microcomputer programmed electro-mechanical manipulator to perform domestic functions. In this scene the manipulator is about to successfully flip a pancake. The contestants were sophomore engineering students at Stanford University. Fifteen groups of three students each were given two weeks to program the manipulator to mix, bake and serve a cake in five minutes. None of the students had had any relevant prior experience.

How shall we judge the efficacy of human-machine systems that are built to test the hypothesis? When and how do the prospective users of such devices (Figure 4) participate in the design and development process?

First, we must understand the human-robot-environment triad as a performance-constrained system (Figure 5). The user is completely cut off from physical interaction with his or her personal environment. Computer-controlled electromechanical manipulators (robots) have been developed to interact physically with that environment on behalf of the user. The timing, format, and quality of this interaction will be an expression of the user's personal style filtered through the machine's technical performance specifications. The manner in which the user commands and controls a robotic servant will be an important determinant of the overall effectiveness of this triadic relationship as a productive and socially acceptable partnership. It is clear that prospective users can and should be consulted regarding the desirability of such an assistive device. Ideally this would take place prior to any large investment of resources in the project. This was done, but the results were fuzzy because it was very difficult to visualize the personal experience of working with such a machine. It seemed good, but was it really feasible?

Prior to preparing a project-funding application, we used an early laboratory version of the manipulator with 45 sophomore engineering students at Stanford University to hold the "World's First One-Armed Robotic Cake Baking Contest". As the task was an activity of "daily living", student success or failure would be an indication of larger project's feasibility. The contest was a great, if sometimes messy, success (Figure 6). However, it was still unclear that the robot could be used with sufficient subtlety to be acceptable in one's living space. To examine this issue, a contest was held the following year in which students were assigned the task of programming the manipulator to "Serve a Meal in the Manner of a Three Star Restaurant". Again the contest was successful, entertaining and educational (Figure 7). These contests provided us with visual examples of the robot at work. It was now possible to reassess the desirability of a rehabilitative manipulator by interviewing candidate users in the Spinal Cord Injury Service of the Veterans Administration Medical Center in Palo Alto. The results were now positive and unequivocal, in part because an effort had been made to facilitate the prospective user's participation in the project.

In the pickup truck metaphor used earlier, the user has been brought into the cockpit and an effort made to clean the windshield. The user begins to function in a supervisory role.

The manipulative aid project is now under way, and the next phase of consumer involvement depends on the user's obtaining a general understanding of the man-machine system under construction. A block diagram of the system is presented in Figure 8. The diagram is intended to show the major logic components of the system and how their functions interconnect. The manipulative aid itself is shown photographically in Figure 9 and labeled schematically in Figure 10. This system was assembled during the summer of 1980. Computer programs will be written during subsequent months to control interaction between various elements of the system and the user.

User involvement in the inner loop of the control process (Figure 3) is planned to occur in two ways. In the predominant case, a variety of candidate users will be trained to operate the system. Development of a training program is now under way. It proves to be a major task in that using the robotic aid is something of a cross between flying an airplane, programming a computer, and talking to a rather hard of hearing friend. Here the disabled user will truly occupy the driver's seat during the development process. For, as in the development of a new aircraft, the design engineer is rarely the test pilot (there is very little chance that any form of bodily harm can befall a robotic aid user).

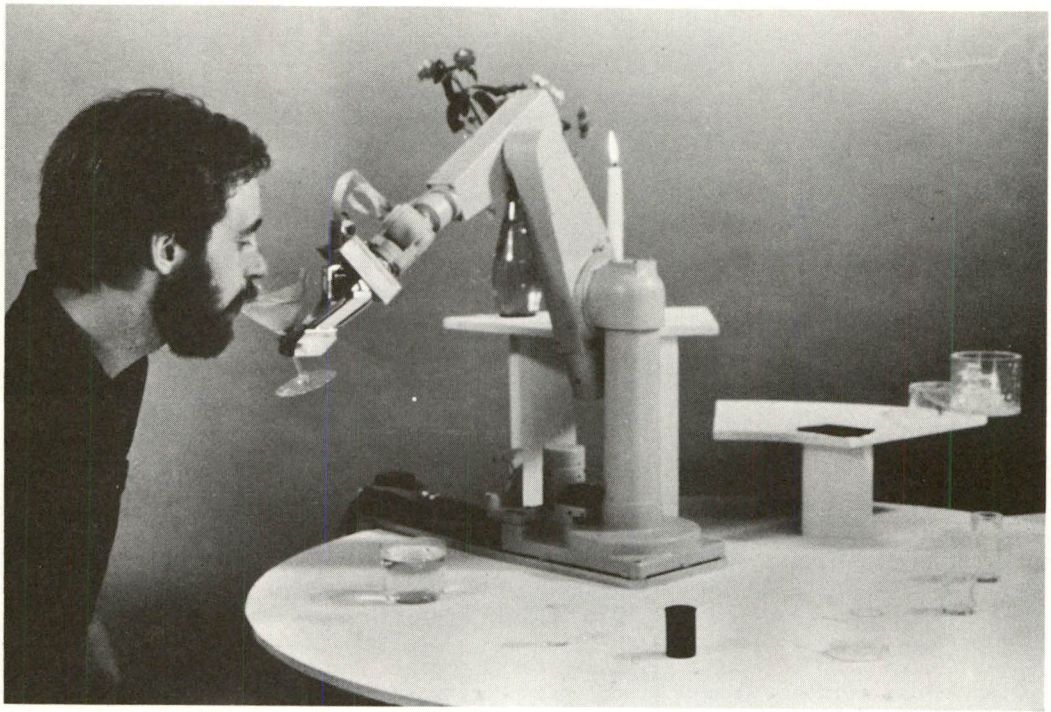


Figure 7. A second contest was held to determine if the manipulator could be used to "Serve a Meal in the Manner of a Three Star Restaurant." The student group which mixed and served a martini with hors d'oeuvres was, by popular acclaim, most successful.

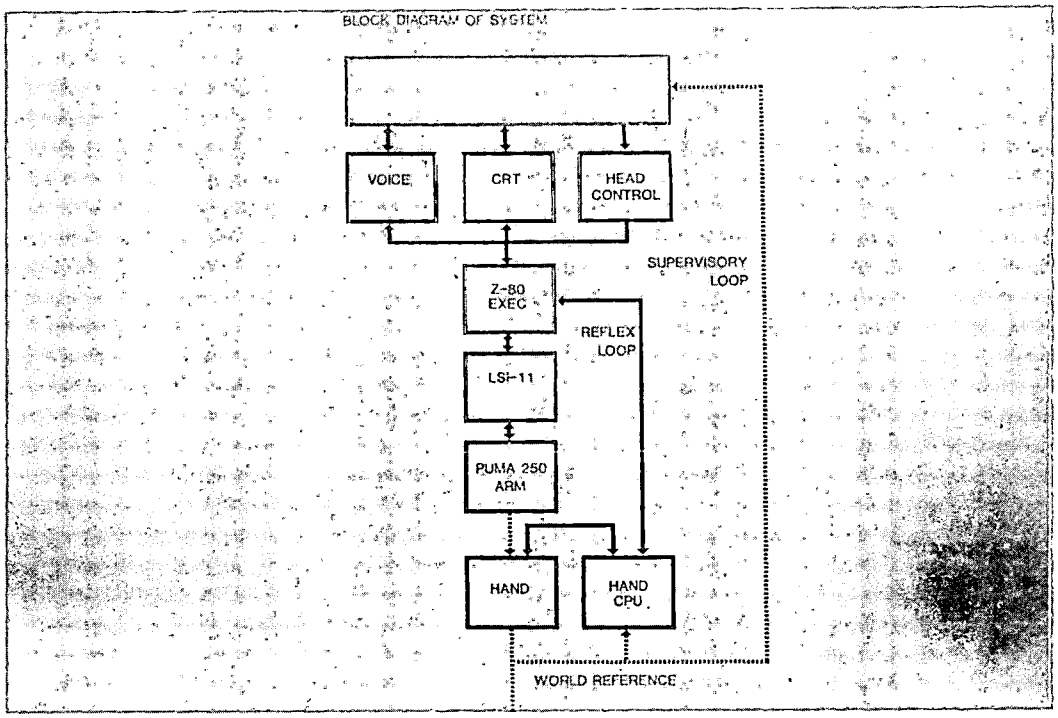


Figure 8. A block diagram of the Robotic Aid shows the logical relationship between major elements in the system. The USER is in the top block to command and control the manipulator. VOICE commands are recognized to tell the system what to do. Confirmation and warning messages are conveyed back to the user by computer synthesized voice. The CRT (cathode ray tube) display is used to advise the user about various aspects of the system's performance. The HEAD CONTROL unit allows the user to control motion of the hand in much the same sense as one would fly a radio controlled model airplane. The Z-80 EXECUTIVE is a microcomputer used to integrate the function of other computers in the system. The LSI-11 is a microcomputer dedicated to controlling the electromechanical ARM (PUMA-250). A sensate HAND is under development to allow the arm to "feel" objects in its environment. The "HAND CPU" is a microcomputer dedicated to controlling hand motion and interpreting sensations felt by the hand. In the REFLEX LOOP hand sensations are used to control motion of the arm without user intervention. In the SUPERVISORY LOOP the user ensures that his or her commands are being performed correctly by the manipulator.

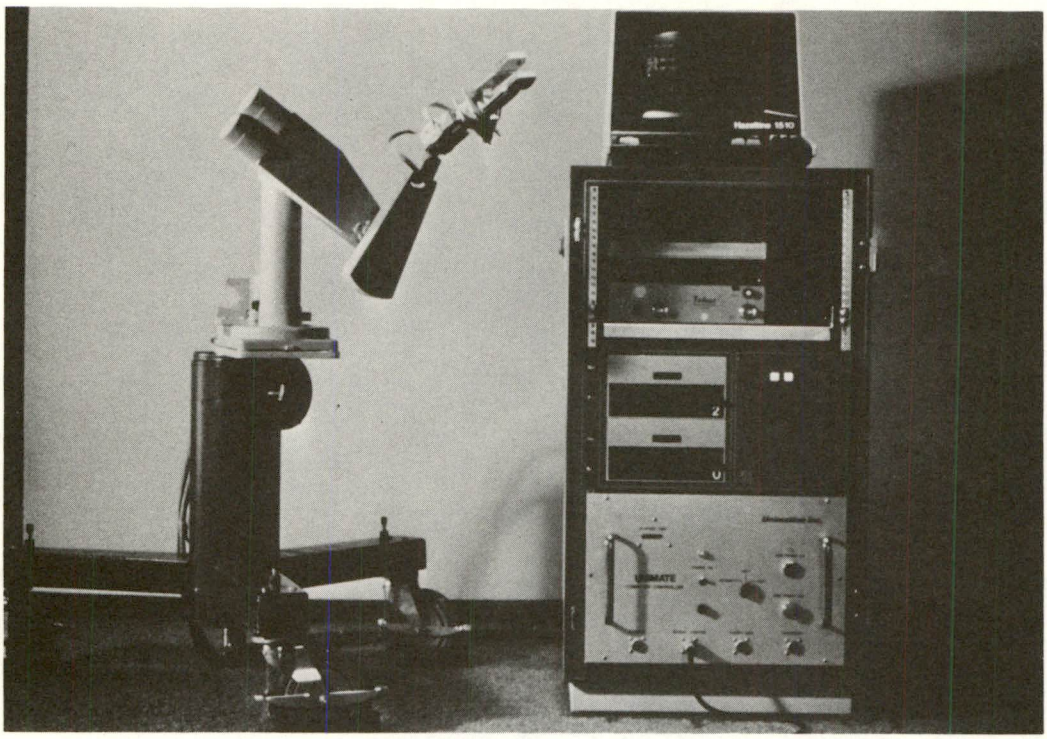


Figure 9. A photograph of the assembled Robotic Aid as of September 1980. At this time no attempt has been made to miniaturize the electronics, which are expected to fit below the arm on its mobile platform.

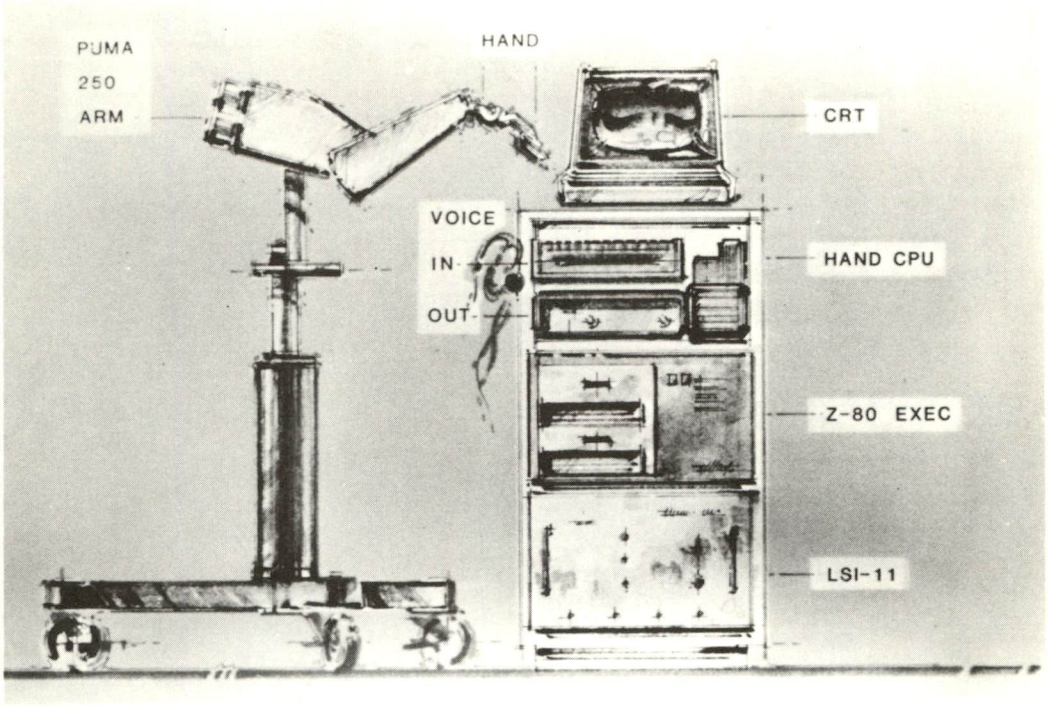


Figure 10. A schematic equivalent to the photograph in Figure 7 used to identify various elements of the Robotic Aid.

A disabled design engineer is being recruited to participate in technical evaluation of the human-machine system. In this role our objective to involve disabled individuals in project initiation, performance, and evaluation will be operational.

Summary

While it is easy to say that disabled individuals should be involved in the design and development of assistive devices, it requires an explicit effort by technical, medical, and user groups to make it happen. In this effort, research, design, and development processes need to be understood to assure that the results of our labor are useful products, not promises. And, just as we know that the disabled are individuals, we must realize that technology transfer into rehabilitation is done by individuals. Technology is not something one buys by the carton. It is people, skilled people, motivated to work on rehabilitation problems.

Barry Leshowitz

The Infrared Hearing Aid

The major limitation of the partially hearing listener with sensorineural hearing damage is the inability to understand speech, especially when heard in a background of competing sounds. The listener often reports hearing the speech, but it sounds muffled and garbled. This perceptual deficit has long been recognized by physicians and audiologists, but not until recently have there been attempts to describe in detail the properties of the auditory deficit.

Responding to a question about the seriousness of his patient's hearing loss, one physician described his patient's sensorineural hearing problem this way:

> I'd say his hearing loss is moderate. It's more noticeable on the right side than on the left. It might make communication in a crowded room more difficult. During social gatherings, anyone with a hearing loss has more difficulty because of all the background noise. Similarly, at a press conference, if a lot of people were stirring around and making noise, it would be difficult to hear questions.

The description was provided by Dr. John Reynolds in an interview published in *U.S. News and World Report* on the health of his patient, President Ronald Reagan.

The Conventional Hearing Aid

The description of President Reagan's hearing difficulty is consistent with the observation that President Reagan does not use a conventional hearing aid. It is well known that under conditions of background noise, the conventional personal hearing aid often fails to improve speech reception. Since the hearing aid provides indiscriminate amplification of both speech and noise, the clarity of the partially masked speech is not improved by the prosthetic. Listeners often turn off the device in these noisy situations and may totally reject the hearing aid on the basis of these experiences.

Forty years ago when the electronic hearing aid was first introduced, it was thought that it would help the hearing impaired as much as eyeglasses helped the visually impaired. Unfortunately, hearing aids, which have never been altered in basic design since their inception, have never lived up to these optimistic expectations.

Although in most cases of hearing loss the only possibility of assistance is a hearing aid, less than 15 percent of persons in the potential market ever purchase an aid; still fewer use the aid on a regular basis. The hearing aid's poor acceptance is attributable mainly to its limited usefulness. It is only in those moments of near total quiet that amplification performs a useful function. In most everyday situations ordinary background noise is present, and the hearing aid is inadequate.

The Close-talking Microphone Hearing System

If aided speech reception is to be improved significantly, the speech signal must be selectively amplified; alternatively, the background interference must be suppressed. A straightforward approach is simply to detach the microphone from the hearing aid and give it to the speaker. With this arrangement, the auditory message from the speaker is sent directly to the listener without the loss of level that accompanies propagation of sound in space. Selectively amplifying the speech signal in this way is equivalent to suppressing the interfering background noise. Providing a hard-wire connection between speaker and listener is believed to be totally impractical and therefore has never been seriously considered.

The benefits of close-talking microphone systems have long been demonstrated in educational settings. Auditory training units utilizing hard-wire or radio links to the student's hearing aid have served as the basic communication system in schools for the deaf for many years. What is not generally appreciated is that this proven approach to improving the clarity of the speech message would be useful to a much broader class of impaired listeners. In everyday noise, listeners with moderate or even mild hearing loss are often every bit as incapacitated as listeners with severe hearing loss.

The Infrared Hearing Aid

Recognizing the inherent shortcomings of the conventional hearing aid, I have developed a new approach to the design of the personal hearing aid. Borrowing from recent breakthroughs in light transmission communication, I have developed the infrared (IR) light transmission hearing aid (see Figure 1). The IR aid transmits the message not as an acoustic wave, but as an infrared light beam. With this system, a "hard wire" provided by the invisible light beam carries the signal directly from the speaker to the listener. The net effect of light transmission is to suppress the unwanted background noise and acoustical reverberation that destroy speech intelligibility.

The IR aid consists of two components: (1) a transmitter given to the speaker, and (2) a receiver given to the listener. In the transmitter, the sound is first transformed into an electrical signal by the microphone. The electrical signal is then used to modulate an invisible IR light beam produced by the light-emitting diodes (LEDs). The LEDs are mounted so that the light signal is emitted in all directions, permitting reception of the signals from any position in the room. Thus, the listener does not have to be seated directly in front of the transmitter. The modulated light beam containing the auditory message is then received by the listener's receiver, where it is converted back into an electrical signal, which is amplified and used to drive the listener's earpiece.

Evaluation of the IR Hearing Aid

Measurement of Speech Intelligibility

The effectiveness of the IR hearing aid was assessed by comparing its performance to the conventional personal hearing aid on a sample of 119 hearing aid users. Under standard conditions of hearing aid evaluation, word discrimination was measured with the listener's personal hearing aid and the "off-the-shelf" IR prototype.

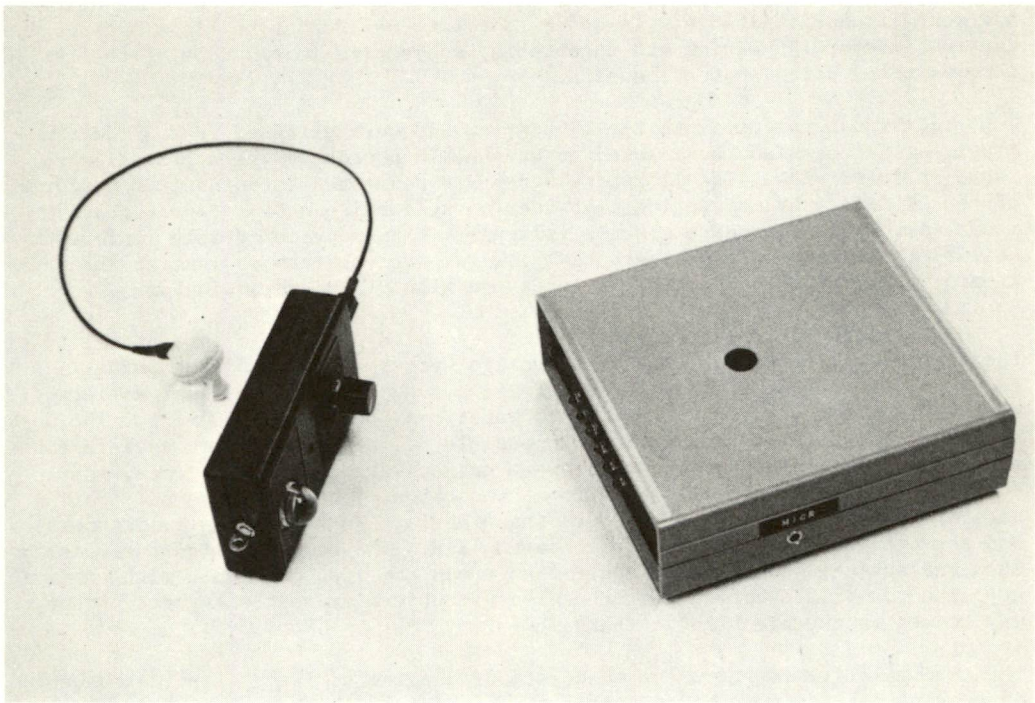


Figure 1. Infrared hearing aid consisting of portable transmitter and receiver (with earpiece).

The results showed a clear superiority of the IR device over the personal hearing aid under everyday noisy conditions. In the quiet, speech discrimination scores using the IR aid were almost identical to scores obtained with the personal aid, but in moderate noise (55 dBA) there was, on the average, a 55 percent improvement in speech discrimination with the IR aid over the personal hearing aid. Moreover, it was observed that using the IR aid the speech source could be reduced in level by 15 dB and still maintain the performance achieved with the personal aid. These results constitute empirical confirmation of the IR's capacity to enhance significantly the clarity of the signal under noisy conditions encountered in many typical listening situations.

Measurement of Acceptability of the IR Hearing Aid

Although the above findings demonstrate the high quality of speech transmission delivered by the IR hearing aid, they do not bear directly on the bottom line, namely, acceptability of the IR hearing aid. In other words, we have no assurance that impaired listeners would use the more cumbersome two-component IR hearing aid were it made available. In order to determine whether hearing-impaired listeners find the IR hearing aid acceptable, subjective impressions of the IR aid were examined using a questionnaire.

Individual reactions to the IR hearing aid were elicited from 17 hearing-impaired listeners who were asked to use the IR prototype while listening to radio or television. The listeners were then requested to assess the performance of the IR device by completing a 15-item questionnaire. Some representative items on the questionnaire are the following: This device greatly improved my ability to understand the speech on TV; I was not embarrassed wearing this type of aid; noise in the room did not interfere with my understanding of TV.

The results of the preliminary study revealed substantial acceptability of the device. All items on the questionnaire were positively poled so that a score of 5 represented greatest satisfaction and a score of 0 least satisfaction. There were a total of 227 responses to questions about the IR device. The mean score per question was 4.3 (out of a possible 5), indicating high satisfaction and acceptability. A few questions were not answered by all subjects, most notably those questions dealing with a comparison with other personal hearing aids. These questions may have been inappropriate in that not all listeners had had previous experience with a hearing aid. The only question for which more than one subject gave a score lower than 4 was the item concerned with cosmetic appearance. This suggests that the greatest objection to the current prototype may be its inconvenient and cumbersome form.

The majority of responses to questions dealing strictly with improvement in hearing ability were given scores of 5. It is felt that this study clearly demonstrates a need as well as potential acceptability of the IR hearing aid.

Alternative Technologies To Improve Hearing Aid Performance

Directional Microphones

From an analysis of the nature of the perceptual deficit characterizing hearing loss and the acoustical environment experienced by the impaired listener, it appears that the effectiveness of an auditory prosthetic is related to its selective amplification capabilities. This requirement has not gone unnoticed by hearing aid manufacturers who have added microphones with directional pick-ups in an effort to reduce unwanted noise. Unfortunately, in an effort to maintain the hearing aid's cosmetic appearance, the addition of these "noise suppression" microphones has not been successful.

While various sophisticated approaches to enhancing the desired signal through digital signal-processing techniques are actively being pursued, this work is probably years away from practical application. Under the present state

of technology, the only feasible method of significantly enhancing the quality of the speech signal is to employ a close-talking microphone system. Of the available close-talking systems we have examined, IR light transmission is, we feel, the system of choice.

