DR. ELIZABETH PAN: Thank you Marvin.

Distinguished speakers, ladies and gentlemen. I'm honored to have this opportunity to address you on a subject of concern to all of us, the dissemination and utilization of rehabilitation research results. Earlier you heard previous speakers explain the primary purpose of this workshop which is to aid in understanding what may constitute full implementation of the National Institute of Handicapped Research. The existence of NIHR is based on the assumption that research can make a positive difference in the lives of disabled people.

I did not come here to challenge that assumption. Let us accept the assumption for the sake of argument. Research can make a difference. I say "can" because it won't unless research results are disseminated and used.

I am reminded here of a story of a scientist who proposed the hypothesis that ether extends throughout the universe. A colleague raised the question, "Suppose we were to move the universe five miles to the east, so to speak, in relation to this ether. Could we tell the difference?" The first scientist had to admit that there were no available scientific operations that could be performed to ascertain any resulting difference. The two scientists agreed that if a difference does not make a difference, it is not a difference.

information if it is delivered through a radio or television talk show. The transformation of research results for specific audiences is what I mean by repackaging research results.

In some cases, research utilization requires technical assistance and even training in the use of research results. I'm sure all of you have, at some point or another, assembled a bike for your child or at least watched someone do this. We all know what a bike should look like when assembled properly, but we cannot do it ourselves without the instructions that come with the bike. Technical assistance can be this simple, or it can be a lot more complicated, depending upon the nature of the research results being implemented.

When we say disseminating rehabilitation research results, who are we talking about as the user of this information? I would like to classify the users of rehabilitation research results into three categories. First, the public; second, disabled people; and third, service providers including researchers. We will now look at each category of users in terms of who they are, what kinds of information they need, what we are doing to meet these needs, and what we are not doing that we should be doing.

Let's take the general public first. Who is the public? The public consists of everyone who has an impact on the lives of disabled people. That includes the bus driver, the storekeeper, the housewife, the postman, the farmer, the plumber, you, and me. It is also important to remember that the public also includes disabled people.

I've worked with disabled people for many years, but I had never thought about how deaf people are awakened in the morning. A scene in this movie showed Kitty explaining to the motel manager that she wouldn't be able to hear a wakeup call, or a knock on the door, and that the only way she could be awakened was for her to leave the door unlocked, so that someone could come in and awaken her.

Films like these go a long way in presenting the public with positive images of disabled people as well as conveying a remarkable amount of factual information about specific disabling conditions. There are also programs like the "60 Minutes" presentation on sheltered workshops and a CBS special on the cost of accessibility which aired issues of importance to disabled people and presented them in human terms--a home, a job, a decent wage, or a day in court.

Both fictional and documentary forms of presentation are effective vehicles for breaking down the barriers of ignorance which exist between the disabled community and the general public, as well as among various disability groups.

They provide a subtle form of information about new innovations. An example of an effective use of mass media penetration to familiarize the general public with innovative technology was the media blitz which introduced audiences in the 1950s to the space age and prepared the public mind to accept the coming developments in space exploration and related technological improvements and advancements.

number live in the community. Some disabled people have obtained the highest educational degrees; others have mental limitations which may prevent them from attaining any degree.

What I'm trying to say is that there is no such thing as the disabled population as far as information dissemination is concerned. Where we live, whether or not we work and where, or educational background--these are only a few of the variables which determine what we need to know and how we get our information. In spite of these differences, the kinds of information needed by the disabled people are remarkably similar: where services can be obtained, how to pay for them, where to get assistive devices, how to get from one place to another, how to get a job, legal rights, etc.

Where do disabled people go to get this kind of information? It was only when I asked myself this question that I realized that we don't know for sure. There are no studies that I know of that could tell us how disabled people behave when they seek the information they need to cope with their disability.

As a trained information scientist, I know of studies of the information-seeking behaviors of physicists, chemists, x-ray crystallographers, engineers, physicians, and other groups. I know of no similar studies for disabled people.

In spite of this lack of basic knowledge about how disabled people behave in the various information-seeking situations I just described, there are many existing resources. The directory of the

She goes on to say:

> Upon occasion I have sought information from rehabilitation agencies without success. Therefore, I am now reluctant to utilize these sources of information. Perhaps by doing this I lose out on information that can make a difference in my life. I'm certain that there are many developments which would be of assistance to me if I were only made aware of their existence through the channels which I normally use.

If this statement is true, the problem clearly does not lie in the lack of technologies for reaching disabled people; we have the best mass media communications in the world. Rather, the problem lies in our not using these technologies.

I would like to offer another reason which might possibly explain why we may not be getting research results through to disabled people. Earlier, I defined what I meant by research dissemination and utilization. You may recall that I included storage, retrieval, and distribution under "dissemination," and repackaging, technical assistance and training under "utilization." How much is NIHR/RSA spending on research dissemination and utilization by disabled people? Most of the funds spent on research dissemination and utilization are targeted toward the service delivery system.