Radio Broadcast Systems

In order to understand the basis for our preference for IR, it may be helpful to compare IR technology with its principal competitor, namely, the FM radio broadcast system. The principal advantages of employing a radio wave link in the close-talking microphone system are the reduction in battery consumption and the nondirectionality of the broadcast beam. It is out of the following practical considerations that, I believe, IR light technology is the preferred medium for implementing a close-talking microphone hearing aid.

Ensured Privacy. With IR light confined by any opaque partition, there can be multiple users on the same premises, as in a nursing home. Radio waves, on the other hand, even for low-powered devices, radiate more than 100 feet. This would be intolerable for many institutional conditions. Also, with radio transmission, intrusion from other high power sources such as CB radios and police broadcasts could not be avoided, especially in large cities.

Enhanced Flexibility. It is anticipated that, in time, the totally portable IR system will be used in personal as well as institutional settings, for example, by hard-of-hearing children in school and at home. With the standardized IR system, the listener's receiver could also be used in a theater, where a large permanently installed transmitter would provide the source of IR sound. Several major institutions, including the Kennedy Center in Washington and several Broadway theaters, have chosen IR sound systems to reinforce existing public address systems to assist the hard of hearing.

In radio transmission, transmitter power and frequency band would have to be carefully adjusted to accommodate other potential (and often unknown) users in the vicinity.

Price. The projected retail price of the IR hearing aid is competitive with the conventional personal hearing aid and is less than one-third the price of commercially available radio-link auditory trainers. Considerations of commercialization suggest that IR technology is the more affordable.

Federal Regulations. Licensing by the Federal Communications Commission (FCC) of very scarce radio frequencies would be a major impediment to installation of large radio transmitters. In many countries in Europe, there are no radio frequencies available for auditory training devices. In contrast, IR lightwave communication systems are not subject to any federal regulations.

Induction Loop Amplification

Induction loop systems have even a longer history of use than radio systems as close-talking microphone systems in schools for the deaf. In the induction loop system, a loop of wire or antenna connected to an audio amplifier generates a magnetic field, which is modulated by the acoustic input. The major advantage of this system is that the listener's own hearing aid equipped with a telephone connection is used to pick up the transmitted signal. Many institutions and individuals who have installed portable induction loops for home use report success. However, there are technical problems encountered with the loop system, namely, (1) spillover between rooms, (2) constancy in signal strength throughout the room, (3) interference from other magnetic sources, and (4) low fidelity of acoustic output.

Again, it is principally out of practical considerations that, I feel, an IR link is the system of choice vis-a-vis induction loop amplification. The

prime disadvantages of the induction loop system include (1) limited mobility, since large loops in theaters require permanent installation and even smaller portable loops cannot be carried in purse or pocket; (2) most hearing aids are not equipped with the required telephone connection; (3) many elderly hard of hearing do not own hearing aids at all, and (4) telephone connections in hearing aids are often unreliable and usually have different acoustical properties from the aid's microphone input.

Experience suggests that increasing auditory accessibility for the hard of hearing requires appreciable public support. A sensible strategy, it seems to me, is to combine the forces of the hearing impaired and the elderly. IR technology appears to be adaptable to the needs of the greatest number of people in the community and suffers from the fewest encumbrances. It therefore has the best chance of acceptance throughout the community.

Marketing the IR Hearing Aid

The IR hearing aid certainly appears to be a potential solution to many of the hearing problems faced by millions of hard-of-hearing consumers. With the device, such activities as personal conversation, watching TV, attending a lecture, or seeing a play would be facilitated to a degree never believed possible. Many of life's most valued activities could be made available to the vast majority of the 15 million hard-of-hearing Americans who are presently denied access to those activities.

But is there a market for such a device? The only way to determine whether any product is acceptable to the general public is to attempt to commercialize the product. Profits gained from sale of the device provide the definitive answer to the fundamental question. Thus, in an effort to bring the device to the marketplace, a private business, Audio Devices, Inc., was established, and the scientist-inventor was transformed into a business entrepreneur.

Preparation of the Business Plan

The commercialization process begins with preparation of the business plan. The principal purpose of the plan is to attract the financial commitment of venture capitalists. Before risking their money, investors insist that the entrepreneur thoughtfully prepare a plan that considers

- the company's activities and management capabilities
- distinguishing features of the product
- attractiveness of the market
- financial projections
- amount and kind of start-up capital

Not only is the plan important for the investors, it also serves a useful function for the entrepreneur. Preparation of the plan forces one to think carefully through all facets of business, including marketing, operating, and financial resources required. Often the seemingly inevitable costly mistakes of trial-and-error operation can be averted by preparing a written plan before start-up.

Market Analysis

The cornerstone of a business plan is the section describing the market for the product and setting forth the argument that targeted sales can be achieved in the face of present and future competition. Not only are sales forecasts and anticipated profits closely related to the market analysis, the

latter determines working strategies relating to marketing and advertising campaigns, size of the work force, inventory levels, and financing requirements.

Assessing the IR Hearing Aid Market

The Elderly. The majority of the 25 million Americans over 65 are hard of hearing. A hearing difficulty, often either undetected or ignored, may force the individual to alter his or her lifestyle. Such everyday activities as enjoying coffee with a friend, playing bingo, watching TV, going to church, and attending the theater are precluded by what may appear to be a mild hearing loss.

The manifestations of hearing loss are particularly graphic in nursing homes, where, as a result of advancing age, almost 90 percent of the residents are incapacitated to a significant degree by a hearing difficulty. One elderly resident observed the devastation as follows: "It's like watching TV with the sound turned off--people are there but they don't touch you or hear you." Yet rarely do we observe residents of a nursing home wearing hearing aids.

That installation of an IR hearing system can make a major difference was demonstrated in a project directed at changing the auditory environment of residents of a nursing home in Mesa, Arizona. A public address reinforcement system consisting of an IR transmitter and several receivers was installed by Audio Devices in the home's recreation room, where all the social and group activities are held. Residents who had not taken part in the home's program and residents who received only marginal enjoyment from the various programs began to fully enjoy church services, lectures, bingo, and slide shows at levels they had not experienced in years. The home's director viewed the change this way: "You can see the change in the attitude throughout the home. Now if they fall asleep, I know they are physically ill."

Children. For adults who develop hearing loss later in life, communication and intellectual capabilities remain intact. However, for a child born with a hearing impairment, these skills never develop normally. The congenitally hard-of-hearing child who cannot hear speech clearly probably will never learn to speak normally. With deficient language skills, conceptual development will be severely restricted. Since the critical period for language development is between 3 and 5 years of age, unless the hearing impairment is diagnosed early and treated effectively, the child will be permanently deficient in cognitive skills.

Unfortunately, even when the child's hearing loss is detected and a conventional hearing aid prescribed, only marginal assistance is obtained. Especially in the classroom, where the room acoustics are notoriously poor, no matter how hard the partially hearing child tries to "filter" out the background noise, he or she simply cannot understand the teacher's speech. No matter how hard the child tries, the TV's sound track seems "too fast" to follow. These negative experiences often lead to complete rejection of the hearing aid.

An IR hearing aid could make a major difference in the rehabilitation of the hard-of-hearing child. The value of close-talking auditory training units has long been known in resident schools for the severely deaf. The benefits of this system for the moderately hard-of-hearing child would be every bit as dramatic, especially when combined with a program of auditory training at home.

Overcoming Shortcomings. Using present technology, there is no possibility of developing "auditory eyeglasses" capable of reinstating normal auditory function to the hearing impaired. Hard-of-hearing listeners will have to settle for something less than the "complete fix". Test results show that the IR hearing aid does offer major benefits to the vast majority of the hard of hearing who wish to take part in many of life's most important activities. Indeed, in situations where the source of sound is fixed, installation of an IR transmitter in conjunction with an inconspicuous IR receiver provides an ideal solution.

There are, however, situations where using the IR hearing aid may prove difficult, if not impossible. Inasmuch as the device consists of two components, it presents an obvious limitation for personal use. Eliciting the cooperation of the speaker may be awkward, and may be viewed by some individuals as a public admission of a hearing loss. Those individuals who are so vain as to be unable to acknowledge their hearing difficulty certainly are not prime candidates for the IR aid.

Circumstances may also preclude effective utilization of the IR hearing aid. A cocktail party with its multiple sources of sound is generally incompatible with the present approach. But how often is the average retiree invited to a cocktail party? Unquestionably, the IR aid is not suitable for everyone for all occasions. There are, however, many hard of hearing who will go the extra distance to hear. For them, the solution is at hand.

The Road to the Marketplace

The processes involved in bringing the IR hearing aid to the marketplace are presented in Table 1. In general, the chronology of the steps progresses from top to bottom, but the various steps interact and do not occur in a fixed time sequence. For example, commercialization and product development must proceed as parallel operations. Efforts to keep projected manufacturing costs within an acceptable limit largely determine the nature of the prototype. In other words, one keeps an eye on the potential marketplace throughout the entire journey. The aim of the venture is to transfer the technology to the public using market forces, and to avoid at all costs developing still another laboratory curiosity.

Operating Principles of the IR Hearing Aid

Incorporating the technology of lightwave communication, the IR hearing aid transmits the sound directly to the listener over an invisible and silent light beam.

The device consists of two components: a transmitter and a receiver. The desired sound message is converted by the transmitter into a modulated light beam which is picked up by the listener's receiver. The inconspicuous receiver worn by the listener then takes the beam and converts it back into sound.

Advantages of IR Sound

The virtue of the IR system is that it eliminates background noise. Because the sound is transmitted on a light beam directly to the listener, it is uncontaminated by noise and reverberation that normally destroy intelligibility. Regardless of the distance from the source or the room acoustics, the listener receives a perfectly clear sound.

Conventional hearing aids amplify the desired speech as well as the unwanted noise. As a result, the aid does not improve the clarity of the speech. Thus, for many impaired listeners in everyday situations, the hearing aid provides little assistance. The infrared hearing system, on the other hand, by transmitting only the desired message, delivers speech of a quality never believed possible. For the vast majority of hearing-impaired listeners, tests show that the device produces remarkable benefits.

Where IR Sound Systems Can Be Used

With the exception of direct sunlight, there are no limitations on using the IR system. Portable transmitters, about the size of a pocket calculator, are useful for home and school. Larger transmitters can be added to existing public address systems in theaters and churches. The basic receiver used by the listener is compatible with all IR transmitters.

TABLE 1

THE INFRARED HEARING AID: FROM THE LABORATORY TO THE MARKETPLACE

Establishing the Need

personal experience *research findings* *market research data* *governmental reports*

Verifying the Solution

research findings *demonstration experiments* *personal experience*

Development and Demonstration

examine alternative technologies
breadboard the device (generic technology)
package first prototype (specific application)
laboratory and preliminary field testing
second prototype (ergonomics)
extensive field testing

Commercialization

assess potential market
promotional activities
manufacturing cost estimates
establish business entity
prepare business plan
solicit private and public support
prepare advertising and marketing campaign
add personnel (financial, marketing)

Business Operational

refine prototype
prepare for large-scale manufacturing
product development
begin serious marketing effort

Delivery to the Public

IR sound systems can be used in a great many situations, such as

- personal hearing assistance
- wireless transmission of home TV and stereo
- public address reinforcement in church, theaters, and nursing homes
- auditory training for children in school and home
- noisy communication situations

Audio Devices, Inc., is pioneering the development of personal IR hearing systems. Its most advanced receiver, which is presently being market tested, includes an IR light receiver and a conventional body level hearing aid in a single package. The completely portable transmitter is about the size of a pocket calculator. Both units use rechargeable batteries.

Increasing Accessibility for the Elderly and the Hearing Impaired

In a recent survey of individuals over the age of 65, more than 70 percent reported that they could not understand most of what is said in a theater or church. The addition of an IR transmitter to the existing sound system would make these facilities auditorily available to the great majority of individuals now denied access because of hearing difficulties.

Robert Radocy

Strategies for Developing and Marketing Products for Special Populations

Product development and marketing are integrally related processes. The research required to develop a product for a special population will also provide much of the information necessary to market that product. That is, products are usually developed due to a particular need that is not being adequately satisfied, or not being satisfied at all. Needs and problems are discovered via basic research, extensive communication, and, in rare instances, purely personal insight. Basic research attempts to assess target population characteristics. These include population size and geographical distribution as well as educational, economic, vocational, and recreational profile statistics. Sources for such information are limited when referring to special populations. Studies conducted by the National Center for Health Statistics have provided some of the best information available even though the studies are almost a decade old. Several other literature sources exist as well and are listed under References.

Direct Communication

Direct communication with individuals of the target population is an important source of information regarding their needs and problems and their opinions of existing products. Although time-consuming and tedious, direct communication still provides the most reliable source of information to the product developer. Some criticism exists as to the value of consumer input in product design. However, it is not clear whether there has been a problem with consumer input per se, or the problem has been poorly designed research methodology. It is important to stress that consumers cannot just be asked what they want. The consumers' technical backgrounds may be limited and their experience may be biased by products that not only limit their capability but also limit their expectations. A poorly constructed questionnaire will result in a poor or confused answer. Therefore, an interview or questionnaire must be constructed by a professional to ensure that the data sought are collected without bias, in order to be of any value at all. Communication with any professionals who deal regularly with individuals of the target population, such as doctors or therapists, will also prove invaluable in assessing the situation. Finally, previous research regarding the target population should be investigated. A thorough literature review is an initial step in evaluating any problem. University graduate schools may provide some assistance in these basic research areas and can also aid in developing sources of funding for the research.

Evaluation of Products

The next step in the process is the formal evaluation of other products to determine their design, manufacturing and marketing characteristics. The investigation should include a thorough patent search, in addition to an evaluation of existing products. A patent search can result in uncovering ideas that may have great potential but were never incorporated into a product, while existing products can provide information on the quality and performance that has been generally accepted. The government documents section of a large metropolitan or university library can provide the needed patent abstracts with which to assess previously patented ideas, while existing products can be purchased from local retail sales establishments for evaluation.

After the basics are complete, the direction of actual product development can be set forth. Creative ideas usually occur only after one has a thorough knowledge and understanding of the entire situation.

Invention and Design

Invention, of course, cannot be taught, only nurtured, and so novel ideas are scarce. Brainstorming has been a successful way to generate new ideas. Several people, totally aware of the scope of the development, provide alternative points of view which can lead to innovation. Innovation may be dependent upon the designer's perception of the goals. Most products developed for special populations have been designed to create "normalcy," i.e., allow the handicapped person to meet average needs. This attitude towards design has in many cases prevented handicapped persons from achieving better than "normal" goals, due to the technological limitations designed into the products.

Designing for high performance, or for the "high end" rather than for "normalcy", can solve this dilemma and prevent technological limitations from handicapping special populations. If a product is designed to meet high performance criteria, most likely it will easily satisfy average or normal criteria as well. Furthermore, the product should be designed to meet the needs of the majority of a special population. This rationale has two bases. One is obviously economic. If a product is designed for the majority of a market, more products are likely to be sold. The other base of rationale is performance. If the product is designed to satisfy the needs of only a small segment of a special population, that product may very well limit the capability of members of the majority of that same population. This has occurred in prosthetics. The split hook mechanical hand was designed to meet the needs of a bilateral amputee, but has been recommended for use by unilateral amputees as well. Unilateral amputees represent the majority of upper extremity amputees. Over time, this basic design became the norm, even though many amputees were frustrated with the performance of the split hook. These unilaterals were being forced to use a device that literally handicapped them, since it was not designed to meet their needs, but the needs of bilaterals, the minority. Recently this problem has been solved by a new mechanical hand called the Prehensile Hand. This product was designed by a unilateral amputee to meet the needs of unilateral amputees, and therefore appeals to the market's majority interest. Minority markets are not to be ignored, but a product perspective must be maintained, especially in a new business. Minority markets can be satisfied when product sales from the majority markets begin to provide adequate profits. This enables a small business with limited capital to design and promote a product for a minority market which by itself was not sizable enough to financially support an emerging small business.

Testing, Patenting, and Marketing

Prototyping or idea testing is the next step in the process. This is time-consuming but necessary and critical in importance. An open flexible mind is an asset in new development. Lab testing, revision, field testing, and

further revision will eventually generate a reliable product. Structural, material, and manufacturing problems need to be taken into consideration during prototyping, in order to develop a satisfactory product. The information previously generated in basic research and communication with the target population will direct the development and ensure that the consumer will be satisfied.

The importance of protecting novel ideas cannot be overemphasized if the fruits of one's efforts are to be realized. Log books illustrating the product's design and describing the design rationale and progress can be an initial form of idea protection when notarized regularly. Patents, however, are the only real means of legally protecting novel ideas. Patents may be issued for novel ideas, improvement over the art, or purely for design. A reliable patent lawyer is needed unless the developers intend on educating themselves in the patent application process, and submitting the patent personally.

Marketing a product can be as complex as developing one, but it need not be difficult. Decisions should be made based upon the statistical data already compiled. The crux of the marketing problem is how to effectively communicate with the target consumer population. The remainder of this paper deals with the various decisions a product developer must make to successfully market the product.

The main advantage the developer has is that the product has been designed for a special population. Such a product has human interest appeal to the media and this appeal needs to be utilized to the fullest, since it can generate free publicity. It will be assumed, due to the nature of this paper, that the developers intend to market the product themselves, rather than contract out this task.

Creating a marketing program involves posing a multitude of questions. Answers to those questions are dependent upon the type of product, the characteristics of the target consumer population, and the amounts of capital to be committed to the program. A marketing program can be initiated locally, regionally, nationally, or internationally. Both the Small Business Administration and the U.S. Department of Commerce provide information and services regarding national or international endeavors.

Reaching the Target Population

Communication to the target population, as mentioned, is the primary goal. Many special populations are difficult to access directly. Problems can exist involving the invasion of privacy of individuals. This prohibits some organizations or associations from making their membership lists available to allow this direct access. Certain groups of handicapped consumers are isolated. They do not subscribe to special publications and do not belong to groups or associations related to their handicap. Special marketing tactics are required to reach these groups, but unfortunately no rule of thumb exists to point out the most successful direction. Trial and error is required.

Advertising always plays an important part in marketing a product. Effective advertising can reach the consumer, but the cost of mass media coverage is prohibitive to small businesses, which often use selective advertising instead. Choose magazines and journals that can serve the handicapped directly, such as the ones in the resource list, or magazines that communicate to the health service professionals who deal with the target population. Magazines read by doctors, physical and occupational therapists, and rehabilitation specialists are good examples. Each group's interests are represented by national or international organizations like the American Occupational Therapy Association and others that publish journals or newsletters. Occupational therapists in particular seem to be very interested in new product developments that can increase the capabilities of special populations. Lists of these professionals are sometimes

available for purchase through the national organizations and, if affordable, provide a direct mail link that can prove valuable in the marketing program.

Special interest magazines can be a target for advertising as well. If the product falls into a particular category, such as sports or recreation, for instance, magazines specializing in these areas may prove useful. Certain publications exist to serve special populations directly. *Sports and Spokes*, *Accent on Living*, and others in the resource list focus on handicapped populations specifically. Consideration of these publications should be made when budgeting advertising dollars.

An effective alternative to purchased advertising involves the solicitation of "New Products" listings or special editorials in magazines and journals. This is especially important for developers of products for special populations, since the human interest aspect of the product can be utilized. The product may offer new capabilities for independent living and thus merit media consideration.

Local radio or television stations may be enticed into providing air time if they deem the product worthy of public attention. Solicitation of such media coverage can't hurt, and when successful, provides invaluable benefits to the marketing program.

Contacting state vocational rehabilitation offices, workmen's compensation boards, and major national insurance companies is suggested for products that improve the health of individuals, aid in their rehabilitation, or provide increased vocational capabilities.

Conventions and trade shows sponsored by professional organizations such as AOTA, APTA, or private promoters specializing in the handicapped field are an excellent means for "hands on" marketing of new products. The Abilities Unlimited Exhibition in Los Angeles, now in its third year, and others such as the International Handicapped Exposition in Chicago are growing in popularity and are attended by the handicapped public and related health professionals. Such shows offer exhibition space and promotional opportunities such as directories and guides of service organizations, consultant services, and products for special populations.

Thus far we have assumed that the product developer is responsible for marketing the product, although there are other avenues of marketing. Many distributors and retailers of manufactured goods exist in the health field. Distributors and retailers should not be ignored as a source of marketing and sales. Existing corporations may have the financial power to develop a cooperative program in return for exclusive distribution rights or greater profits.

Education

If the product is truly innovative, an educational as well as a marketing program must be considered. Professionals, the general public, and members of special populations develop mental attitudes or "mental sets" regarding certain types of products, techniques, etc. Mental sets, like any other old habits, are difficult to break, and limit a person's perspective and attitude toward new products or developments. Education is a means of effectively breaking these mental sets. Education is at the root of communication. The public and professionals must be informed of the products' uses and advantages. An educational approach is low key and can generate significant interest in new products. Visual aids such as films or slide presentations can be low-cost, effective means of communicating ideas that educate and market products simultaneously, thus relieving the pressure of a hard line advertising campaign.

In concluding, let's review some of the most critical aspects of successfully developing and marketing products for special populations. Preparation through basic research and communication with the target population cannot be overemphasized. A thorough understanding of available products, their pros and cons, and previously protected ideas will avoid duplication and prevent loss of time, effort, and money. An open mind during development and an intensive testing program will ensure a reliable, useful product. Evaluating all marketing opportunities prior to committing budget dollars will allow the most efficient use of the funds available. Utilize the human interest appeal that is inherent in most products for special populations to solicit as much media coverage as possible. Be relentless in this pursuit, requesting coverage every few months if a positive response is not the result. Topics of media interest constantly change, and what might not be of interest at one time could be of great value at another. Equally important is to sincerely thank those organizations and publications that do provide media coverage. Regardless of their reasons, such coverage is invaluable in reaching the special populations.

Finally, possibly the most important aspect of product development and marketing is a positive attitude. A positive attitude, even though I have not mentioned it previously, will bridge the valleys of uncertainty and provide footing in the face of the most overwhelming circumstances. Belief in one's product and oneself, combined with the tactics discussed, will ensure a successful product.

References

"Biometrics and Research, Reports and Statistics Service," U.S. Veterans Administration Office of the Controller, September 1978.

Firing, M., "The Physically Impaired Population of the United States," Firing & Associates, San Francisco, 1978.

Glattly, H., "A Preliminary Report on the Amputee Census," American Orthotics and Prosthetics.

The following magazines and journals are of interest to handicapped persons:

Accent on Living

Rehabilitation Literature

Sports and Spokes

Archives of Physical Medicine and Rehabilitation

Rehabilitation World

Barry Unger

High Technology for the Handicapped: Roles for Consumer Involvement and the Small Business Sector

The themes of this conference are "appropriate technology" and "reimbursement realities of the 1980's." In this paper, it is intended to make these concepts more relevant to the development of high technology for the handicapped. Emphasis will be put on: 1) what can be added to the innovation process to make its products more appropriate; and 2) identifying the sources of technological innovation, the economic problems these sources face, and the relevance for the handicapped system of proposed remedies.

The case of the Kurzweil Reading Machine, with which I have been involved, exemplifies the fact that while those in the handicapped field may have a preference for simple, inexpensive solutions, in some cases costly high technology is necessary; and in these cases we must know how to properly influence the design process to ensure that the resulting products are truly "appropriate." The huge costs involved in the development of the machine also demonstrate the necessity of a systems view of the financing of technological development--a view that concerns itself with more than just the reimbursement of purchases of the final product.

The term "appropriate technology" has sometimes been used as a slogan of opposition to expensive, technologically complicated solutions to human problems. The concept first gained prominence in the field of Third World economic development. Observing the application of American technology in situations of great poverty and unemployment, many concluded that technological solutions are too expensive for widespread dissemination, often too complicated for the intended users to operate, and too difficult to maintain in a non-industrialized environment.

Also products/solutions have frequently not been used/implemented because they were not designed with the user's culture in mind or, in the case of equipment for the handicapped, failed to acceptably build upon users' existing capabilities.

In many situations, therefore, the inexpensive "low tech" approach is indeed more appropriate even though it may not do the job quite as completely. This would seem especially true where the economics of efficiency are altered by such conditions as a relative excess of labor and shortage of capital, as in less developed countries. This would also seem to be the case when addressing needs of extreme low incidence (such as certain multihandicap combinations) with potential markets not large enough to economically sustain the R&D and manufacturing start-up costs required for a somewhat more elegant technology-based solution.

In the handicapped field, two examples of less complex technology that appropriately accomplish their purpose and make adequate use of clients' own abilities are: the use of video enlargers by partially blind persons with relatively substantial residual vision, and the use of a "doorbell" signaling device for the deaf-blind person which mildly vibrates the floors of a house when pressed.

The nature of certain problems, however, requires and economically permits a high-technology solution.