There are some funds being spent on repackaging for disabled people as the audience, but I personally know of no program funds available for providing consumers with technical assistance and training in the use of rehabilitation research results. We should expect to reap what we have sown.

providers was that they were inundated by more information than they could absorb. With the exception of researchers, practitioners in general wanted to have information screened and pre-digested for them.

We found that there was little reliance on existing formal information systems, especially computerized data bases such as the National Technical Information Service, even though such systems contained relevant information. The small number of interviewees who were familiar with these data bases did not perceive them to be useful. "Takes too long" was the gist of the responses we received. Researchers as well as practitioners preferred to rely on the informal network for their information needs. What was needed to complement the informal network was a central repository of rehabilitation knowledge which would serve as a switching point for accessing other formal information systems, such as MEDLINE for medical information, and ERIC for educational resources.

We also found that there were many organizations which were already providing information to this group of users, each one with his own target audience, geographic scope, and subject specialty. The technology used for research and retrieval of information was primitive. In one site we visited, the information was stored on McBee cards and retrieval consisted of threading a needle through holes punched around the edges of the cards. There were few trained information specialists involved in these activities.

Service. Efforts toward the development of an information network started with a conference attended by over 70 information providers last year.

There are many other projects funded by NIHR which deal with information dissemination and utilization. At the Rehabilitation Information Network Conference I mentioned earlier, it was reported that the Rehabilitation Services Administration research program, now NIHR, was spending over $3 million a year, or nine percent of the R&D budget on information-related activities. This is a conservative figure, because it does not include the cost of certain projects like NARIC whose budget is approximately $250,000 a year, nor does it include the cost of dissemination activities imbedded in most research-oriented projects.

While I can feel comfortable in saying that what we are doing in disseminating and promoting the use of rehabilitation research results is a good start, there is still much room for improvement. The most basic problem facing us is the lack of coordination and stability of existing information resources.

Earlier I told you that NARIC's collection now holds all of the research reports funded by NIHR and its predecessors. What I did not tell you is what this collection does not include. It does not include any of the research reports funded by the Developmental Disabilities program now run by the RSA, or the products resulting from our State training projects, much less the research products

to the importance of reaching the public and disabled people through the mass media. I've given you some examples of how information is currently disseminated to service providers and the need for better coordination and appropriation funding mechanisms.

One might ask at this point, if we are to do what we should be doing, what is it going to cost? I can't answer that question without making a large number of assumptions, most of which would be tenuous at best.

Perhaps a more useful question to be posed would be, how can we more effectively allocate available resources; that is, assuming we don't have any more resources than we have now, how much should we allocate to research as compared to research dissemination and utilization?

Earlier, I reported some figures taken from the proceedings of the rehabilitation information network conference that would indicate that NIHR is currently allocating about nine percent of its R&D funds to research dissemination and utilization. Is this the appropriate allocation of resources between research and the dissemination and utilization of its results?

My answer is no. If we allocate nine percent to dissemination and utilization, we are either ignorant of the true costs of such efforts, or we are satisfied with an inadequate job. In my opinion, the ideal allocation of resources between research and research dissemination and utilization is 50-50. Before some of you protest,

for consumer of goods? After all, information products are consumer goods. Will the techniques used for selling toothpaste work for selling knowledge?

Using the expertise of various industries is only one aspect of cooperation with the private sector. The interaction can be more direct. Let me illustrate by a few examples. Pfizer Corporation is currently providing funding and expertise for training disadvantaged adults through opportunity industrialization centers. Another example is a national project coordinated by the University of California at San Diego. In this project, courses on such subjects as taxes, investments, etc., are delivered through 400 newspapers around the country as well as through programs broadcast by the Columbia Broadcasting System. Commercial publishers are also involved in publishing materials used in conjunction with these courses. People who are interested in pursuing further any specific subject area can take credit courses at 300 universities around the country. This is an example of using the mass media to deliver education. The project is funded by the National Endowment for the Humanities and other Federal programs like the National Institute of Mental Health as well as by Exxon Corporation.

Still another example of private/public sector cooperation is closer to home. The Institute for Information Studies is negotiating a contract with Control Data Corporation to develop a data base containing descriptions of existing technological aids for disabled people. This data base, initially to be limited to

providing technical assistance, and training where necessary to promote the use of research results by disabled people. It is also important that we involve disabled people in these activities and use the channels of dissemination that they prefer to use.

(2) That we recognize the equal importance and equal complexities of the process of generating new knowledge and the process of disseminating and implementing that knowledge and allocate our available resources accordingly.

(3) That the problem that we need to address is not so much how we can get more funding, but how we can leverage what we have, first, by working with the private sector, second, by coordinating both research and research dissemination and utilization, and third, by using existing knowledge ourselves whether this knowledge happens to reside in a private sector or other parts of the public sector.

Ladies and gentlemen, we already have the means, the resources and the technology to ensure that research will make a difference in the lives of disabled people. The task before us is to use these resources and these technologies. Thank you.

KORNBLUH: We are running about 10 minutes behind schedule. I would like to ask you to stay until about 10 or 15 after 12:00 for the questions and answers if you can.