The need for direct access to the printed page by the totally or near totally blind person is this kind of situation. Other less elaborate solutions were created before the Kurzweil Reading Machine and made an important contribution to the field. However, these earlier approaches had serious deficiencies--they were rather slow, they required too much work by the user and thus distracted from the content of the material being read, and they required lengthy and substantial training. The optical character recognition computer-based reading machine, while expensive and exotic in its technological base, avoids all of these major impediments to active reading.

So low tech or high tech can be appropriate, depending on the complexity of the problem to be solved, the characteristics (e.g. residual skills of users) and size of the population to be served, and so forth.

In either case, however, solutions should not only appear to meet a set of needs, but should work in actual operation by the intended users. Solutions should be appropriate, i.e., "suitable or fitting for a particular purpose, person, occasion" (*The Random House Dictionary*, 1979). Innovative solutions using high technology often come from engineers and scientists outside the professional rehabilitation system and thus may not incorporate enough knowledge of the needs and preferences of those served, or their financial realities. It is therefore particularly necessary that conscious and formalized efforts be made to guarantee appropriateness of these projects.

A key way to do this is through the use of active consumer involvement in the design and testing of the new technology. The author has elsewhere described the rationale and mechanics of using consumer involvement to optimize the design of new technology for the handicapped, stressing the necessity of involving independent organized consumer groups with sophisticated technical leadership as co-equal partners to the designer in such an endeavor.

Michael Hingson's paper on the results of the National Federation of the Blind's consumer evaluation project on the Kurzweil Reading Machine shows how a device based on intellectual breakthroughs in the fields of artificial intelligence and speech synthesis was made appropriate to the needs of a specific population of handicapped users. It is hoped that this project can serve as a model of handicapped consumer involvement in the design and evaluation of technology-based products.

A second way to approach the subject of appropriate technology is to look at the sources of invention and the financial tradeoffs that allow inventions to be commercialized, or tailored to customer preferences, and then produced and disseminated. It is now clear to those who study innovation that independent inventors and small technology-based firms have been the key sources of successful technological innovation in the United States, and that this has been accomplished in spite of the minuscule proportion of total economic resources committed to small firms. As we will note, the leadership in innovation by small business has been particularly evident in the area of technology for the handicapped.

Numerous studies in the last 20 years have demonstrated small business' record for producing innovation and its consequent contribution not only to

employment generation and productivity growth, but to meeting pressing national and social needs. A few 20th century examples of such innovation are: antibiotics, pesticides, instant cameras, automatic transmissions, minicomputers, large-scale integrated circuits, oxygen steelmaking, and air conditioning. A National Science Foundation study (*Science Indicators*, 1976) showed that smaller firms were responsible for half of all major industrial innovations since World War II.

Moreover, these small firms produced 24 times as many major innovations per research dollar as did large firms (*Science Indicators*, 1976), created 87 percent of all net new jobs between 1969 and 1976 (*The Job Generation Process*, David Birch, M.I.T., 1979), and had an employment growth rate in the electronics industry that was a remarkable 115 times greater than that of mature companies (*American Electronics Association Study*, 1978).

Other studies that have been done of the steel industry, the aluminum industry, the petroleum industry, and most recently the food manufacturing and processing industries, confirm the pattern of about one half to two-thirds of the most significant innovations coming from small firms and independent inventors (see Jewkes, Hamberg-University of Maryland, Peck-Harvard, M.I.T. Enos, and Mueller et al.)

Small firms dominate in creating new technology for the handicapped. The U.S. Department of Justice in Washington, D.C., maintains a Sensory Aids Center for its visually impaired and deaf staff members. The Center evaluates, customizes, and makes available the best of modern technology for the use of Justice Department employees--lawyers, computer programmers, top officials, and legal research assistants. It also consults to other government departments on their accessibility programs. The Center has three rooms full of equipment that is regularly used or is in the process of becoming so. With the exception of several electric typewriters connected to some of the specialized equipment, all of the devices bore the name tags of small firms, not exactly household words outside the handicapped system.

Various reasons are given for the extraordinary role of small companies. It is said that they have little or no marketing clout and thus have to rely on innovative products that meet customer needs--indeed firms are often started specifically to commercialize an invention or technical idea. Conversely, in some cases, the marketing plans of large companies dictate that technical improvements to their products be held to a minimum--this charge has been leveled at certain of the firms in the wheelchair business. There is also a possibility that researchers in large firms and non-profit research centers tend to overspecialize and avoid using ideas from outside their field, while the tiny independent research staff is actually less cumbersome, better able to focus on a problem rather than a set discipline, and better able to use radical new approaches.

Finally, particularly in the handicapped field, the potential markets for new products--even when subsidized by third parties such as the government--are often too small to have a significant early impact on a large corporation's earnings per share, and are thus of less interest to these firms.

In any case, this leadership in innovation has a definite policy implication for the handicapped field: the small business sector is key to developing new technology for the handicapped and to taking insights developed in government and university basic research and commercializing these into practical new products. Those concerned with the economics of appropriate technology for the handicapped should also be concerned with the growth and vitality of the small business sector, especially its science and technology based component. In the following pages, we will address some of the factors that affect these companies.

Two of the financial factors that affect the small firm's capability to create appropriate high technology products are 1) the availability of government funds for support of research and development, either directly as in the case of the Optacon from Telesensory Systems Inc., or indirectly through support for purchase and testing of early models, as in the case of the Kurzweil Reading Machine; and 2) the availability of private investment or venture capital.

Government funds can have such a crucial impact on the development of new technology because such support often comes in the early stages of development when a technology is not sufficiently proved to attract investors. Lasers, semiconductors, ultrasonics, robotics, and digital computers are just a few of the many areas where early government involvement has led over time to a strong new industry.

Additionally, as in the handicapped system, public policy considerations may dictate that for certain classes of products society subsidize not only the R&D, but also the deployment of the product through the mechanisms of third party reimbursement. This may be done for notions of social justice--society should pay certain costs not the "fault" or choice of the individual--or to achieve other public benefits such as more efficient employment utilization of disabled persons. In these cases, the availability of an innovation may be totally dependent on public funds.

A recent study by Obermayer (NTIS Document No. P.B. 80 108425) of thirty-three innovative high technology companies concluded that "A long gestation period is required between the conception of an idea and profitable sales of a high technology invention" and that government R&D contracts "provided an important source of funding for the development of technology later used commercially by the companies and an important source of cash flow required during the early years of a significant percentage of these companies."

While stressing the importance of government funding, the study also concluded that "Market forces were the critical factor in successful commercialization...government R&D contract money alone was insufficient...to make a viable business." This is a felicitous finding for those concerned with appropriateness; bad technology does not survive even when the government initially funds it.

Federal support of R&D can be of great benefit to innovation, but except for small firms with unusual Washington expertise, most small firms have fared extremely poorly in comparison to universities and big businesses in their efforts to win federal R&D awards. A 1977 study by the U.S. Office of Management and Budget noted that despite small business' record of innovation and greater productivity per research dollar, small firms and independent inventors receive only 3.5 percent of total federal R&D money. (By comparison, small business receives about 30 percent of general federal procurement, such as that of office furniture, food and laundry service contracts, and so forth.)

It is widely believed that research proposals by small firms do not get approved for government support in proportion to their relative excellence, and that this de facto discrimination is the result of a pervasive prejudice against small firms by government R&D procurement officials. The Lockwood Report to the President's Domestic Policy Review on Industrial Innovation (1979) concluded, as have several other studies going back to 1965, that "small science and technology based enterprises are virtually excluded from effective participation" in federal R&D funding. It was observed that regardless of the actual quality of proposals it is bureaucratically safer to award funds for state of the art research and development to larger established businesses and universities: if a prestigious organization fails to produce, it is harder to fault the awarding government officer for lack of judgment or due diligence.

A number of efforts are currently being made to rectify this problem. For example, several bills have found considerable support in Congress in the last two years that would after a break-in period require that small businesses receive up to 10 percent of each federal agency's research and development budget. On the administrative side, the Office of the President, while not willing to target specific percentages, has directed agencies to make efforts to award to small firms a greater share of their R&D funds--especially for "unsolicited" or self-initiated research projects (e.g. the Kurzweil Reading Machine or the Optacon), as these are felt to offer the best opportunities for significant innovation.[1] So far this directive does not appear to have had a significant impact on the agencies. Fair access to government research monies is critical to innovation and national economic competitiveness, so this issue is certain to reemerge in Congress.

While these efforts to allow small firms to compete more fairly for the federal R&D dollar are important, the actual number of innovations that can be assisted in this way is necessarily very limited by budget considerations. This is particularly the case now, in the 1980's, when the efficiency of direct government intervention is under serious re-evaluation.

Considering this and the greater size of the private sector, we therefore move on to the subject of venture capital availability and other indirect ways in which the federal government determines the overall climate for private sector technological innovation--especially that by small R&D firms.

The availability of private capital is a key element of innovation and economic growth in America. Yet for a large number of reasons, not essential to repeat here, the amount of capital invested in small firms, especially the technology based startups that most need capital, drastically declined in the 1970's after the peak innovative decades of the 1950's and 1960's. Every panel of experts that has looked at the decline of innovation, has viewed capital availability as the number one barrier to innovation and incentives to investment as a solution. Although this recognition is at least twenty years old, only in the last few years as our economic and productivity woes have worsened, has momentum built to do something about the "capital gap."

In this regard the 1978 capital gains cut, although not particularly targeted to small firms, was a very important first step, reversing as it did a two-decade trend of increasing taxation of investment. We are just beginning to see the effect of this in terms of documented dramatic increases in the flow of venture capital in the last two years.

Another step is the 1980 revision to the Investment Company Act, which will make it easier for venture capital companies to go public and thus raise funds to reinvest in businesses. Unfortunately, most venture capital companies currently tend not to invest in startups but in companies that are established and need more financing, so until startups can be made more attractive, the effects of this revision may be limited.

Some of the proposals currently under active consideration by Congress are targeted both to improve the lot of R&D based small firms and to make risky high technology startup situations more attractive to investors. For example, under one set of proposals directed at firms which maintain certain levels of R&D investment:

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1. In the handicapped field, the Veterans Administration and the Department of Health and Human Services (formerly HEW) have supported several innovative projects proposed by small firms, although problems with patent policy and overhead costing have tended to inhibit small business participation.

- Investors in these firms would be allowed to indefinitely defer or "roll over" capital gains from the firms' stocks if the proceeds of such stock sales were invested within one year or 18 months in other qualifying firms--much like current tax laws which use this rollover feature to encourage home buying.

- Qualifying capital gains that were not reinvested would still be taxed but at the lower rates that prevailed before 1969.

- Corporate tax rates on the qualifying firms themselves would in effect be eased by extending carry-forward time for startup losses from five years to ten years (most small businesses cannot use up their loss carry-forwards in the first five years).

- Depreciation allowances would be adjusted to permit faster write-offs to be made for specialized R&D equipment.

- Such firms would be given more leeway in competing for key personnel by restoring the qualified stock option plan for key employees and allowing the period of exercising options to increase from five to ten years.

- State equity capital program would be created to leverage private capital investment in high technology startups with public co-investments; a small existing National Science Foundation federal program that does this would be expanded.

Currently there is a debate among lawmakers on whether the proposed changes are too narrowly targeted or should be even more narrowly targeted.

Those who advocate broadening the proposals feel that their limitations to one class of company represents unacceptable interference by the government, that free market forces are best at distributing capital between innovation and other uses; therefore proposed incentives for economic development should be designed to benefit all businesses in an even-handed way.

Those who favor more targeting believe that the free market system does not always work where there is oligopolistic control over resources; that bureaucratic pressures within private financial institutions inappropriately steer investments away from the projects with the best chances for innovation, employment development, and even profit; and that narrow gauge reforms are the best use of incentives with the least cost to the Treasury in terms of lost taxes. Even narrower targeting is proposed, such as restricting benefits to investments in firms doing R&D in nationally designated areas of need like alternative energy systems and health and handicapped technology, and/or restricting benefits to investments in startup situations as these appear to generate the most major innovations of all, dollar for dollar.

Several other changes that have long been recommended to support small business innovation have been enacted by Congress or administrative action in the last three months including:

- Government regulations have been revised to allow pension fund managers to invest up to five percent of assets in qualifying small firms.

- Securities and Exchange Commission regulations have been modified to simplify and shorten registration requirements for small firms doing limited offerings thus providing greater access to securities markets.

- Government agencies are now required to tailor their regulations to the size of companies, giving special consideration to smaller firms (Regulatory Flexibility Act of 1980).

- Patent laws have been strengthened to better protect the rights of independent inventors and small businesses unable to afford extensive litigation (Patent Act of 1980).

- Federal procurement rules have been changed to allow small businesses conducting federally supported research to retain, with certain conditions, exclusive rights to their inventions and thus greater incentive to commercialize (Patent Act of 1980).

In the coming years, we can expect major national debate on the tax and capital formation proposals as well as other attempts to strengthen the innovative sector. As the two examples of direct vs. indirect intervention and broad vs. targeted incentives should indicate, the process will occur in the gristmill of conflicting interests and philosophies that normally characterizes decision making in Washington.

For those concerned with appropriate technology for the handicapped, the important point to understand about this debate is that the promotion of such technology is linked to the broader discussion of the health of our sources of innovation and economic development.

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4 Technology for Employment

Steven L. Jamison

The Role of Technology in the Employment of Hearing-Impaired Persons

Unemployment among deaf people is somewhat higher than in the population as a whole. A more significant problem is the considerably higher rate of underemployment. In fact, the average deaf wage earner has a salary of only 70% of the national average. So the hope for the future is not simply more jobs for deaf people but better jobs as well.

Special technology can play an important role in helping hearing-impaired people achieve appropriate employment. However, to put technology into proper perspective, it should be viewed within the following general framework: (1) attitudes are far more important than devices, (2) technology has its greatest benefit when introduced early in the deaf person's life, (3) accommodative equipment on the job is minimal.

The well-being of a deaf person is vitally dependent on self-image, and self-image is critically conditioned by parental attitudes during early childhood and, to a lesser degree, by the attitudes of teachers and employers in later years. Technology cannot substitute for parents who love their child, who accept his/her deafness, who establish early a mode of easy two-way communication, who foster independence, who have high expectations, and who are encouraging and supportive. Unless teachers and counselors also demonstrate positive attitudes, the child's enthusiasm for school may wane, and he or she is less likely to go on to college to prepare for professional-level employment. The attitudes of employers toward deaf applicants are also a major factor in either deterring or facilitating employment. But most important, of course, is the attitude of the deaf individual himself. Collectively, proper attitudes tend to dwarf the significance of technology.

Even so, technological developments do have an important, though largely indirect, role relative to the employment of deaf persons. This role is much greater during the preparatory years than during the years of actual employment. The nature of a person's career depends heavily on educational preparation. Unfortunately, too many deaf students do not achieve their educational potential because of underdeveloped language skills. Therefore, the most significant applications of technology should occur early in the child's life and should focus on facilitating communication skills and language development.

Of the various things that can be done on the job to accommodate a deaf employee, very few involve special equipment or special modifications to existing equipment. Typically, such accommodation is less extensive than for a blind employee and considerably less individualized than for an employee who is neurologically or orthopedically impaired.

This introduction is not meant to minimize the importance of technological developments but to put them into proper perspective. It reflects, perhaps, the role that technology has played and now plays in the lives of deaf persons, more than the role that it may play in the future.

Prevention and Cure of Hearing Loss

Not only has technology helped to compensate for the implications of deafness, it has also helped to prevent or cure hearing loss. In particular, medical technology is responsible for the development of an inoculation against rubella, a mild disease which, among pregnant women, can result in major impairments, including hearing loss, for the baby. But almost any severe infection, especially during the first three months of pregnancy, can cause congenital deafness. Medical technology has done much to control diseases such as typhoid fever, diphtheria, and meningitis which, in the past, have been responsible for causing deafness in children. Hopefully, other technological developments can be found to retard or eliminate the hearing loss that frequently accompanies the aging process.

Unfortunately, some hearing losses are a by-product of technology: machines, explosives, amplifiers, etc. Prolonged exposure to noise can significantly diminish a person's ability to hear. Technology is constantly being applied to the reduction of industrial noise, and legislation currently exists to protect people from acoustic trauma in the work environment. But the prospects for outlawing war and rock concerts are not so promising.

But can medical science do anything to cure hearing impairments? The answer depends largely on the kind of hearing loss involved. Roughly speaking, hearing losses can be grouped into two categories: sensory-neural and conductive. Although some claims have been made for acupuncture and other forms of treatment, they are not substantiated; and it is generally agreed that, at this time, nothing can be done medically to cure or improve sensory-neural hearing losses. But various forms of conductive loss can be successfully treated medically and surgically.

Early Detection and Intervention

Babies with normal hearing react to sound and begin to process spoken language very early in their lives. Indeed, it appears that the first few years of a child's life are the prime years for language acquisition. Children who are born deaf or who become deaf very early in their lives are cut off from the principal source of language development. Unless appropriate steps are taken, the child will be "playing catch-up ball" during all his growing-up years. Unfortunately, rather than catching up, he will typically fall further and further behind.

The vast majority of deaf babies are born to parents who have little or no understanding of deafness or its implications. Furthermore, understanding does not start until the child is diagnosed as deaf, possibly at age 2 or 3 but frequently much later. This understanding sometimes grows very slowly and haphazardly as parents react to persistent problem situations that arise at home, at school, or in the community.

But new equipment and techniques are now emerging which make it practical to perform screening tests while newborn babies are still in the hospital. In particular, the Stanford University School of Medicine and Telesensory Systems, Inc., have jointly developed a screening unit that employs microprocessor technology coupled to sensitive motion detectors to identify babies with severe to profound hearing impairments. Early identification of a hearing impairment, coupled with appropriate educational and counseling services for parents, not only allows those early years to be more productively used but also makes it possible for parents to set goals, to make enlightened judgments, and to establish a reasoned course of action.

Technology to Aid Hearing

Probably the most obvious application of technology to meet the needs of hearing-impaired persons is the hearing aid. It is perhaps also the device of greatest benefit. Even for most individuals who are profoundly deaf, hearing aids can give an awareness of environmental sounds. If deaf children are properly fitted at an early age with two hearing aids (binaural) and are given appropriate auditory and speech training, many can develop communication skills that will be helpful to them throughout their lives.

Although technological developments have significantly improved the quality of hearing aids during the past few decades, a great need for additional research and development still exists. Currently, it is impossible to obtain hearing aids to match an individual's specific need; the audiologist simply recommends the commercially available aid that seems to come closest to meeting the requirement.

Electronic technology has made it possible to miniaturize circuitry; thus powerful aids that formerly were carried in a pocket can now be worn behind, or even in, the ear. But, unfortunately, the microphone and speaker elements of the hearing aid do not lend themselves to miniaturization as well as the purely electronic components, resulting in some loss of fidelity.

Since a great deal of electronic complexity can be accommodated within the space and power limitations of currently available aids, there is a wide variety of possible ways the input signal can be processed to produce an output signal. Amplitude clipping, amplitude compression, frequency compression, and frequency transposition are some of the alternatives that have been tried. The value of some of these signal-processing techniques depends on the nature and severity of the hearing loss, and so they are not likely to become generally available until some way is found to economically produce a prescription hearing aid.

Another type of "hearing aid" currently being investigated utilizes a microphone and signal-processing electronics but not the traditional speaker. Instead, the output of the aid is an electrical signal delivered to the deaf person by means of one or more surgically implanted electrodes. These electrodes may be placed in the cochlea or may bypass the inner ear entirely and be imbedded in the eighth nerve. In either case, results demonstrate that the deaf person becomes aware of sound. The major question is whether or not the signal which reaches the brain can be made rich enough and differentiated enough to provide speech discrimination. Experimentation along these lines is being conducted at the Ear Research Institute in Los Angeles and at Stanford University.

Technology to Aid Lipreading

Contrary to popular belief, not all deaf people are good lipreaders. Indeed, it is remarkable that anyone can be skilled in this method of receptive communication. Many of the speech sounds in English are made farther back in the mouth and do not show up on the lips. For example, it is possible to say "onion" without moving the lips at all. Many of the sounds which are visible on the lips are ambiguous; the sounds P, M, and B are not visually distinguishable. In general, lipreading is a game where the reader uses the context of the more readily discernible words in a sentence to guess at the other words that he can't decipher directly.

A system called DAVID has been developed at the National Technical Institute for the Deaf which combines two powerful teaching technologies: Computer-Assisted Instruction and Instructional Television. Although the system has potential for effectively teaching a very broad spectrum of subjects and skills, one of its first applications is training in lipreading. Not only is the

content of the presented material tailored to the individual's needs, but each user of the system controls the rate at which he progresses through the material.

Any additional clues available to the hearing-impaired person can substantially improve his lipreading ability. Actually, a good lipreader reads much more than the lips. Facial expressions, body language, the context, the physical situation all are "read" and contribute to improved understanding. In fact, the word "speechreading" often replaces the word "lipreading" because of this broadened set of inputs.

Whatever residual hearing the person may have also enhances understanding. A hearing aid, therefore, can also be thought of as a lipreading aid. Many individuals with profound deafness, who are unable to understand any speech even with powerful hearing aids, are much better lipreaders with their aids than without them. With amplification they are able to pick up some of the prosodic features of speech (rhythm, emphasis, etc.) to augment the visual clues.

Several years ago, Dr. Orin Cornett at Gallaudet College developed a system called Cued Speech as an adjunct to lipreading. As a person speaks, he simultaneously uses various hand shapes and positions to provide additional visual cues. These shapes and positions of the hand only have meaning in conjunction with lipreading by making all sounds visible and eliminating the various ambiguities. It would be nice if these or similar cues could be automatically generated and delivered to the deaf lipreader without requiring the speaker to learn and use the system. Dr. Cornett and others have been working on an automatic cuer which would accomplish this objective.

For many years, various researchers have investigated tactile devices as a means of communicating speech to deaf persons. At best, these devices have had limited success. However, if the tactile device is regarded more as a lipreading aid than as a substitute for hearing, better results can be expected. Dr. Frank Saunders of Smith-Kettlewell Institute is currently evaluating a device (the Teletacter) which he developed and is using with hearing-impaired young people.

The value of any lipreading aid, whether augmenting with auditory, visual, or tactual cues, can only be fully realized if the aid is wearable and becomes a full-time partner in the communication process.

Technology to Aid Speech

Trying to establish proper speech patterns without being able to hear others speak is a most difficult undertaking. Children who hear learn to talk not only by hearing others but also by hearing themselves and, being able to compare the two, they make adjustments and perfect their speech. Expecting a person who has been profoundly deaf since birth to speak well is a little analogous to expecting a person totally blind since birth to be an artist: it is difficult to reproduce what one has not experienced.

Various technological aids have been developed to improve the speech of hearing-impaired persons. Many of these speech training aids involve special electronics that interface a microphone to an oscilloscope or other display device. Individual speech sounds or words spoken into the microphone generate distinctive visual patterns. The speech therapist uses the system by verbally creating visual patterns that the deaf individual tries to match.

Another approach involves interposing a computer between the microphone and the display device and employing a game strategy to motivate the production of desired voice characteristics. For example, by properly vocalizing certain sounds or words or by modulating the voice in certain prescribed ways, the

user can move a spot across the display tube to hit a target or to avoid certain pictured obstacles. Bolt Beranek and Newman and other organizations have done interesting work along these lines.

Some of the previously described lipreading aids are also speech aids. For example, the tactile display of the Teletacter provides feedback from the deaf user's own speech as well as the speech of others. Through experimentation and practice, the deaf person can learn to improve his speech by more closely reproducing the desired tactile patterns.

Speech synthesizers are not so much a speech aid as a speech substitute. By depressing keys in appropriate sequences, these units can give voice to the various messages the user wants to communicate. For deaf people and for others who have speech impairments, this is an expensive substitute for pencil and paper. The primary advantage of these devices is realized when other handicapping conditions preclude written messages.

Technology to Aid Reading

The skills a deaf child acquires, with or without the aid of technology, in areas of hearing, lipreading, and speaking can contribute significantly to his success at school, in the community, and in future employment. But reading skills are even more critical to his well-being. Employment opportunities are directly related to educational preparation, which is dependent on reading level, which in turn is tied to language development. For profoundly deaf children, a real breakthrough in the area of reading seems more likely to result from parental concern for language development than from exclusive emphasis on the oral skills of lipreading and speech. There is a danger that technological developments in support of oral skills will tend to bolster many hearing parents in their resistance to the use of "total" communication. The key to language development, and therefore to reading, is easy two-way communication between the deaf child and other family members during the child's preschool years. Supplementing oral methods with sign language is frequently the best means of achieving this easy interaction.

Although there are few technological devices aimed specifically at improving the reading levels of deaf children, equipment (alluded to previously) that facilitates the early identification of hearing losses allows parents to take actions during the critical years that will establish a sound basis for the development of reading skills. As the child becomes older, he may benefit from Computer Assisted Instruction (CAI). Dr. Patrick Suppes of Sanford University pioneered in the application of CAI to the language development and reading skills of elementary school children who were deaf. Captioned television, especially of children's programs, also has the potential for strengthening these skills.

Until recently, telephone devices for the deaf were not widely used by deaf children of hearing parents. Not only do deaf teenagers deserve the same right as hearing teenagers to talk endlessly to their friends by phone, but there is also the added benefit that such use tends to improve the child's reading and writing abilities.

Alarm Systems

Over the past two decades, more and more devices have come on the market that employ a flashing light to alert the deaf person that someone is at the door or on the phone, that it's time to get up, that the baby is crying, or that the fire alarm has sounded. Vibrating paging systems carried in a pocket or worn on the wrist can provide similar information while allowing the individual more freedom of movement. Although such devices are likely to grow in number and sophistication, the use of "signal" dogs for similar purposes will also become more widespread.

Telephone Devices and Systems

For many years, deaf people have been able to use obsolete teletypewriters to communicate by telephone with other people having similar equipment. A special modem developed by Mr. Robert Weitbrecht makes it possible to acoustically couple this equipment to standard telephone handsets. In recent years, a wide variety of commercially available telephone devices for the deaf (TDD) have come on the market. Although utilizing modern electronic technology, they have been designed to be compatible with the older teletypewriters.

All such equipment has built-in modems for easy coupling to the telephone, and keyboards similar to typewriter keyboards on which users type their messages. The message is displayed both on the sender's unit and on the unit of the person receiving the message. On some units, this display is a printer, giving the user a paper copy of the conversation. Other units display the message on the face of a tube or on a liquid crystal or LED display register. Some of these TDD's feature the ability to store messages in memory. Others have automatic answering and message-taking capability. Some are fairly large and some can fit into a coat pocket. One recently announced unit will even allow the deaf user to communicate with a hearing person who has no TDD: using synthesized speech, the unit says or spells what the deaf user types, and displays what the hearing person keys (using a special code) on his touch-tone phone.

Although new TDD's employ modern electronic technology, most of them are tied, for reasons of compatibility, to an otherwise obsolete character code, i.e., the Baudot code employing 5 bits per character. Most data transmission equipment, including computer terminals, currently uses the ASCII code employing 8 bits per character. But converting to modern data transmission standards implies more than a change from a 5-level to an 8-level code; it also implies different signaling frequencies, data rates, character sets, etc. Some TDD's now being offered are switchable between these two modes, thus providing compatibility with both the 5-level equipment owned by most deaf telephone users and the 8-level equipment in more general use.

Indeed, as TDD's become indistinguishable from computer terminals, a whole new spectrum of computer-based services will become available to deaf users: information storage and retrieval, computation, games, text processing, instruction, etc. Stanford Research Institute is currently evaluating a computer-based system called Deafnet, which provides users with an electronic mail capability for the exchange of personal messages as well as news and other information services.

Earlier this year, the telephone company announced a nationwide 800 number which provides toll-free access to operator services for TDD users. Deaf persons can now contact a telephone operator in order to make person-to-person, collect, or credit card calls. These operators will not interpret voice to TDD or TDD to voice messages. However, a number of organizations are now offering such services on a local basis.

Captioned Television

One has only to turn off the sound to understand the rather limited appeal that television has for deaf viewers. This limitation can be partially overcome if prerecorded programs are captioned before being broadcast. But many hearing viewers object to open captions, saying they are a distraction. After several years of development and testing, a system of closed captions has been introduced. Now broadcasters can encode the captions so they do not appear on the screen of the television unless the set is equipped with a Telecaption Adapter, which decodes the captions and displays them as subtitles. Currently, three television networks provide a total of about 20 hours a week of prime-time television especially captioned for deaf viewers. In addition to

the direct entertainment and educational value afforded by such a system, this added exposure to the English language could have an indirect but positive impact on the reading skills of deaf youngsters.

At the present time, only prerecorded programs can be captioned, but experimentation funded by the Bureau of Education for the Handicapped is under way that will make possible the captioning of live programs. This involves the use of a stenotypist who keys what is said into a computer that immediately transcribes this input back into English captions for transmission to TV sets. Perhaps some day it will be possible for generalized speech recognition by computer to eliminate the human stenotypist and thus provide a completely automated real-time captioning system.

Speech Recognition

Programming a computer to recognize speech is a much more difficult task than programming it to speak. Considerable development effort has been and is being devoted to solving key problems in this area. Although some success has been achieved, and commercially available systems exist for certain applications, they tend to impose significant limitations on the speaker: preconditioning the equipment to the individual's speech characteristics, limiting the vocabulary size, speaking with brief pauses between words, etc. When these limitations are relaxed, the analysis programs become more complex, the computer spends more time executing these programs, and the accuracy of the resulting translation is degraded.

But when computing systems have developed to the point where they can handle the broad, general aspects of speech recognition and do so accurately, economically and in real time, there will be a large number of applications that can benefit deaf people: (1) telephone systems allowing deaf TDD users to communicate freely with hearing people; (2) fully automatic real-time captioning of television; (3) real-time display of classroom lectures replacing interpreters and note takers; and (4) perhaps the ultimate speech trainer. Such systems are not likely during this century but may begin to appear early in the 21st century.

Summary

In many ways, technology has tended to isolate hearing-impaired individuals. The telephone, radio, "talking pictures", tape recorders, and television are so pervasive in our society as to be taken for granted by many, and yet their inaccessibility to those who are deaf magnifies the disadvantage they experience. But technology is not only a villain ... it can also be a hero. Many devices that benefit deaf people have been referred to in this article, and the pace of such technology seems to be accelerating.

Some of this technology (hearing aids, TDD, and visible alarm systems, for example) can be relevant on the job. But, as mentioned in the introduction, the greatest impact of currently available technology on the employment of deaf persons is during the many growing-up years. Screening devices to identify hearing-impaired infants allow for early fitting of hearing aids and parental involvement in language development during those critical first years. Additional devices or systems that facilitate lipreading, speech, and reading can all contribute to improved communication skills, and to better educational preparation, and therefore to enhanced employment potential.

Although the attitudes of parents, teachers, counselors, and employers, and of deaf individuals themselves, are the most critical factors in preparation for and success in employment, technology is also playing an important role. An average salary 30% lower for deaf workers than for those who hear is not an acceptable prospect for the future. I hope that the combined effect of improved attitudes and advancing technology will result in enhanced employment opportunities and economic equality for those who cannot hear.

Kalisankar Mallik

Rehabilitation Engineering: Making the Disabled Person Able

The Fifth Institute on Rehabilitation Issues defined the objective of Independent Living Rehabilitation as "the ability of severely handicapped persons to determine their own destinies, to participate in all aspects of society, and to contribute, as well as share responsibility, in community life." The Institute further clarified that the statement of ability to actively participate in society means "to work, to have a home, raise a family, and generally share in the joys and responsibilities of community life."[1] The main purpose of this paper is to emphasize how rehabilitation engineering aids and devices enhance independent functioning of severely disabled persons in the areas of better positioning, improving communication, increasing mobility and other activities of daily living. After improving these skills, persons with various disabilities can be placed in gainful employment provided that their abilities are clearly matched with the job task requirements.

For most of us, preparation to enter the job market is a function of developing marketable skills through a process of socialization, education, and training experiences. If we add to this the additional burden of severe disabilities, the complexities of becoming "job ready" can be overwhelming. Opportunities for full participation in education and training programs may be hampered due to inaccessible facilities, classroom materials, and equipment. Instructors may lack appropriate skills or materials to teach students with learning disabilities. Socialization experiences may be limited due to mobility difficulties, limited exposure to the general population as a result of attending specialized institutions, and overprotective families and professionals. In addition to such problems, possible dependence on others for self-care activities (dressing, feeding, toileting, and personal hygiene) may directly affect a severely disabled person's vocational readiness.

As rehabilitation professionals we seek to help resolve or minimize the additional burden presented by severe disability through provision of appropriate services. Through research and demonstration projects conducted at the Job Development Laboratory, Rehabilitation Research and Training Center of The George Washington University, Washington, D.C., we have demonstrated that, with the provision of simple aids, devices, and techniques, many problems related to preparation for employment as well as to actual job performance can be eliminated or minimized. To illustrate this application, consider the following examples.

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1. "The Role of Vocational Rehabilitation in Independent Living," *Fifth Institute on Rehabilitation Issues* (Hot Springs: Arkansas Rehabilitation Research and Training Center, University of Arkansas), May 1978.

A high school student with spastic cerebral palsy had difficulty participating fully in his high school program due to his inability to take class notes and prepare written assignments. Since writing was a problem, this student was provided with a tape recorder for taking notes. Due to coordination problems, the tape recorder switches were difficult for him to press. Switch surfaces were added which extended from the existing switches at incremental lengths in a stepped pattern, thus adding a slight mechanical advantage to overcome this problem. Since this student could not write legibly, a solution was also found to allow him to prepare written assignments. The student was provided with a typewriter adapted with a keyguard to prevent his striking the wrong keys. Proper positioning was essential for this solution to work. A comfortable chair with arms and a back was provided to improve his stability. The typewriter was placed on a height-adjustable table set at a comfortable height for the student. With these simple devices this student was able to prepare his school assignments.

A student with severe disabilities attending a specialized program for slow learners was unable to understand and follow instructions for using some of the equipment in his classroom. For example, when instructed to turn cylindrical knobs on a standard record player, this student would pull the knobs instead. Since the student also lacked conventional grasp, the knobs were difficult for him to turn. To resolve these problems, the knobs were replaced with faucet-type knobs for greater mechanical advantage, and the knobs were tapered to prevent the student from pulling them. The redesign of these switches provided this student with additional stimuli in learning the correct method of using the record player (Figure 1).

A person with spinal cord injury, interested in attending a vocational training program, was concerned about his dependency on others for toileting. This person required frequent assistance in emptying his leg bag which collected urine. The problem of who would assist him in this activity while at the training facility as well as after he began working was a major concern and an obstacle to his vocational progress. Through careful analysis of the problem with this person it was realized that the problem could be eliminated if the leg bag were replaced with a larger urine container. A special box was constructed and attached under this individual's wheelchair seat to conceal a large plastic urine container. The tube attached to the large plastic bag was connected with the individual's catheter. With this simple modification this individual would not have to worry about emptying the container for up to 12 hours, thus removing a major obstacle to his vocational progress.

A 20-year-old individual with Werdnig Hoffman's disease of muscular atrophy was offered a job as a mail clerk provided he could do the job productively. This individual was functionally quadriplegic and used an electric wheelchair for mobility. Upper extremity functions were very limited although he had some pinch, grasp, and reach. The job functions included opening envelopes, stamping the contents, stapling when necessary, and sorting the mail into appropriate files. With the addition of simple aids and devices this person was able to demonstrate adequate productivity and obtain the job. A height-adjustable table was purchased to allow close wheelchair access and a comfortable work surface height. To facilitate easy sorting of mail, two mail sorters were designed according to ideal height and angle for this person. The slot design provided convenience of sorting mail by the clerk as well as easy removal of sorted mail by others (Figure 2). An electric letter opener was also provided to increase speed and reduce fatigue of opening mail manually (Figure 3).

A 27-year-old male is a quadriplegic of C-5, 6 level due to an auto accident in June 1964. His grasp is moderately impaired; coordination intact; balance severely impaired without the support of a wheelchair; dependent in dressing, except for putting on and taking off his shirt; dependent in bathing, except for upper extremity bathing; independent in hygiene; independent in eating, except for cutting meat; and can manipulate most items, except door

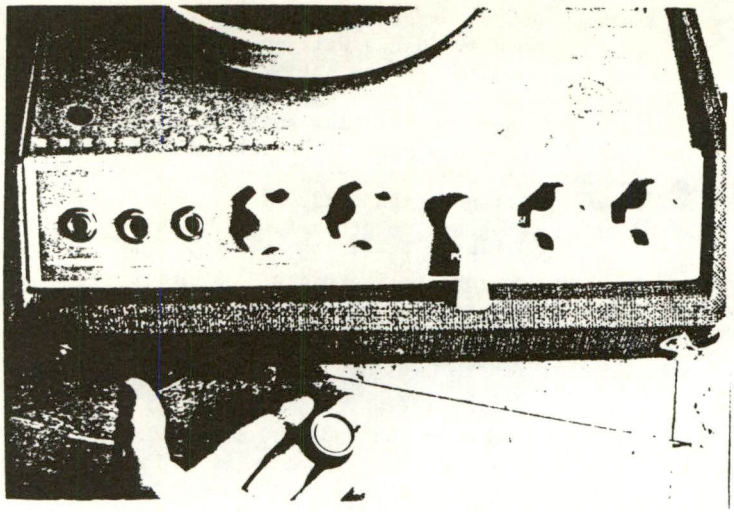


Figure 1. Adapted Record Player.

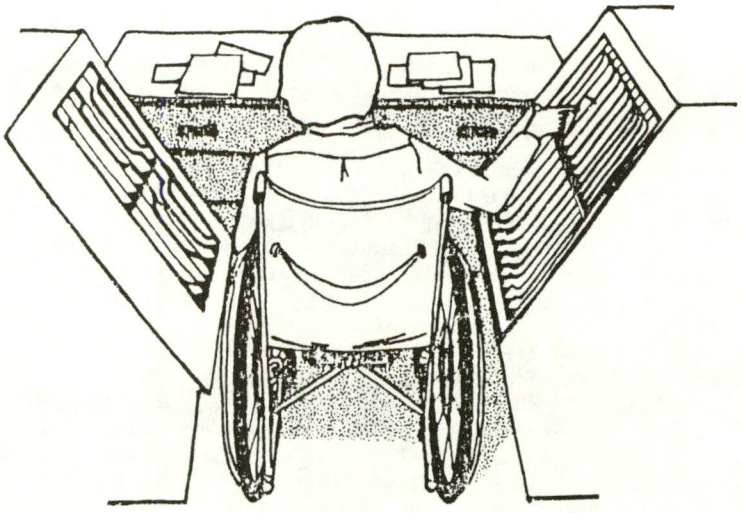


Figure 2. Table and Mail Sorter.

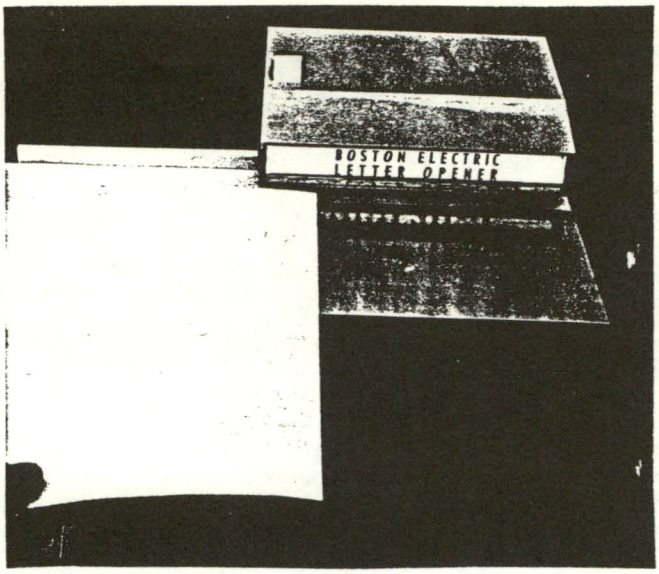


Figure 3. Electric Letter Opener.

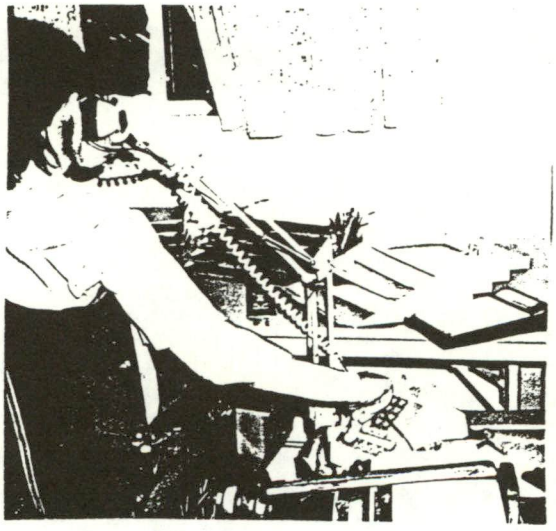


Figure 4. Home worksite of insurance claims specialist includes stack files for document access and telephone and recorder adaptations.

knobs, scissors, and paper clips. He transfers with a Hoyer lift, can write, can use a telephone with an extension arm for the receiver and a universal cuff to dial, and can use an adapted tape recorder. After the injury the client was known to local rehabilitation agencies for six years without successful vocational training and placement. In 1971 the client was trained in microfilm image inspection and worked successfully from his home on a part-time basis (5-10 hours per week) for two years. Being motivated to work full-time, the client was evaluated and trained for the position of insurance claims adjustor. Upon completion of training, the client was hired on a full-time basis as a homebound employee for the Insurance Company of North America (INA), Washington, D.C., at a salary of $7,800 per year. This client is now self-supporting and no longer needs to receive Social Security benefits of $176 per month. The physical functions involved for the position of insurance claims representative are (1) use of the telephone, (2) use of a tape recorder, (3) writing, (4) filing alphabetically, and (5) maintaining a cross-index by date, which he performs optimally using aids and devices (Figure 4).

These examples illustrate only a few applications of ways in which seemingly complex problems can be resolved using simple solutions. Although simple, they do require imagination, a little time commitment, some resources, and a willingness to experiment. Our experience has shown that providing such services can make the difference in preparing individuals with severe disabilities to enter the job market and, once employed, to become productive members of society.

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Barbara Wagreich

Technology for the Sensory Impaired: Present and Future

During the past decade, technology has made rapid strides in helping the physically disabled to lead more independent lives. For the visually impaired, notable advances have been made in reading aids, devices with synthetic speech output, and sturdier canes. For the hearing-impaired, the potential of electronic mail and closed-captioning technology are being realized. Let me first tell how technology has helped me.

Technology Advances

When I went to college in the late 1960's, I could read ordinary print, but with difficulty. However, there were no magnification systems at that time to reduce eyestrain. Xerox Corporation had developed a special process for enlarging print. I had many of my textbooks enlarged by Xerox, and I read other printed material with special glasses. It was necessary to get a copyright release from the publisher before a book could be enlarged. This often caused delays and misunderstandings about the reason for the copyright release. For instance, a publisher of a collection of articles insisted that I personally obtain copyright releases from each individual author of the articles. Some of them lived outside the country, including one in India, but they all cooperated. And a dean at Columbia University refused to give a copyright release for the introduction he had written for a translation of Goethe's *Faust* and had Columbia enlarge it for me.

After I graduated from college, two remarkable reading aids became commercially available: the Visualtek closed-circuit television magnification system, and the Optacon, a portable electronic device that translates the printed symbol into its tactual equivalent. With the Visualtek, it was no longer necessary to secure copyright releases and have material enlarged. All I had to do was place the printed material on the movable table under the Visualtek camera and read the magnified print comfortably on a TV-like screen. And the Optacon offered the same kind of independence to those unable to read the printed word visually. After some training, a user can read printed material by moving a scanner across the printed line and feeling the tactual representations on a tactile array with his forefinger.

When I started working as a programmer for Digital Equipment Corporation, I was using the Visualtek system to read printed material. My manager at that time was not satisfied with my tearing printouts from a computer terminal and reading them on the Visualtek. He wanted me to be able to read what I was typing or the computer's responses at the same time the normal eye does. So he designed and implemented an electronic transport system for the Visualtek

camera. It was mounted on top of a hard-copy terminal. Then I was able to read what I was typing or what the computer was printing out immediately by using a foot pedal to guide the Visualtek camera across the paper on the terminal. It was an excellent demonstration of "Yankee ingenuity" and "fitting technology to the disabled human being." It was custom-made for my work. Unfortunately, I couldn't use it after a while, because I lost my remaining vision.

Now in my work at Bolt Beranek and Newman, I use an Optacon and a braille computer terminal, as well as a print terminal. I have immediate access to all printed material, either on the computer or on paper (such as programming manuals, books and magazines). But these two tools are not without their shortcomings. I have wondered if either was designed with prolonged use in mind. Since the Optacon hand remains in the same position and there is no physical support for the wrist and thumb, I find that I experience cramps and numbness in the hand and lower arm after using it for an hour or more at one time. I have met two other Optacon users who have experienced similar difficulties. Yet, we're all grateful for the benefits the Optacon affords, and we have learned how to reduce the physical discomfort--by taking frequent breaks and spacing out our reading. The Optacon also requires good quality print and paper for maximum reading speed. The braille computer terminal also has its design flaws: the paper advances on vertical tractors and it is difficult to read braille in a vertical position. So the user cannot really read what's on the four lines just above the printhead, unless he struggles. The braille terminal also has a nonstandard keyboard, and the left shift key locks automatically every time it is depressed.

Electronic Mail System

I also use another tool in my work, but it is not a machine like the Optacon or braille terminal. Instead, it is a computer program. It is an electronic mail system that Bolt Beranek and Newman pioneered. This version is called Hermes (the messenger of gods in Greek mythology). This system enables a user to compose, send, read, store, index, and retrieve messages in his mailbox on the computer. Its advantage over the U.S. Postal Service is that messages are delivered immediately to the recipient's mailbox (unless his computer breaks down, and that happens). This permits a much faster exchange of messages, fewer interruptions, and more efficient communication. I am sure you have had experiences where it took more than a week for the Post Office to deliver a letter. Under optimal conditions, Hermes would deliver the message in less than a minute.

A group of deaf adults, families, and schools serving the deaf in the Greater Boston area have been participating in a 3-year HEW-funded project to demonstrate the feasibility of electronic mail communication for the deaf. The project ends in March 1981. The group has formed a separate organization, the Deaf Communications Institute, and is looking for a way to provide electronic message service after federal funding terminates. The advantages of electronic message communication for the deaf are: electronic messages do not require both parties to be on the computer at the same time (as the telephone would); electronic messages make it possible for large groups of users to receive the same information such as the news, weather, and group announcements; and electronic messages enable hearing-impaired people to communicate on the same basis with other electronic message system users.

Communications Devices

It is true that there is a deaf teletypewriter network. However, the equipment, Baudot terminals and nonstandard modem, is incompatible with modern computer equipment. There are now many more ASCII terminals in the homes of computer hobbyists and professionals than there are Baudot terminals in the hands of deaf people. It is intolerable for the deaf to be trapped in an

obsolete technology. Many deaf teletypewriter users feel their Baudot terminals were costly and do not see the wisdom of switching to an ASCII terminal they cannot use to communicate with others who have Baudot terminals.

Two other devices that were developed during the 1970's deserve special mention: braille watches and a communications device for the deaf-blind called the Tellatouch. The Tellatouch is a completely mechanical device, which looks and feels very tinny. The Tellatouch involves a modified typewriter keyboard and a one-character braille display. Each letter that the user types comes out in braille at the back of the typewriter. It is a nice concept, but the individual machines that have been manufactured in the last seven years are of very poor quality. The touch is not uniform at all and it is extremely difficult for even a good typist to type on it. It is also difficult for the deaf-blind person to read the output, because there is no place for his entire hand to rest comfortably. Rather, he must rest his forefinger on the braille display. Currently this device sells for over $300. An electronic version that will use a standard terminal keyboard is currently in the testing stage and is expected to cost at least $3500. It would also serve as a teletypewriter for telephone communication. Still, this is a price most deaf-blind people cannot afford.

To tell the time, a visually impaired user opens the lid of a braille watch and feels the position of the two hands. I own three braille watches. Earlier this summer, they all conked out within the same 24-hour period. I later learned that during humid weather, braille watches are more susceptible to breakdown. I am sure that the frequent contact of the finger with the hands brings in dirt and moisture that affect the mechanism. I have lost track of the number of times I have sent my watches to be repaired, and I have spent a goodly sum on repairs. This is an area that needs some fresh thinking. It is not a case of reinventing the wheel, but of improving an essential device.

Development Criteria

I have discussed briefly the devices I use and some of their shortcomings. What are the biggest problems that face needed devices? For the research and development stage, it is funding; for the manufacturing stage, it is the limited market; for the consumer, it is usually the high cost. What about devices that only one or two people want? History shows that this limited market is usually the first step in the dissemination of devices on a commercial scale. Let us now look at criteria for developing useful and practical aids for the disabled. This is by no means an exclusive list.

Feedback. Several members of the disability group for which the aid is earmarked should be involved in the project right from its conception. The disabled person knows what is best. He is the one who will use the device, not the developer or technician. Some time ago I saw a new device and commented on what I considered to be a poor design from the biomedical engineering point of view. I was told that users would have to adapt to the device.

Ease of Training. The disabled person should be able to learn how to use the device in a reasonable amount of time. There are some devices that do not meet this criterion, such as the Optacon. For most people, the Optacon training period is two man-weeks plus a lot of practice. But the Optacon is a major breakthrough and it has benefited those who have had the motivation to learn to use it.