I'd like to turn to our next speaker, Frank Withrow. Frank received his Ph.D. in Audiology from Washington University in St. Louis. He has been a Research Assistant at the Central Institute for the Deaf in St. Louis; Speech Pathologist at the Irene Johnson Rehabilitation Hospital, St Louis; Director of Research and Critical Services at the Illinois School for the Deaf, Department of Children Family Services, Director of the Division of Educational Services; Bureau of Education for the Handicapped; and more.

Modern transportation, in our own lifetimes, has changed the way each of us looks at the world. With the energy crisis, and I sometimes think that I may have lived through the golden age of the world, transportation may not be as available to my grandchildren and great-grandchildren, as it was to me and my children. Transportation and the energy crisis are both changing the way we think, the way we organize our society, and the way we organize our educational components.

Many of our grandparents were able to live and work and die within a very few miles of the place where they were born. Now, information and communication sciences are rapidly changing our concepts of the world of education. A few years ago, Pat Suppes from Stanford, in discussing the new computer educational technologies, posed the point, "Are universal public schools obsolete?" Are they a technology which is obsolete? These are very profound concepts as we talk about educational technology.

I am addressing that aspect that we have grown up with, thought of, and looked at, and now have all kinds of controversy about--the neighborhood school. Is that the universal educational form for the future? If we look at technology and we look at broadcast technology, and Congressman Brown commented on the FCC hearings about children's television, we see that we can deliver Sesame Street to one child, one show one hour long for less than one cent per person today. The comparable cost of one hour of one child's time in school

not more, concerned with appropriate educational needs for each child. I personally think that without technology we're unlikely to meet the mandates of that act.

And I think that I can divide those technologies up into different kinds of categories. We've heard today of devices like the Kurzweil reading machine, the Optacon, and a number of far-out science fiction kinds of devices that are available today to either ameliorate the handicapped person's problem or to bypass the handicapped person's problem and enable him to participate in society on a more equal basis. We do know, as in the Opticon and the Kurzweil equipment, that we can transform print into a usable medium for the blind. We do know also that technologically it's possible to make speech visible for the hearing impaired.

Back in the 1950s, people like Harriet Kopp Green were developing, in their laboratories, visible speech techniques. Those techniques at that time worked. They were complex to learn and they were not portable. You had to have a room about this size filled with vacuum tubes to get the job done. There are experiments now, however, that are transposing speech signals into tactile and into visual modalities that are usable by hearing impaired individuals.

There are experiments today that are even more exotic. They have demonstrated that you can, in effect, take a television camera and transpose signals from it onto a blind person's back and get visual perceptions. There are some experiments in terms

We have an example of some developmental rehabilitation work in Montgomery County. A few years ago, a 16 year old boy was in an automobile accident and because totally paralyzed from his neck down. The Maryland rehabilitation services and some industries in town developed, in effect, a personalized computer. At that time it cost something like $25,000 to develop a terminal for the young man that could enable him to finish high school. It also enabled him to do a very interesting thing--continue courting his girl friend. He wrote love letters back and forth. He had it dial her phone number for him, and it also enabled him, after completing high school, to work and be paid as a computer programmer. He has now been accepted at the University of California, Berkeley, as a full-time student. He will be living, as I understand it, at the Center for Independent Living in Berkeley. His personal computer will go with him to enable him to interact with society.

The issue with these devices comes down to a very simple one--it's dollars and cents. Who is going to pay for it and what are the principles involved? I would say that one of the critical principles in all of these things is how does the device make the society, in my instance the educational opportunity, accessible to the handicapped person. I would say that the primary measure should be accessibility to participate in a comparable manner with other people who desire to have that resource, whether it is school, whether it is community, dialogue, or what.

Illinois, and New York; they have relatively good services for hearing aids, albeit different services. If you look then at other States, and I don't want to condemn any States particularly, some offer virtually no service in terms of hearing aids for the child; even though they have had rehabilitation services for crippled children and so forth, they simply were not a priority. They either did not have money or they had a minimal amount of money that they gave toward otological, audiological exams and the actual dispensing of the hearing aid. This is obviously not solely a problem of the hearing aids; it is a problem of all of the technologies that we can provide and should be providing for handicapped individuals.

The issue comes up again, as I mentioned, with the Optacon and the Kurzweil machines. How do we make them accessible? It also comes up in general education. That's why I'm shifting now from technological devices to the technology of learning. I want to emphasize that I think the new technology is a technology of learning rather than a technology of instruction. I say this because computer-assisted instruction, the merging of computers and things such as video tape and video discs, is very, very interested in the learner's process. What is happening to the learner during this instruction? The answer is that he or she develops an interacting system and one whereby the learner can hasten his or her own progress.

know or care whether the users are hearing or hearing impaired. We do not need to know whether the people are ambulatory or non-ambulatory. We do not need to know whether the people are in real time in some computer conference formats.

For example, a person who has a great deal of difficulty in communicating can pre-prepare. In many teleconference systems, people need not be present at the same time. You go in and out of the system for 48 hours, or 72 hours, or however long you want to keep the system open. So the technology eliminates that barrier that we might have had in a number of communication problems among our children.