Ease of Use. The disabled person should be comfortable in using the device for a long period of time. He should not experience any physical discomfort. And he should not be expected to adapt or adjust to the design flaws of the device.

Portability. The device should be as portable as possible, so that the disabled person can take it with him wherever he goes. This enhances the usefulness of the device. It should also be battery-operated, if possible.

Simplicity of Design. The assembly of the device should not be too complicated. This is an extremely difficult criterion to meet. But it is one of the key factors that determines the price.

Reliability and Maintainability. The device should be as immune to breakdowns as possible. Servicing should also be available. Computers are notorious for their record of failures. As more and more devices use microcomputer technology, one of two things will have to happen: either the user learns not to become a slave to the device, or the device learns not to break down!

Funding. Funds must be made available at all levels of development. I would welcome the opportunity to sit on a review board to select proposals for grants and contracts.

Reasonable Market Price. The device should be reasonably priced. Most disabled people cannot afford to pay for devices whose cost is at least four digits. It is a myth that the government will pay for expensive devices. And it's no comfort that the cost is tax-deductible, because most disabled people just don't have the money to pay for them. An article in the *Wall Street Journal* on August 26, 1980, estimated that at least 40 percent of disabled people pay for their special devices themselves.

I have felt that there has been the least effort in the development of prostheses for the profoundly deaf and deaf-blind. It's true that there has been much research and development for the visually impaired, but the concerted effort seems to be mainly in devices with synthetic speech output. Such devices won't be of any use to the deaf-blind.

Areas Needing Research

Here are some areas that can use research and development efforts. While they would benefit the deaf-blind, they would also be very valuable aids for the larger groups of consumers who are visually-impaired or hearing-impaired.

- More efficient and powerful braille computer terminals.
- Large-format paperless braille displays. (The most popular paperless braille display now available costs close to $5000 and has a twenty-character display, which is too small.)
- Braille watches. (They are extremely fragile and very costly to repair.)
- A tactile hearing aid that would notify the user of important signals (such as the doorbell, telephone, or smoke alarm).
- Signalling systems that inform the hearing-impaired person when the doorbell, telephone, and other signals are activated. They should not require hardwiring or very costly devices. When I discovered that there are no reasonable signalling systems commercially available, I asked a friend who is an electrical engineer if anything could be done to develop a system that would not require extensive hardwiring. He is presently working on the problem. He predicts that if his design is successful, the signalling system should cost less than $800 commercially. Yet this is a sum that is beyond the reach of most deaf people.

- Intelligent terminals at a reasonable cost for the deaf so that they can access a central electronic message system to communicate with others.

- A cane that would use ultrasonic sound radar to give the user tactual information about upcoming obstacles and their positions. Most advanced mobility aids currently available require hearing and much training.

- Communications devices for the deaf and the deaf-blind.

You have probably heard that several major television networks (ABC, NBC, and PBS) are offering programs that have "closed captions" in them for deaf viewers who have a decoding machine. These machines are being sold by Sears for $250. Since March of this year, Sears has sold more than 24,000 decoders, and I think there's still a backlog of orders. It is true that the market is much bigger for decoders than for, say, a braille computer terminal. I have heard that the quality of print is disappointing, but that does not seem to be a deterrent to success. I myself cannot use a decoder, but I am glad to see that it is helping so many hearing-impaired people. Electronic mail is much more costly now, but I hope that in the not-too-distant future it will be as reasonable as a decoder.

More than 200 years ago, our forefathers signed the Declaration of Independence, which has given every American certain inalienable rights. I would like to emphasize that it is essential to view a disabled person first and foremost as a human being with the same rights and privileges as any other American. A disability becomes a handicap only when it interferes with his independence. As more and better devices are developed and marketed, the distinction between disabled people and their nondisabled contemporaries will be reduced at work and at home.

5 Low Technology/High Technology

Arthur Boothroyd

Communication Aids for the Deaf

Man is, among other things, a social creature. Social organization requires communication, and in man the most effective and widely used medium for communication is spoken language. The natural development of spoken language skills requires an intact hearing mechanism. Hence the devastating consequences of hearing impairment.

Among the many approaches to solving problems associated with hearing impairment, the technological approach has great appeal. "Why," we are asked, "in an age when men can walk around on the moon, can we not develop devices that will eliminate the communication problems of the deaf?"

Much progress has been made in this direction, but nevertheless, a technological solution still eludes us. The history of our efforts might best be described as 50 years of encouraging feasibility studies.

In this paper I will review the current status of communication aids for the deaf and discuss possible reasons for the elusiveness of technological solutions.

Speech Perception and Training Aids

Auditory Devices

The most universally used communication aid is the hearing aid. In technological terms this is also the simplest aid. It accomplishes little more than amplification--making sounds louder so that they become audible to persons with elevated thresholds.

In recent years much progress has been made in miniaturization. Modern behind-the-ear aids can provide as much power, fidelity, and versatility as is needed by all but a small minority of users. There has also been a widening recognition of the need for power limitation and compression circuitry to protect users from the pain and discomfort of excessively amplified sound. Tone control circuits make possible the selective suppression of low frequencies, to reduce the masking effects of environmental sound, or of high frequencies, to reduce the problems of acoustic feedback.

Another way of reducing acoustic feedback is to separate the microphone from the rest of the hearing aid and to place it on the opposite side of the head. This arrangement is known as a CROS (Contralateral Routing Of Signal)

fitting and was originally developed for individuals with a one-sided hearing loss.

A major problem with hearing aids is the poor signal and signal to noise ratio caused by the long distance from the microphone of the aid to the mouth of the talker. In educational settings this problem has been solved by the use of wearable FM wireless microphones that transmit to miniature wireless receivers worn by the students.

There are, of course, limitations to the effectiveness of hearing aids. They make sound louder, but can do little or nothing to improve the discrimination ability of ears with severe or profound sensorineural hearing impairments. Nevertheless, hearing aids represent one of the few examples of a technology that has been applied effectively. Because of the wearable hearing aid, countless individuals are now functionally hard-of-hearing who in former years would have been classified as deaf.

There have been many attempts to improve the effectiveness of hearing aids for persons with only rudimentary auditory capacity by manipulation of the frequency domain. The most popular approach has been frequency transposition--taking high frequency information and regenerating it in the low frequencies. An alternative procedure is "vocoding," that is, the analysis of the acoustic spectrum into discrete frequency bands, the extraction of amplitude information from those bands, and the superimposition of that information on new, more audible, sounds. Both vocoding and frequency transposition have been shown, in research studies, to have potential value, but neither has found extensive practical applications.

Tactile Devices

If amplified speech signals are fed to a mechanical vibrator they can be detected via the sense of touch. Unfortunately, however, the skin is a very poor substitute for the ear. One limitation of the tactile sense is that it responds very badly to high frequencies. Another limitation is its inability to separate complex sounds into their component frequencies. Contrary to the hopes of some individuals, deaf children cannot learn to "hear" with their fingers. In spite of these limitations, single-channel vibrotactile stimulation provides a significant supplement to lipreading: it allows improved control of voice level and voice quality, and it can be a valuable aid in speech development.

Tactile vocoding--that is, the representation of different frequency bands at different places--has been attempted with both mechanical and electrical stimulation of the skin. Clinical tests have demonstrated a superiority over single-channel vibration, but, as with auditory vocoding, the technique has not found wide application.

Visual Devices

Most of the research on instrumental speech training aids has concentrated on the visual modality, this being the modality with an information-handling capacity compatible with that of hearing. Engineers have, of course, had to deal with the fact that vision is well adapted to the processing of spatial patterns, but handles temporal patterns poorly. Since speech, like all sound, is primarily a temporal pattern, some way must be found of representing time in space.

Practical systems have provided visual displays of such things as intra-aural pressure, fundamental frequency, voicing, surface vibrations of the nose and larynx, duration, and acoustic spectrum. Format has ranged from the ultra simple, in which a single light indicates the presence or absence of a particular feature, to the sophisticated, in which a digital computer controls

both the extraction of information and the nature of the visual display. Numerous research studies and trial applications have been undertaken, most with very encouraging results. Nevertheless, visual speech training aids are not in widespread use in educational programs for the deaf, nor are they considered by teachers of the deaf or speech pathologists working with the deaf to be an essential component of the instructional armamentarium.

Most of the visual speech training aids to which I have referred have been non-wearable, and are therefore restricted to speech training applications. There have, however, been two attempts to develop wearable speech perception devices in which the visual display is attached to the frame of a pair of spectacles and viewed via a tiny mirror glued to the center of the lens. Once again, however, we can point to nothing more than encouraging feasibility studies when we look at the history of application.

Neural Devices

The idea of bypassing a defective cochlea and making direct electrical connection with the auditory nerve has great appeal. There are, of course, enormous surgical and technological problems to be tackled in implementing such an idea, but many have been overcome, and at the time of this well over a hundred individuals have had implanted the necessary electrodes and subcutaneous stimulating devices. Most of these have provided only a single channel of electrical stimulation and, like single-channel tactile devices, are limited to the provision of time/intensity information, because frequency resolution is extremely poor. As would be expected, single-channel stimulation provides awareness of sound; discrimination among, and recognition of, sounds having characteristic time patterns; a small but significant improvement of lipreading performance; and improved control of speech loudness and voice quality.

Implantation of multichannel devices--neural vocoders--has been undertaken by some surgeons, but unequivocal evidence of their superiority over single-channel devices has yet to be provided.

Other Communication Aids

The discussion so far has focused on problems of speech perception and speech development. There are also some less demanding aspects of communication for which technology has much to offer.

Paging and Signalling

The conversion of auditory signals, such as those generated by doorbells, telephones, alarm clocks, and paging systems, to visual or tactile signals presents only trivial technical problems. Many such devices are now in use by the adult hearing-impaired. Some are available commercially, others must be made by hand.

Telecommunication Aids

One of the most significant of recent practical developments in this field has been in the use of telephone communication lines for the transmission of typed messages among deaf users. Starting with the renovation of obsolete teletypewriters, this work has expanded in two directions. One is the development of portable battery-operated keyboard units with built-in couplers. The other is the establishment of special services such as the relay of emergency messages, the provision of terminals at airports, and the provision of special long-distance rates by telephone companies.

One limitation of the teletypewriter concept is the need for a coupler, decoder, and display at the receiving end. Recent developments in speech

synthesis, however, make it possible for the keyboard input to be converted to artificial speech before transmission over the telephone line, obviating the need for special equipment (assuming, of course, that the message recipient has normal hearing). Special audio signals, such as those generated by the touch-tone dialing system, can then be used for the return message.

In a related development we are now seeing increasing use of "closed captioning" by the commercial television networks. The rapid expansion of this and the telecommunications work has been made possible by developments in computer technology, particularly those related to the design and mass production of complex circuitry and computer memory within tiny circuit components, or chips.

Problems

In the foregoing I have attempted to provide an overview of the approaches that have been taken in the search for technological solutions to the communication problems of the deaf. I have also tried to emphasize how little of this work has found real application, especially in the areas of speech perception and speech development. In this section I shall examine some of the possible reasons for the apparent failure of much of this work.

Linguistic and Cognitive Variables

The pressure for technological approaches to speech training and speech perception has come primarily from scientists rather than from educators. This tendency is understandable but carries with it the seeds of failure. The designers of speech analysis and display systems have been largely unaware of the cognitive, linguistic, social, emotional, and educational underpinnings of the functions they wish to influence.

They have dealt essentially with one dimension of a complex multidimensional problem. They have assumed, rather naively, that the demonstration of feasibility and objective benefits would be sufficient to guarantee application. In reality the problems to be dealt with after the demonstration of feasibility are several orders of magnitude more severe than those dealt with before.

Several writers on this topic have emphasized the need for collaboration between researchers and educators. Such collaboration is, unfortunately, difficult to establish. Each group is grappling with different problems; each has a different perspective on hearing impairment; each has a different set of priorities and a different system of motivations and rewards. These differences render true communication almost impossible, and without communication there cannot be meaningful collaboration.

Distribution and Selection

Even if we had effective speech perception and speech training aids, we would still need a corps of professionals who could evaluate potential users, select devices, adjust devices to the needs of the users, monitor performance, train and advise teachers and parents, etc. Such a corps does not exist. We are not even able to provide the proper kind of professional support for the selection, fitting, and monitoring of hearing aids within the context of educational programs for hearing-impaired children.

Dissemination

The potential use of new technologies by the adult deaf community is limited, in part, by a failure of information flow. Deaf people frequently receive either no information, or, via the grapevine, misinformation about potentially significant developments. Sometimes, when information is

disseminated, it is misunderstood because the writers of brochures or press releases are unaware of the language levels of the typical deaf adult.

Economics

A major obstacle to commercial development of communication aids for the deaf is an economic one. Since deafness only affects about one person out of a thousand, the potential market for new devices is small. This in turn means higher risks for manufacturers and higher costs for consumers--a particular problem for the deaf community since its members are, in general, underemployed.

Some federal and state agencies provide support for the purchase of certain kinds of communication aids, but regulations and criteria vary from state to state and from agency to agency. Once again we can turn to a successful technology, the hearing aid, to illustrate regional variations of financial support. Some states have provided 100 percent of the cost of hearing aids for children, regardless of parents' financial status. Others have provided no support at all.

Summary and Conclusion

It is clear that modern technology has much to offer in helping to minimize the communication problems of the deaf in educational, vocational, recreational, and social settings. Potential has been transformed into reality, but only to a limited extent. Good examples of practical application are to be found in hearing aids, telecommunication devices, and TV captioning.

The disparity between potential and reality is attributable to many causes, but perhaps the most serious has been a tendency to underestimate the true magnitude and complexity of the impact of hearing impairment on human development and function. Further progress will require attention to the following issues:

- The need for meaningful dialogue and interaction between technologists, researchers, teachers, and clinicians.
- The need to prepare professionals who can distribute and select technical aids, match aids to users, and train users and professionals in the operation of aids.
- The need to establish systems for distribution of technical aids.
- The need to improve the dissemination of reliable technical information to the deaf community (and to parents of deaf children).
- The need to provide financial support for the acquisition and maintenance of technical devices.

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William E. Castle

Application of Telecommunication Devices in the Education of Deaf Adults

My contribution to today's panel deals with the application of telecommunication devices in the education of deaf adults. With your indulgence I will address the topic in the context of the National Technical Institute for the Deaf (NTID) at the Rochester Institute of Technology (RIT) because I believe the application of such devices in such a context has great generalizability to others.

The broad outline I will use will be four main topics: telephone systems, television systems, computer systems, and other special systems.

Telephone Systems

It is singularly ironic that telephone systems that have grown out of the 1876 invention by Alexander Graham Bell, a teacher of the deaf, have not until the 1960's, the 1970's, and now the 1980's, been readily available for use by deaf persons. Today they are available in several ways, all of which are illustrated in the special telephone training classroom at NTID. In each of the eight student stations in this classroom there is a telephone receiver with a built-in amplifier. Deaf students with good spoken language and appropriate usage of residual hearing can, with such a receiver and their hearing aids, use the telephone as you and I do. Others who are not so adept with spoken language or residual hearing may use such a receiver with special codes that they may have worked out with friends or family.

A battery-operated amplifier is also available to attach to receivers that do not have the built-in amplifier.

When amplification is not available, and for deaf persons who cannot use such amplification, telephone systems are made accessible through devices known as teletypes, because of a special acoustic coupler invented in the 1960's by a deaf man, Dr. Robert Weitbrecht, at a time when he was employed by Stanford Research Institute. Many teletype devices are on the market today, including the model 32 TTY, which has the advantages of hard copy and a recording unit for those who call but do not reach their party. It has the disadvantage of not being portable.

Among portable TTY's are the Micon MCM and the Porta-Tel, both of which include circuitry that allows presentation of messages through a lighted Times Square-like mode. The Porta-Printer allows for hard copy messages, while the TV phone allows one to use the picture tube of one's home television

to receive messages and to monitor the messages being sent. There is a pocket sized TTY unit known as the V-I-P, which allows certain deaf persons to communicate with others with or without the telephone.

The ideal telephone system for all deaf persons is the Vistaphone, uses the design of closed circuit television and allows the parties to see one another.

For the deaf-blind, there is the Code-Com unit, which allows transmittal of Morse code to be picked up by the tactile sensory mode. There is today also the capability for transmitting braille, but it is very expensive.

A telephone accessory that is useful for persons who are hard of hearing is known as the Fone-A-Lert. It will help the individual to know when the phone is ringing. For deaf persons, an accessory known as the "sound lamp" is used; the ringing of the phone prompts the lamp to go on.

Television Systems

At NTID a great deal is done instructionally with television systems. Of course, we do not ignore the entertainment potentials. Both are taken into consideration as we process through the versatile television distribution system programs from four channels in Rochester, two channels in Buffalo, one channel in Syracuse, live productions in NTID studios or the central studio of RIT, and specially designed pre-taped programs for instructional purposes. One channel is used to process, on a continuing basis, captioned UPI news, local messages, and the time.

Further illustrating the versatility of television systems are the specific ways in which the NTID color production studio has been used. Taped interviews with graduates from NTID who tell about their post-NTID life, including how they are faring on the job, are a very useful instructional tool. Special programs have been designed to teach policemen about deafness. Entire courses in pronunciation have been put on videotapes, using Webster's diacritical markings; in fact, NTID required that a special ball be designed by IBM to allow for expeditious typing of diacritical markings, both for purposes of TV and other purposes. Television systems are also used for evaluations of interpreters or teachers in training and in action.

Of course, a great deal is being said about captioned television these days because of the closed-captioning system, the special decoder, and the newly established National Captioning Institute (NCI). A great deal of captioning is done at NTID for both instructional and entertainment purposes. There is the typical approach to captioning; but NTID also uses the captioning done by NCI. In addition, for films that may be shown on TV or otherwise, a special system for captioning has been devised which uses a film strip that is tripped as the motion picture film is processed, by virtue of a special timing code track which is put on the motion picture film next to the audio track. Balloon captioning has been tried to simulate intonation. There is also a special device to prompt color separation of various printed matters on film. Finally, in the absence of captioning, there can also be interpreted television.

Computer Systems

The age of computers prompts its own kind of invention, of course. Why not, therefore, the NTID DAVID System, which combines computer power with television power to allow for interactive self-instruction in such things as speechreading, auditory training, and sign language? Why not, therefore, make use of time-sharing possibilities such as the PLATO system, which has its home base in Illinois? Why not, therefore, the use of minicomputers, such as the Apple, to expose all of one's students to computers?

Special Systems

Finally, the broad category of special systems allows for a cursory introduction of a number of special uses of telecommunications and telecommunication-related technology. At NTID there is a ten-carrel classroom for teaching speech communication and a high utilization of spectrographic information for CRT visual feedback to the student regarding his or her speech production. There are special systems for auditory training which allow students to speak to and listen to one another as though they were using a vistaphone. There is a 21-carrel self-instruction classroom in which at 21 different student stations, students can use video cassettes or audio cassettes to help improve their receptive and expressive communication skills.

Classrooms at NTID are generally designed to allow for a highly versatile and flexible usage of audio systems, television, and other visual systems. All of these are controllable by the instructor through a remote control panel.

Within the NTID English Learning Center a system known as Glossynography is heavily utilized. It is basically a system that provides for real-time captioned presentation of what is also being spoken by the instructor. It is designed to force the student to read well-constructed sentences in English as he or she listens to the spoken word through whatever residual hearing may be extant.

Finally, I bring to your attention a special use of television monitors for monitoring how well deaf photography students operate in darkrooms. A special use of infrared rays allows the instructor to observe from outside the darkroom what is happening inside. The system has the effect of putting light into the darkroom with no adverse effect on film development. Without it, of course, the instructor would, like the student, be left completely in the dark.

F. Brantley Scott

The Artificial Sphincter in the Management of Incontinence in the Male

Though the artificial sphincter was developed for primary application to patients with neurogenic bladder dysfunction,[1-4] it has had effective application in the male who has suffered urinary incontinence secondary to urethral injury. The data presented in this paper concentrate on those males who have suffered injury to the continence mechanism as the result of radical prostatectomy, transurethral prostatectomy, posterior urethral surgery, or accidental trauma resulting in pelvic fractures and disruption of the urethra.

The following are the objectives imperative for the development and application of this prosthesis for urinary incontinence:

1. A prosthesis that could be used in both males and females.
2. A prosthesis that would produce urethral occlusion effective for urinary control, but which could so open as to allow free voiding with no interference of flow.
3. A prosthesis that would open automatically should unphysiologic bladder pressures develop owing to detrusor contraction, but that would automatically increase its occlusion should stress occur.
4. The occlusive mechanism and the pressures applied should be automatic and inherent within the design of the prosthesis itself.
5. Should the prosthesis fail, the patient should be no worse off than before.
6. Its implantation should not require extensive alteration of the urinary tract.
7. It should allow subsequent repeated endoscopic procedures if necessary.
8. It should not interfere with sexual function in either the male or the female.
9. It should be dependable for the life of the patient.

The Genitourinary Prosthetic Sphincter

The artificial sphincter that will be described in this article includes two different types. Though the first type, which I initially implanted in June 1972, has undergone many improvements and modifications in its construction and in the

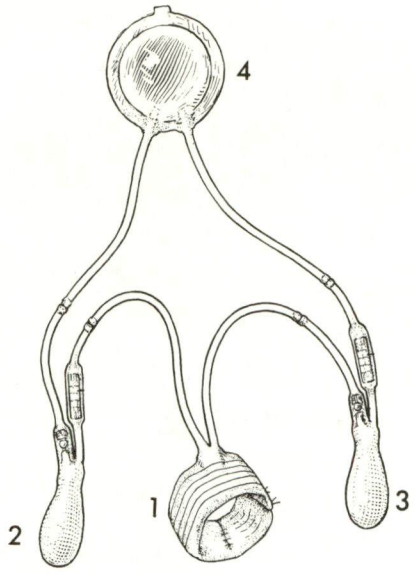


Figure 1. The AMS AS721 artificial sphincter consists of (1) cuff that encloses the urethra, (2) inflating pump, (3) deflating pump, and (4) reservoir that houses fluid and serves to equalize pressures of stress. The valves control direction of flow and the occlusive pressure.

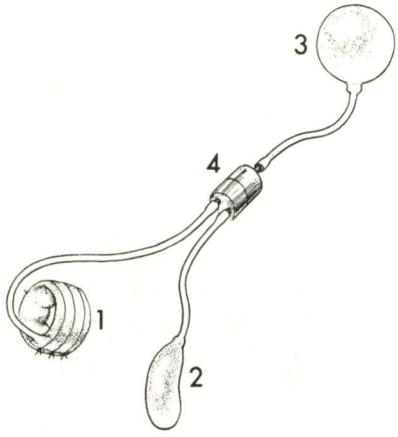


Figure 2. The AMS AS742 artificial sphincter consists of (1) cuff, (2) pump, (3) balloon, which controls pressures at a level safe for arterial circulation, yet provides occlusion, and which also senses changes of pressures owing to stress, and (4) a control assembly that opens the cuff in response to pumping and closes the cuff automatically.

techniques used for its fabrication, it remains essentially unchanged from its original concept. This artificial sphincter has been manufactured by American Medical Systems in Minneapolis, Minnesota, and has been given the code number AS721.

The AMS AS721 Artificial Sphincter

The AS721 (Figure 1) consists of four main parts:

1. An occlusive cuff, which encircles the urethra.

2. A reservoir, which contains the fluid used to activate the device.

3. An inflating mechanism.

4. A deflating mechanism.

The deflating and inflating mechanisms each contain two valves; these valves control the direction of flow of the fluid as the patient squeezes the device. The number 4 valve on the deflating side also controls the pressure that is applied to the urethra. This valve bleeds off excessive pressure regardless of how many times the patient squeezes the pumps, which are placed in either the scrotum or the labia for easy accessibility and manipulation by the patient. The pressure generated by the number 4 valve is that pressure sufficient for occlusion but less than the patient's diastolic blood pressure, allowing perfusion of blood into the tissues contained and occluded by the cuff.

To operate this device the patient squeezes the pump, which has been placed in the scrotum or labia. Squeezing the pump, which lies in a subcutaneous position, transfers fluid from the reservoir into the cuff. The number of squeezes is not critical since excessive squeezing merely forces fluid on through the deflating pumping mechanism and back into the reservoir. The number 4 valve maintains occlusive pressure against the urethra until the patient is ready to urinate. Then the patient squeezes the pump in the left side of the scrotum or labia. This transfers fluid from the cuff into the reservoir and creates a vacuum inside the cuff, thus removing all occlusive pressure from the urethra. Once urination has been completed, the patient then repeats this process. Because of the intra-abdominal placement of the reservoir, the pressures of stress generated against the bladder are offset by the same pressures generated against the reservoir. This arrangement is necessary to permit a temporary transient increase in pressure in the cuff exactly equal to those pressures created by stress. The ideal location is achieved by attaching the reservoir to the posterior rectus sheath, placing the reservoir between the rectus muscles and the peritoneum.