I think there may be emerging a new general education format that is heavily bent upon technology. However, I would not want to leave this morning with the impression that I don't think the teacher is an extremely important aspect of the educational community. In fact, the teacher may be the most important single individual in many handicapped children's lives, because it is through that person's personality, knowledge, and techniques, that many handicapped find an open door to the society that they live in and work in.

The technology that I'm talking about is designed to supplement, to enhance, and to make the teacher's job better. We've often heard people like John Goodlad from Southern California talk about experimentation and investigation into innovation in schools. They

This was the first time a six year old, a cerebral palsied young man, was going through this particular sequence. Well, he was happy with the eggs, he was happy with the bacon, and he was happy with the donuts and rolls, and so forth; except at the end of the sequence the teacher said, "Would you like some pepper?" She began to put pepper on the eggs, and he says "No." To reinforce pepper, she said, "Would you like some more pepper?" He then used an expletive comment, in vocabulary that we did not know he had, and said, "I told you the first time, no pepper on my eggs."

The children reacted to these programs; they knew the devices weren't real people, but still they did talk to them. This was a highly manipulative learning environment that the children had.

These kinds of things can be brought into the home and they can be brought into the classroom. They are certainly possible as we move into microcomputer technology, and as we move into systems that are usable in the home and connected through telephone lines to larger systems. In this country, about 200,000 personal computers have been sold. One of the most interesting aspects of this figure is that is that the purchasers usually have teenage boys. This is not a sexist comment. It's simply a marketing fact that teenaged boys have forced their parents, who are affluent enough and have enough discretionary buying power, into buying personal computers.

Consequently, some of the most exciting programmers in the country in microcomputers now are 14- and 15-year-old kids. In a

He tried to analyze the difference between the teaching machines of yesterday and these new toys, and why the new toys seem to be more successful. He came to some interesting conclusions. We are now in a system that is divergent rather than simply a drill and practice or scenarian learning concept. We are coming closer to the tutor sitting at the end of the log, because these systems are now capable of divergent and parallel programming.

For instance, if I am teaching a child with a microcomputer something about butterflies and cocoons and if the child decides that what he is learning reminds him of mummies in Egypt, there is no reason that a parallel learning program cannot be spun off on that.

This, in a sense, is the way that you and I learn. This is the whole tutorial dialogue opportunity of asking questions and making inquiries. Those systems, I believe, are fully available.

At one of the HEW birthday parties, random access video and computer programming were demonstrated. In that instance, we provided a child with the capability to create a synthesis. It was partially limited in that we did not have all of the visual images of the world available to us and for the computer to shape. The computer, in effect, asked the child his name; the computer then moved forward, shaping and spelling in syntax until the child had typed the correct sentence. The child then got to see the created image acted out in animation, in color, and in sound.

if some of our people who throw cold water on technology aren't the same kind of people who wondered if the telephone would be of benefit to mankind. Certainly it's a benefit to teenagers, and certainly it's beneficial in terms of correspondence. Some of you have may be cognizant of what is being done in Canada, Japan, and England. You thus know that our whole communications system can be used in a much more powerful way than it has been before.

It's interesting that the postal system in England has picked up "viewdata" and combined it with the broadcasting industry to create an electronic mail system. We must do that in this country too, it seems to me.

The third thing that I'm very interested in, and I think is very relevant to handicapped children, is educational management. This calls for the use of information and communication sciences to enable us to manage and learn how to provide human resources and material resources when and where the learner needs it.

To me, personally, the Education for All Handicapped Act means that all of our resources should be brought to bear upon the educational problems of the child. If plans and programs for rehabilitation are to be effective, we must take advantage of this type of technology. It can evaluate where the student is, it can pace the student in his or her learning, and it can evaluate the results of that learning experience.

It seems to me we can no longer stick with paper and pencil to do this; we must go to electronic storage and transformation of information.

Last, is the concept of educational management and the use of information and science technologies to enhance, track, follow, assist, and evaluate children so that they get the education that is appropriate to their needs? We cannot afford to exclude any of our children, much less the handicapped, from these new technologies.

Much of the new technologies, as I have said, put the handicapped person on an equal basis with all other people. The strength of body, the beauty of body, the quickness of mind, are really not essential to participation in the information and communication society. We need to develop a disciplined approach to education based upon the principles set forth in the Education for All Handicapped Children's Act, that is, an appropriate education for every child. And I'm talking about general as well as special education.

It is important that we learn to listen, to speak clearly, to read with understanding, to write clearly, to understand electronic communications, and to develop computer literacy if we are to survive in an information-rich technological society. It is not enough for a few privileged individuals to attain a high level of skill and knowledge. We must have a broad-based citizenry capable of clear and logical thinking and decisionmaking. Carl Sagen has summed up my thoughts very nicely when he said, "Since our society is so profoundly influenced by science

try to ensure that the products that are coming on the market are really going to do the job we intend them to do.

I think we can help directly in the way of contracts to the manufacturers to do some initial development. This should help offset some initial costs that keep manufacturers out of the game because the prospect of profits are, in many cases, very small. This, in turn, is largely due to the limited market that we're dealing with.

I think we also just have to basically reexamine the entire method that we've established to pay for devices. I think there are many things that we need to be doing that I see as being part of research utilization. This is the only way that we are really going to get all the results of research to the handicapped users.

KORNBLUH: Anything that I could say after that would be anticlimactic. Don, in our third session on November 16, one of the nine issues will deal precisely with what you just said. If you look at the background material in the back, I think that the very first issue manifests this kind of problem.

QUESTION: Margaret Schafer, the American Occupational Therapy Association. I happen to be a self-trained information communication specialist, and I'm concerned, Dr. Pan, about how the private sector or the professional sector or the governmental sector can help get all these compartmentalized data bases you mentioned working together or channelled together or linked so that we have information.

to my surprise, that the handicapped community might be leading us in new directions. Then, Dr. Pan said that the access to new information resources as mediated by computer networks and telecommunications devices is continuing to have a very important influence as it has for 20 years on our society. Finally Dr. Withrow pointed out, although perhaps he didn't intend to, that there is a small group of highly privileged people who have access to microcomputer based technology and that group could just as easily be people who have mobility limitations as well as people who have rich fathers.

That group would itself be the aristocracy of the information technology which in turn would be the group that is leading our society in new directions, which are information based rather than based on transportation, mobility, and use of vast energy resources. Isn't it possible that what Mr. Brown said initially, was perhaps more true than he thought? That, in fact, the handicapped could be leading our society and hence, paradoxically, not be in the mainstream but rather be in front of the mainstream.

KORNBLUH: You want to comment on that, Frank?

DR. WITHROW: I would say amen. I think that's true. I think that throughout and I guess Senator Randolph said that the Lord promised us problems. And it is the solution of problems that frequently enables us to have a better life. Certainly the handicapped have been confronted in our society with problems.

In fact, I think simulation and model building are good not for results that they bring, but perhaps more for the processes which they force us to go through. These processes may bring the needed insights.

QUESTION: Dr. Banzibar. I think we better be careful that we don't try to develop the data and information storage retrieval and dissemination systems that are all things to all people. You have requirements for real time, you have to have that. Then you have requirements for those who are just as happy having it Monday as they are happy having it Thursday.

It seems to me that you have requirements in a new institute for an exchange of technology in order to minimize reinventing the wheel, plus requirements for technology transfer to the public. Now those are totally different things. We have scientists talking to engineers and talking to the public. It seems to me we have many information collection and search capabilities. People need people could only to realize and utilize them. We have your NARIC, NASA's RECON, ERIC, MEDLINE, NTIS, SDC and Lockheed, SSIE, the DoD National System, SCORPIO, OCLC, OLEXIS, and that's only the beginning. There are likely 99 information bases on line right now, any one of which can be antiquated. It seems to me if we just have to use what we have effectively. I get concerned when I see how many beautiful systems are on line and overbooked.

I have noticed that the handicapped can help each other. The blind people can help us. They can work for the telephone company because we pay for the telephone every month and we don't get services that are taken for granted by normal people. What's the next step do you project that I should do?

DR. WITHROW: I don't know the next step. But I do know that both Rehabilitation and the Bureau of Education for the Handicapped have been interested and supported experiments and developement in the TTY. There is now a deafnet that is between Boston and Washington and California, that in effect, allows anybody that is using the old five-level Western Electric teletype techniques and microcomputers to talk to one another on an electronic message system. The Bureau of Education for the Handicapped also has a study to look at the next step in modernization and utilization of that TTY system.

As you know, the Western Electric is not giving the old teletypes away anymore. They are out of them. It's an obsolete system and things like MCM were based upon the five-level code. The eight-level code is what microcomputers use and that price is going to come down. However, before they phase out, I think we'll have more of the deafnet kinds of operations where you can call in with the old code and talk to people that have the new code system.

The other problem that comes up is determining what is equity in terms of billing from the telephone company. If you are typing at 20 words a minute, should you pay for the same long-distance

what you were talking about primarily was hard information technologies rather than soft institutional ones. I would just comment that our recent experience with a followup conference to the White House Conference for governors' liaisons and then three consumer conferences indicates one desperate need that is not being met. It is a Government responsibility for a better communications network from program officers of the roughly 350 programs throughout the Government that have an impact on handicapped people and their plights. It would seem to me, that you spoke largely to the hard side and relegated to the soft side insufficient scope.

DR. PAN: I didn't mean to do that. When I said dissemination, I was primarily talking about dissemination of research results. When you are talking about funding opportunities, that is not exactly research results, but it is certainly an important type of information. There are other tools such as funding directories to find out about Federal funding programs. These directories, such as the Catalog of Federal Domestic Assistance, can be searched through a computer. These tools, printed and computerized, are only starting points. When it comes to funding, there is nothing to replace face-to-face contact with the program officers.

QUESTIONER: Something in this regard. One of the things that people do not know who are trying to implement White House recommendations is what has worked where. And they do not know models that are successful.

to be developed which would be most appropriate and effective, which gets into the whole process? This addresses some of the issues which you were talking about and back to Elizabeth's cost of dissemination and utilization of research. After the research has occurred, can you determine whether or not it should be disseminated, in terms of packaging, etc.?