The AMS AS742 Artificial Sphincter

The AS742 (Figure 2) appears to be a much simpler prosthesis and apparently more reliable than the AS721. It consists of the following parts:

1. A cuff that encircles and occludes the urethra.

2. A balloon that delivers to the cuff sufficient pressure to close the urethra, but insufficient pressure to strangulate the blood supply within the urethra. The balloon, which is implanted inside the abdominal muscular cavity, also equalizes intravesical and intracuff pressure during stress, so as to prevent stress incontinence.

3. A pump, which when squeezed in its intrascrotal or intralabial position activates the control assembly causing the cuff to open.

4. The control assembly, which has three functions:

   a. It transfers fluid from the cuff to the balloon in response to squeezing the pump, thus releasing pressure against the urethra to allow voiding.

   b. It slowly allows the fluid in the balloon to then return to the cuff for repressurization, giving the patient sufficient time to void before repressurization and automatic closure.

   c. It releases pressure from the cuff in response to high unphysiologic bladder pressures produced only by detrusor contractions.

To operate the AS742, the patient simply squeezes the pump several times, causing a transfer of all the fluid from the cuff and pump into the balloon. This, of course, opens the cuff, allowing urination. The control assembly contains a resistor that allows the fluid to slowly return from the balloon back into the cuff and pump for automatic closure.

Basically, both of these prostheses are produced with silicone rubber. The production process avoids all vulcanized seams whenever possible, and the integrity of the device is checked by both pressurization and electrical detection, as part of the quality control procedures. It is important for the surgeon to take great care in avoiding any scratching of the surface of the prosthesis, which can weaken it; this is particularly true of the balloon.

While the automatic closure feature of the AS742 represents one of its primary benefits, this also can be its only disadvantage. Because of this feature, it cannot be left in the "open" position, and since the pressures applied automatically are greater than venous pressure, this prosthesis cannot be used around the urethra coincident with urethral reconstruction, since in such cases impairment of venous drainage could result in poor healing. This device is particularly suited, however, for that group of patients presented in this article.

Patients Treated

Etiology of Sphincter Injury

Forty-one patients have received one or the other of the artificial sphincters described. Eleven patients had total urinary incontinence as a result of radical prostatectomy. Seventeen patients had incontinence as a result of sphincter injury created by transurethral prostatectomy. Ten patients were incontinent as a result of pelvic fracture causing disruption of the membranous urethra. Three patients received injury to the sphincter as a result of urethral surgery: (1) a 30-year-old man who had injury to the posterior urethral valve resected during infancy, (2) an 11-year-old boy who received injury to the sphincteric mechanism as a result of a Y-V plasty, and (3) a 37-year-old man who received injury to the sphincteric mechanism caused by multiple transurethral procedures performed in an effort to eradicate prostatitis.

Previous Procedures

There were 14 patients who had undergone previous operative procedures in an effort to cure their urinary incontinence. The procedures that had been performed on these patients included transfer of the gracilis muscle around the urethra, the transcrural procedure described by Kaufman, the implantation of the Berry prosthesis, the implantation of the silicone pillow prosthesis (Kaufman prosthesis), the placement of a fascial sling around the urethra, the Tanagho procedure, the spiral Flock's flap procedure, as well as the injection of teflon paste around the urethra and the reduction urethroplasty procedure described by Leadbetter. All these procedures had, of course, contributed to the difficulty of applying the artificial sphincter because of the previous surgical dissection and fibrosis.

Preliminary Treatment

A number of procedures were necessary in order to prepare the patient so that he would be a suitable candidate for the inflatable artificial sphincter. Several patients who had post radical prostatectomy incontinence also had obstruction owing to fibrosis in the area of the membranous urethra. In order to improve the urodynamics of their voiding, these patients underwent transurethral resection of a segment of this fibrotic stricture until an excellent flow rate was obtained, before implanting the artificial sphincter. Two patients underwent urethral diverticulectomy to eliminate the stagnating infected urine puddling in a large diverticulum. Two patients required removal of the silicone-gel prosthesis before they were suitable candidates for the artificial sphincter because of an infected eroding prosthesis, and because of the obstructive, yet incontinent, effect of the prosthesis. Several patients previously had, and continue to have, chronic urinary tract infections resistant to treatment. One of these persists in its infection because of multiple prostatic calculi, and another because of prostatic urethral diverticula. All patients were treated for their infection, and in those who had no infections, prophylactic antibiotics were administered. Garamycin as well as Staphcillin are administered to achieve a satisfactory blood level prior to the operation. Parenteral administration at least three hours prior to the surgery, during the surgery, and for 24 hours following the surgery was sufficient. Those patients who had chronically infected urinary tracts were treated for a minimum of seven days prior to the operative procedures, and no operative procedures were performed until two urine cultures disclosed no evidence of bacteria.

Evaluation

Urodynamic Evaluation

All patients had uroflowmetry in order to ascertain whether or not there was obstruction to the outflow of urine. The great majority of these patients were totally incontinent and, therefore, temporary occlusion of the urethra by a clamp allowed filling of the bladder in order to obtain the urinary flow rate. The post-voiding residual was determined either by direct catheterization, or in some cases, by the post-voiding film on the intravenous pyelogram. Routine cystometry was performed to detect any evidence of bladder instability.

Urethral pressure profilometry was performed in the majority of patients in an effort to detect points of obstruction along the course of the urethra and to assess the severity of the injury to the continence mechanism, though the occlusive effect of the profile catheter gives false high pressures in the area of the sphincter in some patients. In a very few patients, pressure-flow studies were obtained to rule out evidence of obstruction. By obtaining pressure and flow, resistance defined by P/F^2 was calculated. If this figure was greater than 1.0, some surgical procedure was required to treat the obstruction.

Cinefluorography

A voiding cine cystogram was obtained in all cases to detect abnormalities created by urethral diverticula, strictures, and reflux, as well as to aid in the selection of the appropriate site for placement of the occlusive cuff.

Bacteriologic Studies

Of course, all patients had a careful urinalysis, but in addition, serial urine cultures were obtained to detect any evidence of infection. Sensitivity studies were done to aid in selecting the antibiotic of choice in those cases with infection.

Endoscopy

Panendoscopy was done in all cases, not only to evaluate the urinary tract for incidental pathology, but also to aid in the selection of the appropriate site for placement of the occlusive cuff. Panendoscopic evaluation of the post-operative result was performed in some cases, though this is not required as a general follow up procedure.

Surgical Technique for Implantation

Placement of the Cuff Around Bladder Neck

Most of the males who have received injury to the continence mechanism should have the cuff placed around the bulbous urethra. Placement of the cuff around the bulbous urethra is technically easy in comparison to placement of the cuff around the bladder neck. However, if the bladder neck has not been traumatized, and if the patient is anxious to maintain his fertility, placement of the cuff around the bladder neck will separate the urine from semen, preserving fertility. I have found that if one encounters significant difficulties in dissecting around the bladder neck, that the bladder should be open for direct visualization of the bladder neck during the dissection. However, in most cases, unless there has been extensive trauma and fibrosis in the area of the bladder neck, dissection around the bladder neck can be achieved by the following technique:

A large Foley catheter is placed in the bladder for palpation of the balloon at the bladder neck. The endopelvic fascia adjacent to the bladder neck is opened to allow the introduction of the thumb and the index finger of the left hand. With the thumb and the index finger one can palpate the catheter, the trigone, and, posteriorly, each vas deferens. The trigone can be pinched anteriorly, separating it from the vas deferens. Right angle dissecting scissors can be used to dissect against the fingers, which contain the catheter and the trigone in an anterior position. This then allows dissection precisely between the bladder neck and the ejaculatory mechanism. Dissection in this location will not disturb the ejaculatory or erectile sexual function. Once dissection around the bladder neck has been accomplished, retraction of the bladder neck by means of surgical tape and the introduction of a vein retractor exposes and allows suture ligation of the venous bleeding that usually results from this dissection. The distance around the bladder neck is then measured and a cuff of appropriate length is selected and passed into position. The cuff is secured by means of the sutures lying in its back, thus creating an encircling cuff.

Placement of the Cuff Around Bulbous Urethra

The placement of the cuff around the bulbous urethra is easier (Figure 3). A perineal incision is preferable and is placed over the posteri or bulbous urethra, palpable by means of a urethral balloon created by cutting the finger from a rubber glove and securing this finger to a Robinson catheter (Figure 3a and b). Inflation of the urethra by means of air contained within this balloon allows ready palpation of the posteri or bulbous urethra and facilitates dissection. In addition, this technique of inflating the urethra helps to define precisely the plane of dissection between the urethra and the adjacent pelvic fascia (Figure 3c). The bulbo cavernosus muscles are divided in the mid line and retracted laterally, exposing the urethra and its enclosing spongiosum. Dissection laterally exposes the pelvic fascia immediately adjacent to the urethra. Traction on a stay suture placed on each side of the urethra in this fascia delivers the urethra into the wound. Tension created by traction on this fascia also helps to define the cleavage plane of dissection that needs to be followed by delicate dissection between the urethra and this adjacent fascia (Figure 3c).

The 12 o'clock position of the urethra in this area is quite friable and thin. It should be treated with care and delicate dissection. Upon completion of dissection around the urethra, the urethra is inflated with fluid (after removing the glove finger balloon) to check to be sure that there has been no inadvertent injury to the urethra.

The space around the urethra needs to be enlarged until it will readily accept the cuff (Figure 3d). A cuff of appropriate length is pulled into position and secured by tying the sutures lying in its back (Figure 3e). In addition to enclosing the urethra with the inflatable cuff, a malleable stainless steel strip of metal enclosed in silicone rubber is also secured around the cuff, also by tying sutures lying within its back (Figure 3f). This metal enclosure serves to protect the cuff, so that upon sitting the patient does not compress the cuff, causing the artificial sphincter to open.

The tubing of the cuff is secured to the end of a tubing needle (Figure 3g), and the tubing needle is used to carry the silicone rubber tubing of the cuff through a subcutaneous position anterior to the pubis into a left inguinal incision. The left inguinal incision also allows blunt dissection into the left side of the scrotum for placement of the pump (Figure 3h). The inguinal canal is opened, as well as the floor of the inguinal canal, to allow the introduction of the dissecting finger to create a space between the bladder and the pubic ramus for the introduction of the pressure controlling balloon (Figure 3i). After closure of the inguinal canal, the excess tubing coming from the balloon, the cuff, and the pump is trimmed and then connected to the appropriate three connectors that extend from the metal control assembly (Figure 3j). The tubing is secured to these connectors by ligation with triple zero prolene suture. Before making these connections, however, the appropriate volume of fluid is placed inside the prosthesis according to the directions of the manufacturer. Throughout the dissection the wound is sprayed with an antibiotic solution of 50,000 units of bacitracin and 1 gm of Kantrex dissolved in 300 cc of physiologic saline. The wound is closed in layers. No drains should be used and the skin should be closed with a running subcuticular technique.

Testing the Prosthesis and the Results of the Surgery

Intraoperative testing should be done by filling the patient's bladder with fluid. Once the bladder is full, pressure is applied to the lower abdomen in such a manner as to create as much pressure over the patient's bladder as is applied over the area of the balloon. This is accomplished by placing multiple towels stacked on the patient's abdomen, so that the pressure applied to the abdomen is distributed over a wide area. There should be no leakage, regardless of the pressure applied, and while applying continuous pressure, the pump should be squeezed to open the device to then appreciate the immediate flow of urine from the bladder. Another method of testing the prosthesis intraoperatively is to do direct sphincterometry by inflating the distal urethra. The artificial sphincter should hold fluid distal to the cuff until the pressure in the urethra exceeds the pressure in the balloon, which will range from 60 to 90 cm of water pressure. If equipment and facilities are available for intraoperative urethral pressure profilometry using sterile techniques, urethral pressure profilometry will show the occlusion of the urethra with a pressure ranging from 60 to 90 cm.

Results

Although the first AS721 prosthesis was implanted in June 1972, the earliest successful implantation in this particular group was in February 1973. The most recently implanted prosthesis in this series was placed in November 1977. The patient who received the implantation in February 1973 continues to do well five years following his implant.

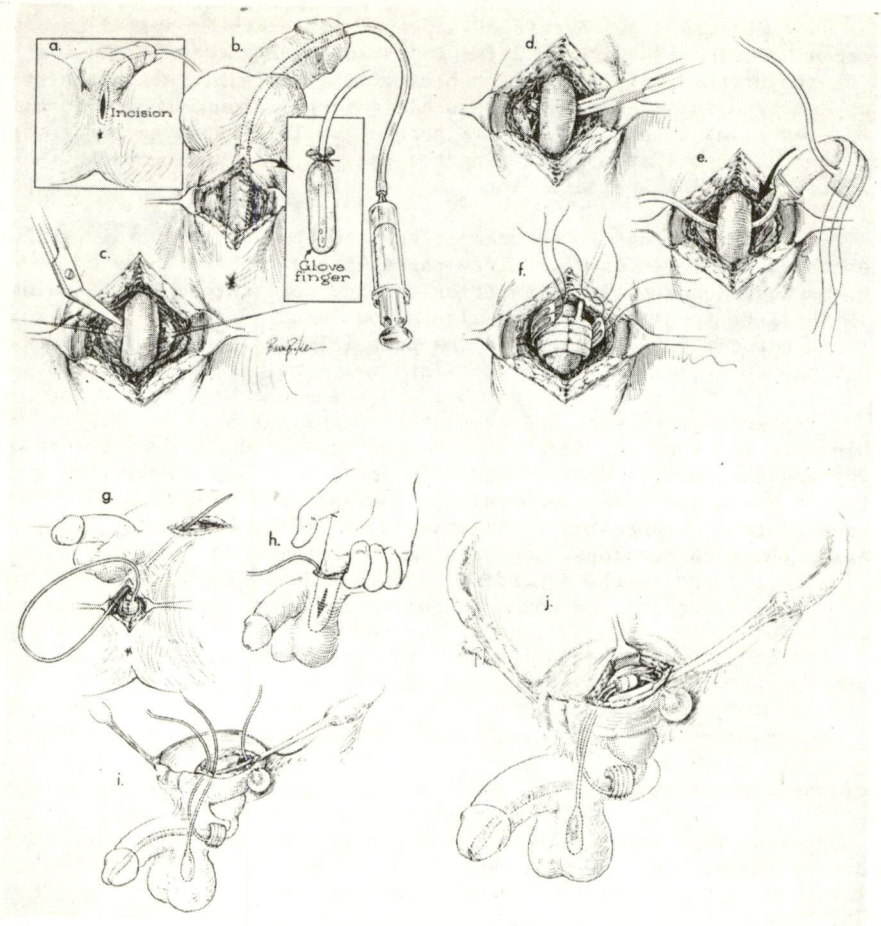


Figure 3. (a) A perineal incision is placed over the posterior bulbous urethra, (b) the urethra is inflated to facilitate palpation and (c) dissection. (d) The space around the urethra is enlarged sufficiently to allow (e) passage of the cuff, which is tied and then (f) enclosed by a metal sheath for protection. (g) A special needle carries tubing through subcutaneous tissues for proper position in an inguinal wound. (h) Blunt dissection creates a space for the pump. (i) The balloon is placed in the prevesical space between the bladder and the pubic ramus. (j) The control assembly is attached after excess tubing is trimmed. The prosthesis is then tested to prove continence and appropriate function.

The definition of success is that the patient should be sufficiently dry that he does not require a pad. He must be continent even with stress, and he must be able to urinate easily with a good urinary stream. Using these criteria, the results to date show 10 successful patients out of those 17 patients who received the AS721 (59 percent success) (Table 1). Twenty-two of 24 patients who received the AS742 are successful (92 percent) (Table 2). The combined overall results of both prostheses showed a 78 percent success rate (Tables 3, 4, 5, and 6). According to etiology, the patients who were incontinent as a result of urethral surgery or following a radical prostatectomy have achieved a 100 percent success result. The poorest success was achieved in those patients with pelvic fractures causing disruption of the membranous urethra, in which only a 50 percent success rate was achieved. Four of the five failed implantations in those patients with pelvic fractures were initially successful, but infection of the prosthesis became apparent and required its removal. There were six patients in the entire series who required removal of the prosthesis as the result of surgical contamination and infection. It is significant that all these had had chronic urinary tract infections that were resistant to therapy. In these cases the infection cleared upon use of antibiotics only for the surgery, but immediately upon withdrawal of antibiotics, the urines resumed their previously infected state with the same previous bacteria. These patients are, therefore, particularly vulnerable to infection.

There were a total of nine failures (Table 7). Six of these were because of an infection. Two of the patients had urinary leakage as a result of a fibrotic urethra that resisted the occlusive effect of the cuff. One of these was a patient whose bladder neck was fibrotic because of previous transurethral resection of the prostate, and the other had fibrosis caused by extensive pelvic fracture and injury. It is highly probable that both of these patients could be made continent by revision of the sphincter and by placing the cuff around the bulbous urethra rather than the bladder neck. Another patient had failure because of an instrumental injury that lacerated the urethra and exposed the artificial sphincter, which had been placed around the bulbous urethra. This injury occurred in another institution where the patient was being treated for cardiac problems. The injury to the urethra was created by a catheter guide used by an individual who was not aware of the artificial sphincter.

Case Report

F. B. is a 51-year-old man who underwent radical retropubic prostatectomy in October 1975 for adenocarcinoma of the prostate. Subsequently, this patient was totally incontinent, as well as impotent. Cystometry was normal. Uroflowmetry revealed no evidence of significant obstruction, though the peak flow was slightly less than normal (Figure 4). Cystoscopic findings disclosed the presence of fibrosis in the area of the membranous urethra, which did not close completely at this point. There was no evidence of obstruction and the bladder was essentially normal in appearance. There was no evidence of recurrence or persistence of his carcinoma.

The AS742 was implanted on December 7, 1976, using the technique described in this article. After the skin was completely closed from the implantation of the artificial sphincter, and the patient had been tested for his continence, an incision was then made in the mid line and an inflatable erectile prosthesis was implanted for the treatment of his impotence. The patient has subsequently had excellent urinary control and has resumed sexual function. His post-operative follow up evaluation in March 1977 disclosed normal urethral mucosa upon panendoscopic examination. The urethra closed in a sphincteric manner. Upon opening of the artificial sphincter, there was complete opening of the urethra. Post-operative uroflowmetry was considerably better than that which had been recorded before implantation, thus proving that the artificial sphincter is not interfering with urinary flow (Figure 5). Urethral pressure profilometry with the artificial sphincter in the open, and then closed, positions (Figure 6)

Etiology	Total No.	No. Successful	Percentage
Radical Prostatectomy	3	3	100%
TUR	8	4	50%
Pelvic Fracture	5	2	40%
Urethral Surgery	1	1	100%
Overall	17	10	59%

Table 1. Results of AS721 Prosthesis

Etiology	Total No.	No. Successful	Percentage
Radical Prostatectomy	8	8	100%
TUR	9	9	100%
Pelvic Fracture	5	3	60%
Urethral Surgery	2	2	100%
Overall	24	22	92%

Table 2. Results of AS742 Prosthesis

Patient	Prior Surgical Procedures	Artificial Sphincter Implanted	Flow Rate Preop	Flow Rate Postop	Implant Result
O.W.	None	2/20/73	None	Good	F
L.S.	None	2/27/73	Good	Good	S
M.B.	None	3/15/73	Good	Good	S
R.H.	None	4/19/73	Good	Good	F
M.J.	Berry Prosthesis Muscle Sling Procedure Muscle Sling Procedure Silicone Gel Implant Silicone Gel Implant	1/28/74	Good	Good	S
R.F.	Reduction Urethroplasty Ischial Fascial Flap Flock's Spiral Flap	2/26/74	Good	Good	S
C.C.	Transcrural Procedure Kaufman Prosthesis Tanagho Procedure	11/22/74	Good	Good	S
G.F.	None	11/25/74	Poor	Poor	F
J.U.	None	11/12/75	Good	Good	S
R.H.	None	1/30/76	Good	Good	S
G.G.	None	2/19/76	Poor	Poor	S
V.F.	Kaufman Prosthesis	4/14/76	Good	Good	S
O.K.	Transcrural Procedure Kaufman Prosthesis	6/2/76	Good	Good	S
A.D.	None	6/11/76	Good	None	S
M.R.	Kaufman Prosthesis	7/23/76	Good	None	F
L.S.	None	5/19/77	Good	None	S
H.L.	None	11/8/77	Good	Good	S

Table 3. Prosthesis Results for Incontinence Caused by Transurethral Prostatectomy

Patient	Prior Operative Attempts	Artificial Sphincter Implanted	Flow Rate Preop	Flow Rate Postop	Implant Result
T.S.	None	2/15/74	Poor	None	S
V.S.	Kaufman Prosthesis Kaufman Prosthesis Kaufman Prosthesis	3/5/75	Good	Good	S
W.S.	None	8/20/75	Good	Good	S
L.W.	Kaufman Prosthesis	3/12/76	Good	Good	S
J.S.	None	11/10/76	Good	None	S
F.B.	None	12/7/76	Good	Good	S
A.B.	Kaufman Prosthesis	3/15/77	Good	Good	S
R.B.	Perineal Plication of Muscle Kaufman Prosthesis Kaufman Prosthesis	4/29/77	Good	None	S
E.G.	None	5/12/77	Good	Good	S
C.O.	Kaufman Prosthesis	9/27/77	Good	Good	S
E.G.	None	10/6/77	Good	Good	S

Table 4. Prosthesis Results for Incontinence Caused by Radical Prostatectomy

Patient	Prior Surgical Procedures	Artificial Sphincter Implanted	Flow Rate Preop	Flow Rate Postop	Implant Result
R.S.	None	5/24/74	Good	Good	F
R.P.	None	2/27/75	Good	Good	F
S.H.	Perineal Procedure	8/15/75	Poor	Poor	S
B.H.	None	11/26/75	Good	Good	F
J.D.	None	12/23/75	Good	Good	F
G.S.	Teflon Injections	2/4/76	Good	Poor	F
J.W.	None	8/9/76	Good	Good	S
R.S.	None	12/22/76	Poor	Poor	S
J.C.	None	7/5/77	Good	Poor	S
G.F.	Bladder Neck Plication	9/27/77	Good	Good	S

Table 5. Prosthesis Results for Incontinence Caused by Pelvic Fracture Injury

Patient	Prior Surgical Procedures	Artificial Sphincter Implanted	Flow Rate Preop	Flow Rate Postop	Implant Result
R.T.	None	9/15/75	Good	Good	S
B.M.	None	7/15/76	Good	None	S
J.M.	Perineal Procedure	5/17/77	Poor	Poor	S

Table 6. Prosthesis Results for Incontinence Caused by Urethral Surgery

Infected Prosthesis	6
Fibrotic Urethra	2
Instrument Injury to Urethra	1

Table 7. Causes of Failure

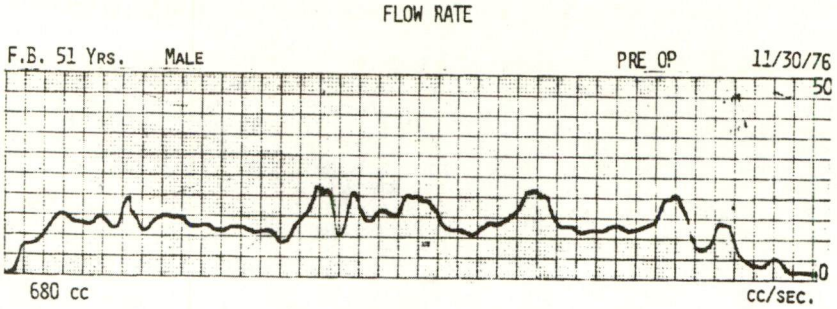


Figure 4. Preoperative flow rate shows no obstruction.

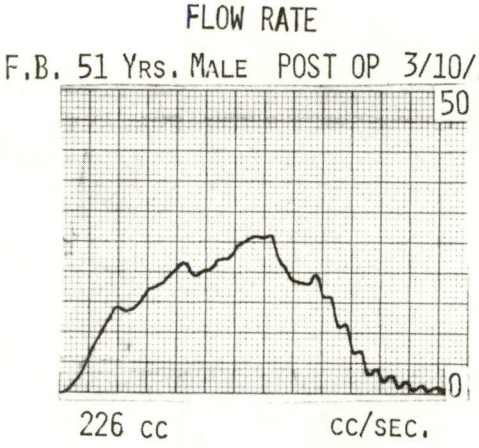


Figure 5. Postoperative flow rate shows no interference of flow by the artificial sphincter.