DR. PAN: I thought I was being very courageous to suggest a 50-50 allocation since I have never seen that implemented. But here we have a view that suggests that perhaps it should be 200 percent of the cost of research.

QUESTION: Eran Lauder from the White House Conference on Handicapped People. Just to follow on that same question, ultimately wouldn't that be an investment that would have some effect on overcoming duplicity?

DR. PAN: That is only one of the benefits of letting people know what research has been done. But even aside from that point, even in addition to that kind of benefit, is the fact that a research study makes absolutely no difference to anybody else other than the researcher unless it is used by somebody else.

QUESTION: Dr. Pan, don't you think that the present economics, whatever that means, and I'm not sure, will dictate that we can continue this implementation. We're not going to be able perhaps to bring together the idealistic datum information. We still may have to go to SCORPIO to get what's in Congress we still may have to go to ALEXIS to get what court decisions have been made that

In the area of rehabilitation, which I suggest is still not yet a mature discipline, the possibility of being able to get access to use the contemporary literature, I think is restricted by the maturity of the discipline. That, however, will change with time.

QUESTION: Helga Roth, Chief of the Clearinghouse for the Handicapped for HEW. I would add that at the moment we have a very poor terminology to add to the field, because you cannot add any of the existing services for research on the handicapped. The word "handicapped" is meaningless. So you have to go through a lot of what does the system use, what kind of words should it feed in, etc. All this work improves as we go along and as people get the idea that "handicapped" is a "roof" word for something which we have always had, but in very many discrete sectors of society.

KORNBLUH: I've just been handed a note that there is another meeting at 1 p.m. I'm very sorry that we have to stop. I thank all of you for attending. I thank all of our guest speakers and thank you all for coming.

AGENDA AND ESSENTIAL DEFINITIONS AND DISTINCTIONS

AGENDA

The second panel/workshop dealing with the application of technology to handicapped individuals concentrated on describing the last three of the five technologies selected for description. The agenda for this session was:

Topics	Participants
• Introduction:	Marvin Kornbluh, Specialist in Information Science and Futures Research, Congressional Research Service, Library of Congress, Washington, D.C.
• Rehabilitation technology:	Dr. Vernon L. Nickel, Director, Rehabilitation Engineering, Research and Development Service, Veterans Administration, Washington, D.C.
• Communications technology:	Dr. Gregg Vanderheiden, Director, TRACE Center for the Severely Communicatively Handicapped, University of Wisconsin, Madison, Wisconsin
• Environmental facilities technology:	Dr. Timothy J. Nugent, Professor and Director, Rehabilitation-Education Center, University of Illinois, Urbana, Illinois
• Audience questions to the panel:	Marvin Kornbluh, Moderator

The interpreters for the deaf were Mrs. Carol Denninger and Mr. Roy J. Craig.

Communications Technology for Handicapped Individuals

Communications technology concerns means for clarifying and amplifying the interchange of vocal and non-vocal information by speech, writing, signs, tactile, and other methods between senders and receivers over one or more communications channels via such methods and media as:

- Various telecommunications aids, such as computer conferencing and telebraille and teletype machines;
- Non-verbal communications systems and techniques including sign language, cued speech, and captioning;
- Computer assisted communications systems, including electronic mail, braille information processors, and talking wheel chairs;
- Generators of synthetic speech, speech amplifiers, and portable speech prostheses;
- Speech analyzing aids providing tactile or visual displays of acoustic events, including the palotometer and wristcom tactile paging;
- Wireless signaling and alerting systems;
- Sensory enhancement and substitution devices and systems, including hearing aids and magnifiers; and
- Recreational games, including electronic and mechanical games.

PANEL/WORKSHOP PROCEEDINGS

MARVIN KORNBLUH: We have an interesting program in store for us and I'd like to welcome you to the second of three workshops dealing with technology for handicapped individuals. I hope all of you have taken the trouble to let the receptionist at our registration desk know that you are here. I would appreciate this if you haven't already done so. I hope all of you noticed that we do have an agenda and a set of background materials for distribution at a table near the door.

For those of you who did not attend the first session a few days ago, my name is Marvin Kornbluh and I will be your moderator for this session and the last session. Let me just quickly review what the session today will be about. We are going to have three speakers and we're going to cover the areas of rehabilitation technology, communications technology, and environmental facilities technology.

I'm not going into definitions of these per se. In the background material you have received, they are listed and examples are given, and I'm sure our speakers will be well prepared to discuss them. I've asked the speakers to limit their talks to 40 minutes, because we hope to have at least 30 minutes or more of the question and answer time. This is one of the reasons I put this in this way. I want to be able to interact with you and have the panel interact with you. I think that's important.

on the agenda or a sheet of paper. I feel this is best because we should have 30 minutes or so to allow you to address your questions to the panel members. Further, they can interact with each other as well on the questions.

Dr. Vernon L. Nickel, who is our first speaker, is an orthopedic surgeon with about 35 years of diverse medical and rehabilitation experience. He has been a medical director, he has been in private practice, he's had many academic appointments, and he's had a number of visiting professorships. He also has served in the military, and has been an advisor to many, many State and local organizations and committees. I'm not going to detail any of these experiences simply because there are just too many of them. I will say that he is now Director of Rehabilitation Engineering, Research and Development Service, Veterans Administration in Washington, D.C.; among his list of half a hundred honors, I picked two of them to share with you. I'm proud to be sitting next to a person who was at one time was named the California physician of the year. He also is an M.D. who was listed in the top ten engineering achievements in the United States one year. I think those two are indeed unique and worthy honors.

I started to count his publications and I got up to 100 and I stopped. He certainly has well over 100 publications on rehabiliation to his credit. I'm just delighted to turn over the program to Dr. Nickel, our first speaker.

The care, the state-of-the-art of prosthetics of amputee care was very bad. In those days, the statement was made, not, "if we can go to the moon we can do so and so;" but, "if we can build a sabre jet we can do so and so."

Northrup Aviation was very much involved in sabre jets; so the word we heard was if we can build a sabre jet, we certainly can get a better prosthesis. So Mr. Allen went around to different places and found that the state-of-the-art of prosthetics in America was pitiful, really bad. It was an isolated craft-type activity with patents and a lot of barriers. So legislation was passed to start a research program in which the School of Engineering and the School of Medicine, in this case the University of California-San Francisco, Berkeley, was chosen to start an organized effort to improve the care of the amputee.

A man named Paul Magnuson was brought into Washington by General Omar Bradley and President Eisenhower to straighten out the VA, which was pretty much in disarray at that time. This is well documented in a book by Paul Magnuson, an autobiography called "Ring the Night Bell." It's an excellent book to give you an idea what happened at that time. Dr. Magnuson was the first director of research as far as I've been able to find out over a long-term basis. His was more than just an ad hoc type of program; they started a true involvement of research for the care of the physically disabled.

Most of us in medicine have been led to believe that medicine cures. If you have acute appendicitis, you do an appendectomy and you're cured. If you have a fracture, it's set, it heals, and you're cured. You don't need much rehabilitation in those cases. But when there is a chronic disability, and that can be again, medical, sociological, vocational, and so on, then you need rehabilitation.

Now here's what we need to do and we haven't done. Actually, the state-of-the-art of rehabilitation in America today is not good. Compared to acute medicine, we're way behind, and I'll bring this out again and again as we discuss this. It appears that medicine and society have not accepted the responsibility of caring for the chronic disabilities. And here I'm listing the locomotor system, the sensory motor system, and the sensory disabilities such as vision and hearing. When these are lumped together the term that is used for this is rehabilitation engineering.

Another problem we haven't faced in chronic disability is the categorization of disabilities. Rehabilitation has been lumped together and called comprehensive, a term that is not infrequently used; it means a little of everything and as far as I am concerned, not really much of anything. So we have to subspecialize as we have done in acute medicine. Whether you like it or not, specialization is here to stay. Rehabilitation doesn't encompass every disability from vision to walking to mental to vocational; all these things just have to be subdivided.

set him on his haunches when I told him that chronic disease, by God, was chosen to be unacademic and acute disease, by God, was chosen to be academic. And I used "by God" rather strongly. This is what we face, this is what exists.

I was at another major medical school where one of the most famous neurologists in this country is totally opposed to any except acute care of neurological disorders. And he is right in what he has seen. What he has seen is bad and he wants no part of it. However, I think he hasn't seen what he ought to have seen, that's my opinion. I'll tell you, this is something we face and we have to recognize, especially those of you in Government, that this is how it is. A lot of legislation and pouring of money has been done into seemingly incompetent funnels isn't going to make it better. The state-of-the-art of medicine and nursing in chronic disease is not good. Most medical schools will have nothing to do with it essentially, and that's a large majority.

The application of space age technology I see as the bright hope. We'll come back to that again later. This is where I think the action is going to be. It's going to do for chronic disease what bacteriology did for chronic infection. And the best example in our country that has been phenomenally good is the care of tuberculosis.

I remember at Los Angeles County Hospital there was a big sign when I was a junior medical student, "no case of tuberculosis will be admitted except when hemorrhaging." There were

Here also the Federal Government has had an enormously good input, because they have cost control and use control in general. However, they have this involved in acute hospitals so you can't keep an appendicitis there more than three days, or a delivery two days, unless you give a darn good reason why you've kept this patient longer. If you have a good reason there is no problem, but if you don't give a darn good reason and document it, you can't keep that patient longer. Now this is what we have to practice in chronic disease. We have to develop the same discipline. Why should chronic disease have bad discipline and acute disease have good discipline?