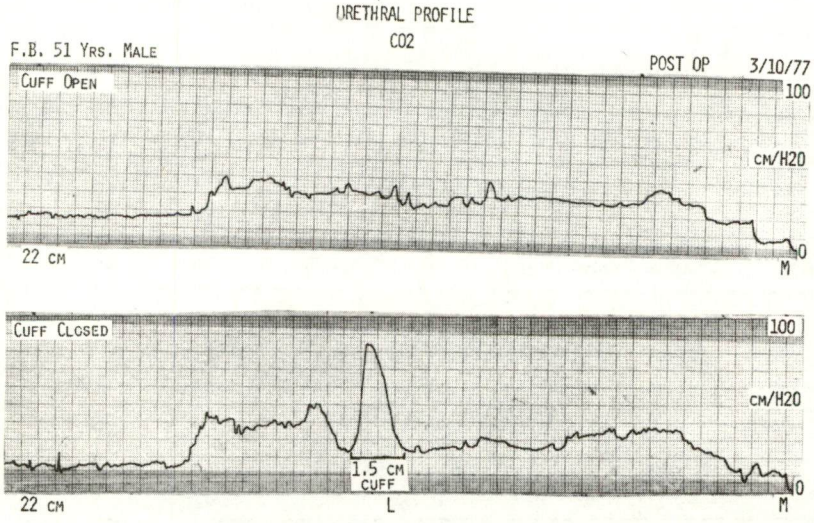


Figure 6. Urethral pressure profilometry shows the open, then occlusive pressures produced by the artificial sphincter. Note the maximum pressure applied to the urethra is less than the patient's diastolic blood pressure.

discloses the location of the artificial sphincter and shows that the maximum pressure being exerted against the urethra is at a safe level, allowing blood perfusion of the occluded urethral tissues. The patient has continued to do well sexually and has complete urinary control.

Discussion

Both of the artificial sphincters are manufactured by American Medical Systems. The AS721 and the AS742 have proved to be effective in the control of urinary incontinence. The AS742, however, is proving to be more effective and more reliable for this particular type of urinary incontinence. Based on my experience in the use of these two prosthetic devices in 243 other patients with urinary incontinence, it appears that the AS742 is generally more effective and more reliable in other groups of patients as well. The most noteworthy exception is that group of patients who must, during a period of recovery, keep the artificial sphincter in an open position; this can be accomplished only with the AS721.

Infection

The most significant complication is infection in the area of the prosthesis. The patient who has resistant urinary tract infection requiring the continuous administration of antibiotics is more prone to develop an infection. To achieve a higher percentage of success, it is obvious that this group of patients should be eliminated. However, we have been successful in achieving continence in a number of patients who have had, and still have, chronic urinary tract infections. Therefore, at this time it would appear that such unfortunate patients still deserve a chance to at least be continent. However, preparatory procedures to eliminate obstructive uropathy as well as other conditions, such as strictures and diverticula, should be done in an attempt to eliminate chronic infections. The patients in this series in whom this could not be accomplished were generally those who had severe injuries leading to various distortions of the urethra caused by pelvic fracture injury.

The manifestations of an infection associated with the prosthesis have been different from what one might expect from infections elsewhere related to surgical procedures. In the presence of a prosthetic device, the body can very often handle the infection rather well for long periods of time. Ultimately, however, the body will reject the prosthesis along with the infection, and this usually occurs by the presence of an erosion of the cuff into the urethra, or extrusion of the pump through the scrotal skin. One of the patients in this series developed an erosion of the pump through the scrotal skin, nine months following his implantation. There was no evidence of any erosion or signs of infection in any other area of the prosthesis, other than that associated with the pump erosion in the scrotum. It was my feeling that this patient had a contamination of the pump and that this smouldered for nine months before finally manifesting itself by an erosion. With the administration of prophylactic antibiotics, the signs of infections may be suppressed for some time following surgery. The earliest that an infection was apparent in this series was three weeks following surgery. Most patients who have a prosthesis-associated infection will present with an erosion within three months of their implantation.

Urodynamics

Urodynamically, these patients have done excellently. Generally speaking, the voiding flow rates in these patients since surgery have been as good as, or better than, they were before surgery. The flow rates that were obtained in these patients clearly proved that this prosthesis was effective in not only producing continence, but in doing so without interfering with urination, one of its unique advantages.

Long Range Results

I feel that all of the objectives stated in the introductory paragraph are being achieved by this prosthesis. More time will be required, however, to prove that the prosthesis has a long life reliability. The manufacturer has test-cycled the prosthetic device and has shown that the prosthesis can be cycled over 80,000 times without deterioration in its function. This would be equivalent to the patient urinating four times a day for over 50 years. This fact, coupled with the fact that one of the patients in this series has had the artificial sphincter functioning for 4 years and 9 months, without any evidence of urethral necrosis, without any evidence of urethral obstruction, and with no problems of urinary tract infections, all suggests that this prosthesis should work indefinitely. Silicone rubber is nonreactive and one of the most inert synthetic prosthetic materials available for medical implantation. Since it has been in use for 15 to 20 years in other prosthetic implants, it can be assumed that it will probably continue functioning properly indefinitely.

Costs

The cost of the production of the prosthesis has been significant, and the manufacturer's charge for this prosthesis seems rather high, though by comparison to other prosthetic implants, as for example the cardiac pacemaker, the price does not seem out of line. It is hoped that the manufacturer will be able to reduce this price, should there be an increase in volume. Unfortunately, however, there does not appear to be a sufficient population that needs the artificial sphincter, for the cost to come down. With the additional requirements of fulfilling FDA regulations on devices, as well as product liability insurance requirements, it is likely that the cost of this prosthesis may indeed increase.

The results achieved in this series of patients have been most gratifying. Even greater has been the gratification received from the "thanks" expressed by these patients, many of whom had undergone multiple prior operations before finally achieving successful continence.

Acknowledgments

The development of these prostheses required the essential contributions of the engineering staff in American Medical Systems, both in new engineering design, as well as in new construction technology. These contributions include those especially made by G.W. Timm, J.H. Burton, and M.A. Mikulich.

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Erectile Impotence Treated with an Implantable, Inflatable Prosthesis: Five Years of Clinical Experience

Treatment of erectile impotence by implantation of a prosthesis is a relatively recent medical advance. Progress over the last decade now allows, with a minimum of surgical risk, functional restoration of erectile capacity in the impotent patient who is qualified for the operation.

Several different approaches have been used in the development of a suitable prosthesis. Treatment of erectile impotence by the implantation of semi-rigid rods inside the penis has had some success; most of the patients are able to have sexual intercourse, but these prostheses leave the penis permanently erect, carry a risk of perforating the soft tissue, cause painful intercourse in some patients, and make other urogenital procedures, such as cystoscopy, more difficult.[1]

In 1973, Scott et al[2] described an implantable penile prosthesis that could be inflated and deflated. This dynamic device mimics the natural physiology of erection and the patient can produce an erection at will. Between February 1973 and December 1977, we implanted this prosthesis in 245 patients selected by a team of specialists. This report describes the prosthesis, our procedure for selecting and treating patients, and our results.

The Prosthetic Device

The inflatable penile prosthesis is a modification of an implantable, dynamic, artificial sphincter designed to treat urinary incontinence.[3] The penile prosthesis consists of a reservoir of radiopaque isotonic fluid, a pump to move the fluid, and two inflatable cylinders, all of which are connected by tubing.

The patient activates the device by repeatedly squeezing the bulb pump, in the scrotum, to pump fluid from the reservoir, which is underneath the abdominal muscles, but exterior to the peritoneal cavity, into the cylinders implanted inside the corpus cavernosum of the penis. A pressure of about 250 cm of water usually makes the penis sufficiently rigid for intercourse. After intercourse, the patient activates a release valve in the pump by pressing a button-like spot on the pump for a few seconds. This allows the fluid to move back into the reservoir and the penis to become limp. Accidental release of the fluid is not likely because the button-like spot is small (2 to 4 sq mm) and the pump is freely movable inside the scrotum. The prosthesis can be expected to function for at least 20 years, based on mechanical testing. How much the elasticity of the silicone rubber, which lies in body fluids, changes with time is not known now. Surgeons can learn the implantation

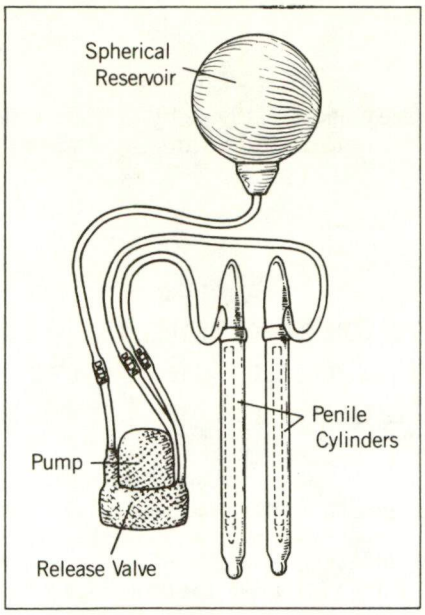


Figure 1. Implantable, inflatable prosthesis currently used.

Causes of Impotence Related to Age of Patients Receiving Implants

Causes	Age, yr						Total
	20-29	30-39	40-49	50-59	60-69	≥70	
Organic							
Diabetes mellitus	1	8	15	21	4	2	**51**
Organic, unknown	0	0	12	14	19	5	**50**
Vascular disease	0	0	2	9	14	4	**29**
Pelvic trauma	7	5	7	2	0	0	**21**
Prostatectomy	0	0	3	8	7	0	**18**
Peyronie's disease	0	0	4	9	5	0	**18**
Spinal cord injury	3	6	4	2	2	0	**17**
Radical surgery	2	2	5	4	2	0	**15**
Genital trauma	1	1	2	0	0	0	**4**
Psychogenic	0	2	2	5	1	0	**10**
Various other causes*	2	2	3	4	1	0	**12**
Total	**16**	**26**	**59**	**78**	**55**	**11**	**245**

*This category includes such causes as multiple sclerosis, reconstructive urethral and penile surgery, androgen deficiency, and antihypertensive drug therapy.

Table

technique by attending workshops at centers that implant the device, by studying audiovisual programs, or from another surgeon who has been trained. The device is sold to individual hospitals, which then sell it to a surgeon qualified to implant it. The manufacturer maintains a list of trained surgeons.

Since our preliminary report,[2] we have modified the original design so that today we implant the device shown in Figure 1. The original model contained two pumps, one to pump fluid from the reservoir into the cylinders and one to pump fluid from the cylinders back into the reservoir. The original model also contained four valves, but the prosthesis has been redesigned so that the newer version contains only one pump and one valve. This simplification has increased the reliability of the device because there are fewer components. The design of the cylinders was also changed. They are now expandable, allowing them to conform to the patient's own corporal bodies and giving the penis an erection indistinguishable from the natural one. Most of the patients in this report received the newer design.

Surgical Procedure

The surgical procedure has been described elsewhere.[4] Briefly, a low midline incision is made from the base of the penis to a point above the symphysis pubica. Through an incision of the tunica albuginea, tunnels are created with dilators inside the corpora cavernosa. The silicone elastic cylinders are inserted into these tunnels. Blunt dissection into the scrotum, through the original incision, allows placement of the pump and its release valve. Incision of the midline abdominal fascia allows placement of the fluid reservoir in the prevesical space. The tubing connecting all three parts is connected and the incisions are sutured.

We have found it difficult to eradicate infection in the presence of an implanted , inert material such as silicone rubber, so special precautions are taken to prevent infection at the time of operation. In addition, each patient receives prophylactic antibiotic therapy from 24 hours before to 24 hours after the operation.

The operation involves little blood loss, minimal disturbance of tissue, and light anesthesia. If a component of the device needs replacing, a relatively minor operation suffices.

The patient is advised not to have intercourse for three weeks after the operation. He is instructed to inflate the penis at least once a day starting six days after the operation. The discomfort decreases until, at about six weeks after the operation, the patient experiences no discomfort but pleasure.

Patient Selection

The operation was originally designed to treat patients with organic impotence who could not be treated otherwise. Since then, we have broadened our criteria to accept men with psychogenic impotence who have not been nor can reasonably be expected to be handled by psychotherapy or sexual therapy. We do not, however, accept anyone with a psychiatric contraindication to the operation no matter whether his impotence is diagnosed as organic or psychogenic. Because natural erection may no longer be physically possible after the operation, we recommend this operation only after other possible treatments have been tried or considered. Men over 50 years of age with psychogenic impotence of long standing may be considered for implantation after failure of a serious attempt at behavior modification in a reputable program. Younger men with psychogenic impotence may be considered only after a longer, more concerted attempt at nonsurgical treatment.

A team of specialists conducts preoperative evaluation of each prospective candidate to determine if he meets the criteria. Besides having impotence

refractory to other treatment, the candidate must be physically able to withstand the stress of the anesthesia and the operation, he must be emotionally stable, and he must have realistic expectations about the results of the operation.

The Team

The basic preoperative evaluation, which usually takes four working days, is conducted by a urologist, a sleep researcher, a psychologist, and a psychiatrist, using a quadruple-blind approach. In complex cases, additional evaluations, some by other specialists, such as an endocrinologist, a cardiologist, a radiologist, a neurophysiologist, or a vascular surgeon, may be required.

The prospective patient is referred to the urologist by his physician. The patient is sent a questionnaire that requires data about his medical and psychiatric history and some aspects of his current sexual and social functioning. If, on the basis of this information, the urologist believes the patient can be helped by this operation, the patient then must undergo a complete evaluation by the entire team. This evaluation consists of a history and physical examination, sleep studies of nocturnal penile tumescence on three consecutive nights to determine if the complaint of impotence reflects erectile deficiency, a battery of psychological tests, and a psychiatric interview to evaluate the patient's mental stability and ability to adapt to the new device after the operation.

The Urologist

The urologist is the team captain; the other team members send their data and evaluations to him and he makes the final decision regarding whether to operate. The urologist interviews the patient, performs the indicated physical examination, specifically looking for Peyronie's disease, evidence of urinary tract abnormalities, infection, or cancer, and conducts any other special analysis the history may suggest. He also conducts a limited psychiatric interview to evaluate the patient's mental stability and expectations, and he selects laboratory studies, including measurement of blood and urine levels of glucose and blood levels of testosterone, as well as the standard battery of studies for patients about to undergo a major operation.

The Sleep Researcher

The patient spends three consecutive nights in the Baylor College of Medicine Sleep Disorders Center where erectile activity during sleep is recorded. In men capable of normal erections and those impotent for psychogenic reasons, erections occur at 90-minute intervals during sleep. In men impotent for organic reasons, these erections either do not occur or else are greatly diminished from normal.[5]

The procedure for measuring nocturnal penile tumescence has been described previously.[6] Briefly, two strain-guage transducers are placed around the penis, one around the base and the other just below the glans. Using two strain guages ensures that certain organic problems that affect only one area of the penis, such as Peyronie's disease, will not produce confusing or erroneous data. Extensive measurements of blood pressure are made, including measurement of penile arterial blood pressure. During one night (usually the third night), the patient is awakened during a typical erectile episode, and the degree of penile erection is evaluated by the patient and an observer. Erectile rigidity is measured, and photographs are made to record the appearance of the penis.

The sleep researcher sends to the urologist his evaluations of the nocturnal erections, the data from the analysis, and his conclusions regarding whether the patient's erections were normal, borderline, or abnormally diminished for his age. If the studies indicate normal nocturnal penile tumescence, a decision against the implantation is usually made.

The Psychiatrist

The patient is then seen by the psychiatrist, who has no prior information about the patient except that he is interested in obtaining the penile prosthesis. The psychiatrist interviews the patient and records the facts and observations on a form developed specifically for these patients.[7] In brief, this form gathers information about the patient's personality, his sexual relations, and the personality of his spouse (or sexual partner). On the basis of these data, the psychiatrist determines the patient's mental stability and makes a prognosis of the patient's ability to adapt to the new device after the operation.

Each patient is usually seen by the psychiatrist only once before the operation. The interview is designed to detect relevant marital discord; if this is detected, the psychiatrist alerts the urologist. The urologist then discusses this problem with the patient at their next meeting.

The Psychologist

Each patient completes a carefully selected battery of psychological tests.[8] These tests are designed to disclose potential problems in four performance areas, which may in turn relate to erectile functioning: (1) mental efficiency, (2) emotional stability, (3) interpersonal compatibility, and (4) susceptibility to performance anxiety. Ordinarily, the psychologist does not see the patient, but if this screening raises the possibility of serious problems in any of the assessed areas, the patient may be referred for a more intensive psychological evaluation at the surgeon's discretion. This latter procedure may include an extensive interview as well as additional tests.

Consensus

The sleep researcher, the psychologist, and the psychiatrist send their written evaluations to the urologist, who reviews this information and his own evaluation of the patient. If the patient meets the criteria, the urologist notifies him that he may have the operation and reviews with him the rationale for this treatment, the operative procedure, possible complications and their treatment, and how this treatment compares with other surgical treatments. If the patient decides he wants this type of prosthesis and signs an informed consent form, he and the urologist select a date for the operation.

If any member of the evaluation team recommends further evaluation or if the recommendations are conflicting, the patient is scheduled for further testing or the team meets to discuss the case. Occasionally, sex behavior therapy is recommended in conjunction with the implantation.[9]

Results

As of December 1977, a total of 322 men have completed the initial questionnaire and 245 have received the inflatable penile prosthesis. Most of the men not receiving the implant were rejected because their impotence was not organic and the problem was not amenable to treatment by implantation. Some men chose to delay receiving the implant. A few were rejected because other health problems precluded implantation.

The interest in this treatment has grown; in 1977, we evaluated 107 prospective patients and implanted the device in 78 patients. The patients who have received the prosthesis range in age from 21 to 85 years, ten patients being over 70 years old (Table). The impotence of most of our patients has been associated with diabetes mellitus (Table). The category labeled "organic, unknown" designates patients whose sleep studies showed that their nocturnal penile tumescence was diminished, but in whom no specific cause could be found. The category "psychogenic" designates impotent patients whose sleep studies

gave normal results, yet in none of these cases were we able to relate the impotence to an event or environment in the patient's history.

The operation was a success in 234 cases; that is, these patients can use the prosthesis to their satisfaction. In 102 of these cases, an additional operation was required to correct a surgical error or flaw in the prosthesis or because the patient requested a new model. Revision is, in most instances, a relatively minor procedure for the following reasons: (1) a superficial incision is required; (2) special techniques have been developed that allow a failed component to be detected by simply exposing the connectors, so that complete dissection and inspection of all components is not necessary; (3) the new component simply replaces the old component within the sheath that previously formed; (4) postoperative pain is slight; and (5) hospital stay is usually only overnight for recovery.

The need for an additional operation has greatly decreased with experience: five (42 percent) of 12 patients receiving the implant in 1973 (our first year of implantation) required revision for success, whereas 13 (17 percent) of the 78 patients in 1977 required an additional operation. Just as important is the decrease in the number of failures. Of the 12 patients who received implants during 1973, five were unable to use the device to their satisfaction. Of the 152 patients receiving the implant during 1976 and 1977 (74 and 78 patients, respectively), none has been dissatisfied with the results. Of the ten patients whose impotence was diagnosed as psychogenic, nine have been satisfied with the prosthesis and one has been lost to follow-up.

Comment

For the first time, to our knowledge, a treatment for impotence that functionally simulates a natural erection can be offered. With the inflatable prosthesis, an erection occurs when the cylinders within the penis fill with fluid, mimicking the natural process that occurs when the corpora cavernosa fill with blood. The prosthesis does not leave the penis permanently rigid, nor does it carry a risk of perforating the soft tissue as do semirigid plastic rods. The dynamics of our device enlarge the diameter of the penis as well as its length, as does a natural erection; this is not possible with a static prosthesis.

The inflatable prosthesis is designed to produce an erection whenever the patient desires. It neither contributes to nor detracts from the capability of the patient to experience an orgasm. The prosthesis does enable the patient to penetrate the vagina and, if he was capable of it before becoming impotent, to ejaculate and impregnate a woman.

Mechanical failure contributed in part to failure in 11 cases, all of which occurred early in our experience. Of the 152 prostheses implanted during 1976 and 1977, only 27 have failed mechanically; all were corrected by an additional operation, enabling each patient to then use the prosthesis to his satisfaction. The eventual success of these cases, even in instances of temporary mechanical failure, reflects not only the careful selection of patients by our team but also the amount of education the patient receives about the operation, the device, and its use. These patients have been able to surmount the relatively minor, correctable problems that mechanical failure introduced.

Although more comprehensive psychiatric or psychological evaluation is available for complex cases, we have found that a one-hour interview by a psychiatrist, using our seven-page form, complemented by a screening battery of psychological tests, is an efficient and adequate way to obtain the necessary information for 98 percent of those interviewed. The psychiatric form is designed so any psychiatrist can use it to interview candidates for the penile implant operation and so the information from various centers using this form can be pooled or exchanged. We do not routinely interview the patient's wife or sexual partner. The psychiatrist or psychologist reports evidence of

conflict or hostility to the urologist. If the patient is a likely candidate in other respects, the urologist will strongly recommend that the patient resolve the conflicts with his partner, but the urologist does not act as a mediator. If the conflict is not resolved and the patient is otherwise acceptable and wants the operation, we will implant the prosthesis.

The incidence of impotence is generally believed to be around 1 percent. Although we have made no statistical analysis, the number of inquiries we get, both from the lay public and from other physicians, suggests to us that the incidence is higher, perhaps as high as 8 percent to 10 percent.

Of the patients we have selected for implantation (about 70 percent of those evaluated), 96 percent had organic impotence, and more than 25 percent of those patients were impotent because of diabetes mellitus. While the causes in most of the cases of organic impotence can be readily discerned, the category "organic, unknown" is of interest to us. Sleep studies and psychiatric evaluation show that patients in this category have an organic problem, yet the exact cause cannot be discovered. Without the sleep studies, such patients would likely be classified as psychogenically impotent. This means that the category of psychogenic impotence may be artificially inflated by the inclusion of such patients and that estimates of the incidence of psychogenic impotence may be too high. For the individual patient, this may mean that months or years of psychotherapy or behavior modification programs may be useless in treating the basic problem.

Our team approach has been invaluable not only in making decisions about individual patients but also in yielding insights into the problem of impotence, such as the "organic, unknown" category. We use a quadruple-blind approach in which the surgeon, psychologist, psychiatrist, and sleep researcher each evaluates the patient independently. To date, our individual evaluations have agreed in more than 95 percent of the cases.

In conclusion, an implantable, inflatable penile prosthesis has been used to treat 245 men with erectile impotence, including ten men with psychogenic impotence that had proved refractory to other therapy. Of these 245 patients, 234 are now able to use the prosthesis to their satisfaction. This success rate can be attributed to the design of the device--it mimics a natural erection--careful screening of potential patients, and meticulous attention to surgical details.

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Gregg C. Vanderheiden

High Technology Versus Low Technology Communication Systems for Severely Handicapped Individuals

There are many different ways to give an individual a way to indicate the elements of his message. All of the different techniques, however, can be broken down into two basic approaches. All the various techniques are elaborations or combinations of these two approaches. The two approaches are:

1. Direct Selection (individual points)
2. Scanning (someone/something points for the individual)

With direct selection, the individual points directly to his selection. With scanning, someone or something points to the items for the individual, one item at a time. When the item desired by the individual is indicated, he gives some type of signal. The game "Twenty Questions" would be one example of scanning. A rotating arrow that the individual could stop would be a second example. A person pointing to items one at a time until signaled by the handicapped individual would be a third example.

Direct Selection Approaches

Of the two approaches, direct selection is by far the superior where the individual is able to use it, because it

- is faster
- is more straightforward cognitively
- involves more active participation by the individual, thus increasing attention.

The major drawback of direct selection is that it requires more range of motion (ROM) and control than scanning requires. Wherever possible, however, direct selection is the method of choice.

There are many different specific techniques for providing an individual with a means to point using direct selection. The most obvious is for the person to use his hand. Some individuals can isolate a finger and use it to point (see Figure 1). Other individuals can only point with a closed fist; opening the hand to free a finger causes complications in the arm, and results in a net loss of pointing ability. For those instances where a "finger" is required, special sliding handpieces, dowels, rings, and other indicators can be used. These devices can be used both on a manual pointing board and on various types of keyboards and other direct selection panels.

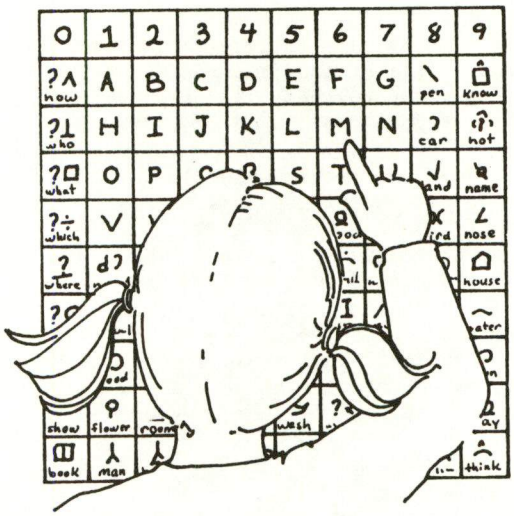


Figure 1. Direct Selection: Pointing with a Finger.

Many individuals can use typewriter keyboards, either in their standard form or with a special keyguard placed over the keys. A keyguard consists of a plate with holes drilled in it over the keys. The individual can then rest his hand, and slide it over the keyguard, poking his finger or a dowel, etc., through the keyguard to activate the keys. Special expanded and recessed keyboards can be used in the same manner by individuals having less range of motion or control.

For individuals not able to use keyboards, several approaches have been developed. One of these, called the "auto-monitoring technique", allows an individual to select the elements he desires by pointing to them as he slides his hand over the flat surface of the "keyboard". Selection of each desired element is accomplished by pointing to it for a given period of time; no push or switch activation is required.

Range-of-motion expansion techniques use small well-controlled movements and yet allow an individual to select from a large array of choices. These techniques can also be implemented on a very simple level, such as by having an individual use a long stick or a miniature light beam. In this manner, very small movements of the hand, arm, or head can be translated into large pointing motions on a communication chart. These techniques can be automated either by providing sensors on the chart or by having the individual operate a joystick that can be electronically controlled to determine his pointing position.

The eyes can also be used for direct pointing. It is, however, difficult to tell when looking at an individual exactly what he is looking at if there are more than 10 or 12 choices. Even with optical measurement systems, it is difficult to have an individual point to more than 10 to 16 items in a reliable and inexpensive manner. For this reason, multi-signal techniques (see below) are usually required with eye pointing. More advanced technologies are now being developed that should lead to direct eye gaze control of communication aids for some individuals.

Scanning Techniques

In the same way that direct selection can be thought of as pointing to items in space, scanning can be thought of as indicating items in time. With direct selection, items are presented in a spatial array, and the individual points to the items of the array that he wants. With the scanning approach, the items are separated by time rather than space. In this manner, the individual need not have any particular range of motion at all, but simply an ability to give a discrete signal at the proper time as the desired selection is being presented. Because of the extremely minimal signalling capabilities required for the scanning approach, no individual who is still discernibly mentally intact and aware can be so severely physically handicapped that he could not be interfaced to some scanning technique. The primary disadvantage of scanning is its very slow relative speed. In essence, most of the time spent scanning is spent pointing to wrong selections and waiting for the appropriate item to be presented. All of these wrong answers, however, must be presented for a period long enough for the individual to be able to respond accurately and reliably. Because of its extremely slow speed, pure scanning (e.g., naming items one at a time until the item that the individual desires is named) is seldom if every used except for very small sets of choices (4 to 16). For most communicative purposes, therefore, some multi-signal technique is used instead.

Multi-signal (or Encoding) Approaches

Multi-signal techniques use multiple signals from the user in order to increase the "selection space" that an individual would have with direct selection, or decrease the "selection time" of an individual using the scanning approach. One multi-signal technique would be the use of a group-item

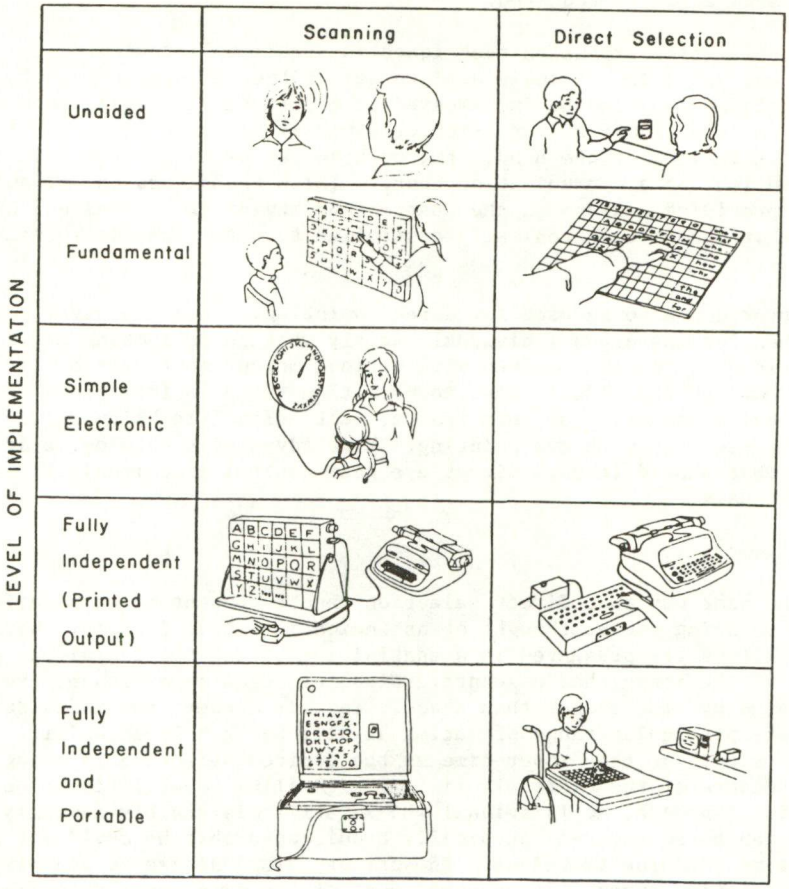


Figure 2. Different Levels of Implementation.

presentation for scanning. With this technique, groups of items are presented to the individual first. Once the individual has selected the proper group, the individual items within that group are scanned, one at a time, until the desired item is reached. The most popular forms of group-item scanning are row-column (or row-item) scanning and page-item scanning.

A parallel to the "group-item" concept in scanning would be the two-number encoding or group-item indication using direct selection. With this technique, an individual who is able to point to only ten numbers could indicate any item from a field of 100 by simply pointing to a pair of numbers. One can think of this either as indicating a number from 1 to 100, or as selecting one of ten groups, and then one of ten items within the group. In either case, the time and movements involved would be identical. The major difference would be in how the information was displayed. There are advantages to either approach, although the pairing of individual numbers (e.g., 24, 45, etc.) with individual choices is almost always the superior approach because of the reduced amount of visual scanning and processing necessary. These individually coded selections can then be grouped if desired or appropriate.

The advantage of the multi-signal approach with direct selection is that it can be used to provide an individual who has relatively little movement or accuracy with the ability to point to a large number of items. Ten widely spaced keys, for instance, could be used in a two-movement encoding technique to allow the individual to indicate all of the keys on a keyboard or selection panel. Three-movement encoding would allow the individual to select one of 1,000 selections.

Levels of Implementation

In introducing the two approaches, we have seen that the techniques within each approach can vary from fundamental techniques to more sophisticated aids. Figure 2 shows the various approaches we have been talking about, characterizing them by their degrees of sophistication. Each of these levels has different advantages and disadvantages for children with differing abilities or in different situations. It is therefore important to understand the significance of these different levels, both when comparing one aid against another and when selecting an aid for a particular individual.

In general, each successive category represents an increase in the complexity of the aid. It generally also represents an increase in the independence of communication for the handicapped individual, as well as a decrease in the amount of effort needed by the message receiver to interpret the handicapped individual's message.

Unaided Techniques

Unaided techniques are communication techniques that do not actually involve any physical communication aid. These systems are very limiting in that they are usually only viable between the child and those few individuals who know him well. The guessing game, or intuition, is often thought to be effective between a mother and child for basic needs. It does not, however, provide the child with any means of asking questions or learning about his environment. This technique also does not provide the child with any viable means for expressing opinion or emotion or for interacting with others in his environment.

Fundamental Aids

Aids in this category represent basic methods of implementing scanning or direct selection approaches. Any of the approaches, no matter how complex it may be, could be implemented on the fundamental level, with the work being done by the person working with the individual. For example, the fully independent, portable encoding communication aid with printer could be implemented on

this level by a person who would watch the individual, interpret his movements, decode them to determine which letters the individual was trying to indicate, and then write down the letters to assemble his message. As can be seen, using the techniques in this manner can require a fair amount of effort on the part of the message receiver. Even when using a communication board, a second person is needed to interpret the individual's movements, figure out which letters he's pointing to, and then assemble them to determine his message.

These techniques, however, do have a great advantage in that they are readily available to the teacher in the classroom. Most of the aids can be very easily fabricated by a teacher or by a local handyman. Their construction doesn't require any special kind of expertise as they generally don't incorporate any moving parts or electronics. It is only the amount of time and effort on the part of the message receiver to use these aids for communication that keeps these aids from being used on a more widespread basis and from fully meeting the communicative needs of many of the individuals.

Simple Electronic and Mechanical Aids

Aids in this category use some electronic or mechanical technique to interpret the individual's motion and to indicate directly to the message receiver the letters, words, pictures, etc., that the child is trying to indicate. With these aids, the message receiver does not have to interpret the individual's movement, but does still have to write down or remember the characters and assemble the message for the individual.

Because the individual can (with the aid) directly indicate the letters, pictures, etc., that make up the message, very little knowledge of the system is required on the part of the message receiver. For this reason, the handicapped individual using this aid can generally communicate with a much greater number of people than would be possible using the simpler aids. Although the amount of work that has to be done by the message receiver is greatly reduced using these aids, the undivided attention of this person is still required. This continues to be a problem if the individual's message is more than a few words or if the individual wants to participate in group conversations or do independent work.

Fully Independent Aids

The last two categories concern fully independent aids. An aid is considered fully independent if it has some kind of printout or display (a calculator-type display, for instance). With these aids, the individual has a fully independent means of assembling his message. The message elements selected are assembled by the aid and printed (or displayed) for the message receiver. The individual needs no help in assembling the message, and only needs the attention of the message receiver for the brief instant needed to read the completed message. With these aids, the individual is able to participate in group conversations or classroom discussions and must only interrupt the group for the brief amount of time that it takes to read a completed message (rather than the entire time that it takes to assemble it).

Many of these aids have some sort of printer, typewriter, or television display. With these aids, the individual is given not only a means of communicating, but also a means of writing. This becomes very important if the individual is in any kind of educational program. If the individual is going to be held responsible for practicing lessons, doing homework, doing independent work, and taking tests, he or she must have some means of writing that does not require the constant attention of a second person. This becomes even more evident when it is understood that a simple three-page book report can take between 7 and 12 hours for someone to assemble, even if the individual is using a relatively fast communication technique such as a letterboard.

Fully Independent and Portable Aids

Like the independent communication aids just discussed, these aids allow the individual to assemble a message completely independently. However, they also have the advantage of being fully portable. As such, they can move around with the individual and function as a "voice", rather than simply as a writing instrument.

In order to be portable, aids in this category incorporate some form of printout or readout other than a typewriter. For some of the aids, the typewriter is available as an accessory that can be controlled by the aid. This provides the individual with the ability to write out longer messages in page form, which is very valuable in educational or vocational settings. Another form of page output is the television display. These displays (which resemble the TV displays giving arrival and departure times in airports) have the advantage of being both highly visible and completely correctable. Because of these features, they are especially popular in educational settings. Their correctability is thought to be very important both for allowing the individual to correct his mistakes and for allowing the teacher to separate inadvertent mistakes (typos) from mistakes made because the individual truly did not understand something. The television display also is often less expensive than the specially adapted electronically controllable typewriters.

Implications and Advantages of the Various Levels of Implementation

As one looks at the various levels, it may appear that the more technically advanced the aid is, the more function one obtains. While it is true that the more technically advanced the aid is, the less work needs to be done by the message receiver, it is not necessarily true that the portable independent aids (the most advanced) are the best aids for everyone. There are many constraints that cause one aid to be more applicable for an individual than another aid. For instance, most of the independent portable aids cannot be used with pictures or other symbols outside of the letters of the alphabet. For this reason, these aids cannot be used by children who are still on a picture level, children who cannot read, or children who will be communicating in one- or two-symbol utterances. For these children, and for other individuals generally who are just starting out with communication aids, the fundamental and simple aids are much more powerful, since they can be used with letters, pictures, words, or special symbols. For developmental reasons or for children who may not be able to read or spell, therefore, simpler aids may be the more applicable ones.

Another restriction--I hope only a temporary one--is that individuals are often unable to acquire the aid most appropriate for them due to financial restrictions. As the technology gets simpler, the cost of the aids goes down rapidly. Aids in the fundamental category generally cost between $5 and $50 if they are fabricated locally (e.g., by a school carpentry shop), or between $10 and $150 if they are bought as commercially available aids. The next level, simple electronic and mechanical aids, generally cost from $50 or $100 up to about $1,000. Fully independent aids can cost anywhere from $1,000 to $7,000, depending on how many accessories and different printouts are desired. Fully independent portable aids cost about the same as the stationary aids. It generally costs more to make something portable, but a portable aid does not have to include the cost of adapting a typewriter. For those aids that are portable and can also be hooked to a typewriter, the cost usually runs about $1,500 more for the typewriter or TV display as an additional accessory.

Relative Advantages of Fundamental vs. Advanced Technologies

Figure 3 lists five areas of relative advantage attributable to either the fundamental or the advanced technology column above them. As an exercise, the reader should fill in the columns in the chart with the attributes listed at

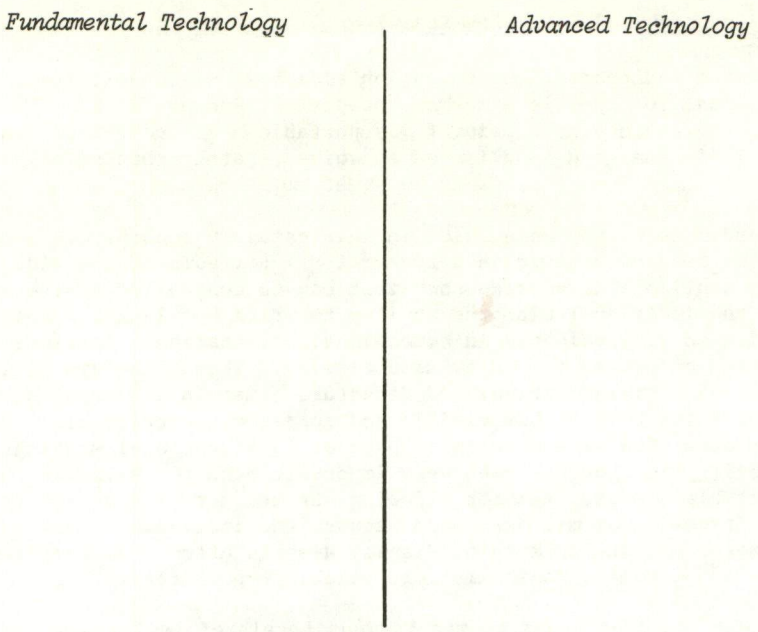


Figure 3. Fundamental vs. Advanced Technology.

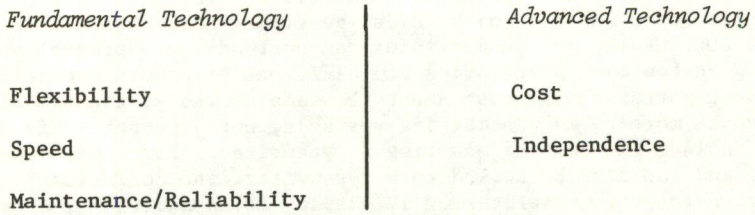


Figure 4. Advantages of Fundamental Technology vs. Advanced Technology.

the bottom, placing each one under the appropriate heading (fundamental or advanced technology). These impressions can then be compared to the text that follows.

Flexibility

Flexibility is clearly an advantage for the fundamental aids. Manual pointing boards can handle any type of symbol system, from pictures to graphic symbols to traditional orthography (letters of the alphabet). They can be used to implement any technique, from scanning through direct selection, and can switch back and forth between the approaches as required. For example, the individual can point directly to the elements on his board in a direct selection approach when he is sitting in his wheelchair, but can use the board in a scanning mode when in bed, on the floor, or in some other position where he is unable to point. Vocabularies can be continually updated and changed, and boards can be converted to new approaches as they are identified or as the individual develops new skills.

Until very recently, advanced aids had almost no flexibility. They were limited to orthography, required spelling or had fixed vocabularies, and operated in only one mode. A couple of aids are now available that operate in multiple modes, and these are beginning to break down some of the barriers. This type of progress is essential, but advanced aids still have a long way to go in this area.

Low Cost

Although one might expect the fundamental aids to have the advantage here, the advantage is very definitely on the side of advanced technologies, except when aids are used in a conversational mode.

When a second person has to be present, as is true in conversational interactions, the fundamental approaches are less expensive, in that the aids themselves can generally be purchased or fabricated for less than the purchase price of advanced technologies. In any educational or vocational program, however, an individual is also required to do an extensive amount of writing. A typical student is required to take notes, do work in class, complete written assignments, do independent work, and take tests. All told, this amounts to a tremendous amount of time spent with pen in hand. For the individual using an augmentative communication system, this time must be multiplied by a factor of three or four, due to the slowness of the communication system. Unfortunately, the writing load cannot be reduced to compensate for this without seriously affecting the quality of education.

With a manual communication board, a second person must be at the individual's side providing undivided attention for the entire time that the individual is "writing". In a normal educational situation, this encompasses most of the day and a good deal of the evening. The cost for even a teacher's aide to work with an individual during the entire time spent writing would be in excess of $4,000-8,000 unburdened or $8,000-16,000 per year including benefits, overhead, etc. This cost would compare to a cost of $600 for a $5,000 communication aid ($5,000 divided by 10 years plus $100 per year maintenance). Thus it can be seen that whenever an individual is going to be involved in any type of meaningful educational or productive activity, the cost of a manual system far, far exceeds the cost of an advanced aid.

The advanced aid only seems more expensive because the teacher's aide is generally not available to the individual, and therefore those costs are generally not incurred except in exceptional situations. The result, however, is that it is impossible for the individual to receive a complete or effective education, or to learn his subjects in any depth. As a consequence of this, most severely physically handicapped individuals, even those with superior

intellects, graduate with spotty educations and severe deficits in a number of areas, especially the communication and writing skills essential to seeking and securing meaningful jobs. If it were impossible for severely physically handicapped individuals to secure jobs, this might seem less tragic. However, nonspeaking, nonambulatory severely physically involved individuals who have had the extensive individual attention necessary to develop communication skills are securing and holding full-time competitive employment positions. Unfortunately, these individuals are the rare exception rather than the rule, largely due to the tremendous support costs involved in their education and development during a period without appropriate aids.

Speed

Speed falls squarely in the low technology column at the present time because the low-technology approach always includes one human being to act as interpreter/recorder. This individual has tremendous processing capability, far in excess of anything implemented in a communication aid. It is usually only necessary for the individual to begin to spell a word before the message receiver can guess the word, thus saving the individual having to spell the word out in its entirety. A couple of key words will then suffice to allow the message receiver to guess the sentence. Except where the individual is being tested for spelling or grammar, it is therefore possible for him to express himself with much greater speed than is possible with an aid that requires the individual to specify each letter or word. (There are some problems inherent in this processing; they are described in the section on Independence.)

There are exceptions to this speed advantage, however, with some complex techniques. For example, if the handicapped individual is using some type of encoding approach, then a combination of an aid and a person may be optimum. In general, aids are much better in handling codes and looking up items in tables. The optimum speed with an encoding technique would, therefore, be reached with an individual who is using his aid to print out letters or words and using a second person to expand those letters or words in the same manner as described above.

However, new technical approaches such as abbreviation expansion and word prediction are beginning to close the gap between the low- and high-technology optimum potential speeds. Systems that use a word frequency count based upon the individual's past word usage to predict the words the individual is spelling out may actually have some edge over a human being trying to do the same guessing. On the other hand, technology will not in the near future be able to use context or communication situational information to predict topics, expressions, and words in the same manner that the human being does. Low technology does, therefore, at least for the foreseeable future, have the speed advantage clearly in its column.

Independence

This one obviously falls into the category of the advanced technologies that provide the individual with the ability either to compile and display or to print a message totally independently. This is important not only for independent work, but also for control of communication situations. Often individuals on manual communication boards will find the message receiver second-guessing them, often incorrectly. Without the ability to reassert control of their other utterances and complete the utterance in the proper manner, mass confusion can easily result and very frequently does. Once this happens, it is extremely difficult to unravel the conversation gone astray and determine what is accurate and what is mapped into the conversation by the message receiver, especially when this same unravelling process must take place through the eyes and mouth of the message receiver.

Maintenance and Reliability

Maintenance and reliability are clear advantages with the low technologies. These approaches generally have no maintenance other than the revisions due to vocabulary growth and other adjustments. It is also frequently possible to create multiple copies or versions of the boards as a backup in case a board is lost, destroyed, or simply left at home inadvertently.

What to Recommend

With advantages and disadvantages clear for both sides, the question comes down to what should be recommended and when.

In general, we have found that:

1. The focus of the entire communication development program should be on *interaction* and not on the aid. By focusing on the individual's current interaction and the major barriers to better interaction, it is usually possible to determine whether an advanced aid or a fundamental aid would better address the barriers faced by the individual at this time. Selecting a fundamental aid does not rule out an advanced aid. It simply acknowledges that the problems faced by the individual at this time would be better addressed by a fundamental aid.

2. Purchase of an advanced aid can advance communication but can also block future potential. Aids are continually getting better, as are the particular physical and cognitive skills of any given individual. When an individual needs an advanced aid, clearly it is time to get one. Securing one before he needs it, however, simply locks the person into technologies available at that time and into the particular technique that he or she is physically capable of at that time.

3. When considering communication needs, it is very important to address both conversational and writing needs. Typically, the need for a writing system begins at about second grade, the same time other children are given pencil and paper to begin learning writing and prewriting skills. Since an advanced aid is almost always required in order to give an individual the ability to write, the need to consider an advanced aid for an individual comes very early in the individual's development. Without an effective mechanism for writing at this early point, the individual usually suffers severe delays throughout the educational program. (The two major reasons for securing an advanced aid are a. in order to develop written skills and b. in order to be able to practice with full grammatical sentences to allow normal language development.)

4. Speed is always crucial, both in conversation and in writing. If an individual is able to communicate or to write at one-fifth the speed of a normal individual, then it is going to take five nights to get one night's homework done. It will also take five hours to get the one-hour test finished. In conversational situations it is difficult or impossible to carry on normal conversation at one-fifth the normal rate.

The Communication Aids and Systems Clinic at the University of Wisconsin Hospitals is set up exclusively to evaluate severely handicapped individuals and recommend appropriate communication systems for them. This clinic sees individuals ranging from 8 months to 90 years of age with about a 50-50 split between children and adults. Although almost everyone coming to the clinic is looking for a recommendation for a technical aid, we currently recommend fundamental aids for about 60 to 70 percent of the client load. Advanced aids are appropriate for only about 20 to 30 percent of the individuals at this time. It should be noted that many of the individuals for whom a fundamental aid is recommended now may need advanced aids at later points in their

development. On a case-by-case basis, I would expect that about 60 to 80 percent of the individuals with severe communication impairments could significantly benefit from one or more technical aids at the appropriate time in their development. (Since one typically sees an individual over several years during the communication development process, and appropriate aids may not be recommended until a later visit, the annual percentage of clients for whom an aid is recommended may be only 40 percent.)

Improvement vs. Sufficiency--Functional Thresholds

One principle that is becoming more and more obvious in our clinical work is the need to focus more on functional thresholds and on making an individual functional, rather than simply on improving a capability. For example, if an individual is trying to climb stairs, it is nice but not of any particular value to increase his ability to raise his foot from 1 inch to 7 inches if the stair riser is 9 inches high. In the same manner, it is nice and very helpful to take an individual who is unable to communicate and provide him with a mechanism for communicating at the rate of 2-3 words per minute. When it is psychologically impossible to carry on a conversation with somebody at a rate of less than about 50-60 words per minute (except for short messaging), we clearly must not stop for very long to rest on our laurels, and surely we must not send the individual forth as cured. Likewise, it is inappropriate and nonfunctional to provide an individual in an education or employment situation with a mechanism for writing that is 10 to 15 times slower than that of his classmates or peers. If that is the best we can do, then we need to understand clearly what we have not accomplished, what the individual is not going to be able to do with what we've provided, and what we need to come up with before we will be able to provide the individual with any functional communication system.

Conclusion

If there is one thing that our recent clinical work has clearly shown us, it is that the largest single barrier to the handicapped individual today is us. It is our underestimation of the end-point potential of these individuals, and our overestimation of the quality and usefulness of our solutions. Unless these individuals are provided with truly effective mechanisms for communication and writing, mechanisms that we could survive with ourselves in our education or employment, how can they be expected to get an adequate education or hold a job with their handicap and that same tool? Yet I know of no researcher or developer of communication aids who would even consider trying to use those aids over any extended period of time (much less permanently) while trying to do a job, or to do notetaking or homework. Why not? When will we have aids for our clients that we would be willing to use ourselves...even for a day?

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