This is going back to the same thing that I talked about before. I say it can be done, and I know it has been done and is being done in a number of places. But I tell you there are still a lot of places where they sit around and sit around and sit around and everything goes to pot. Some of you know exactly what I'm talking about. This is something that the Federal Government can have a very good input. The word "triage" is frequently used in the military. It was Napoleon's chief surgeon who decided to divide his wounded at the battle of Waterloo into three categories: those with such severe injuries that they would probably not survive; those with injuries that needed attention to survive or they would not survive; those whose injuries were milder and could get along without immediate attention. Those are the three areas that the word triage was derived from in French.

head, or inside the middle ear; in speech we're dealing with what is actually expressed; in hearing, external to the middle ear; and in vision, external to the cornea. In the neuromusculardskeletal system we're dealing with the function of the extremities of the spine. This is area that essentially has been so very badly neglected. The term that is used for this to encompass this type of activity is rehabilitation engineering.

Now in the VA there is a slight mistake. Larry Hobson of the VA, a man of wisdom and a grammatical interest, thought it should be "rehabilitative engineering." So if you wonder why the VA is "ive" and the HEW is "tion" that is Larry Hobson's fault.

There is a very famous man who was chairman of orthopedics at Duke and then started the DuPont Institute in Wilmington; his name is Dr. Shans. Dr. Shans said in 1949 that, "There is no doubt at present that rehabilitation is poorly understood. Few of us feel competent to practice it, and there is a vast job of education needed to bring to importance the knowledge newly gained in the mind of the average physician." Dr. Shans said this in 1949. It's just as true in '59, in '69, and '79. I hope not in '89. But this is what the nursing students and the medical students think of rehabilitation. It's something out there that most of them have had essentially no contact with it.

How many of you in this room know about Dr. Jennifer Kelsey's report? Please raise your hands. This is a very

to me is easily number one as far as payoff, real payoff; I'm talking money as well as social, vocational, and so on.

So we're talking about billions of dollars. I happen to know Dr. Roger Eggerberg who is the chief medical advisor for medicare in this country; he was dean at USC and undersecretary of HEW for a period of time. The cost that seems to be really out of control in our country today is generally in the field of chronic disability. Appendectomies are out in two days. If you can get them out in two instead of six days, the cost isn't that much. That's true of deliveries, that's true of fractures. More and more fractures than not are treated in traction for six to eight weeks, but some are put in casts and braces and they are out in maybe a week and one-half, to two weeks.

So there has been a gradual reduction of the time of hospitalization. The costs, I admit, are going up, but the thing that's eating us out of house and home is chronic disability. What to do with this stroke when they have no place to go in two weeks. They ought not to be in an acute hospital at $400 a day; they should be in another area for $100 a day or less. Now this is what we have to do. So we're eating up billions of dollars unnecessarily as far as I'm concerned.

Now for discipline. I've talked some about this. When I am in the operating room I'm in an environment of discipline. There is a hierarchical structure of command and things are tight. If they are not tight, you just raise hell with it. You would

I'm enormously impressed with what has happened in Congress the last few years. First there was the committee Mr. John Clements was on, the Teague committee of science and technology. They met for about two years and it's the best thing that I know of that happened. That led, as I understand it, into the Randolph Committee in the Senate and then the Brademus Committee in the House.

The establishment of the National Institute for Handicap Research is the most far-reaching legislation that I know of that has ever happened in the field of physical disability and physical and vocational rehabilitation and so on. We have some representatives of this NIHR here today. Now I hope the thing doesn't get too loosely disconnected as it moves into education, because here for the first time is something that I now see is absolutely essential--that is interagency collaboration.

In the field of data acquisition and collection, there are about six agencies we named yesterday at a meeting, that are competing with each other. I think we need to be kicked in the shins. We have three in the VA alone. I need to be kicked in the shins. Somebody has just got to pull the rope on us and cut out the monkey business as I see it. But we have three different services in the VA that we just can't seem to get together. Maybe I shouldn't say this, but I hope somebody does kick me in the shins and the rest of us in Federal agencies. If we can't get together on a data base, it is to me is just ludicrous.

they said, call the engineer. The elevator wasn't working properly, call the engineer. And so the word engineer in the medical system has meant someone who fixes things. As more complex systems developed, they had to be maintained. Things became more complex and harder to install. To see that the surge of power from the x-ray doesn't mess up the electrocardiogram, you see. That's what engineering is in hospitals. There is an enormous amount of confusion here.

The next group I want to discuss is the engineer. The engineering group that will provide devices, and technology, and so on for the disabled is just evolving. This is in great need and there are a number of these that have been started. Joe Traub is back there. He has led this effort. When I was involved in it at Rancho Las Amigos Hospital, there was a unit, which is now working with the State of California Vocational Department, which provided an area where a disabled person came to see what type of devices he might be best served by.

This is quite new. In the past, this did happen in the field of prosthetics and orthotics. There are now certified prosthetists and orthotists in the country who have limb shops, and brace shops that are very effective. So don't tell me it can't happen, because in my lifetime it happened in prosthetics and orthotics. And that's needed now for better fitting of wheelchairs and all kinds of environmental control devices that we'll hear about. That's also true of communication aids and so on.

Counseling has to be kept in mind. We are not talking about somebody who fixes things. And I've seen this cause enormous confusion. So we have a new member of the team and he must be brought into the clinical environment.

Now where has it really happened? It happened in the eye. Because the optical physicist and the engineer have been intimately involved in the development of opthalmology. And it's worked beautifully. Why can't it develop for, say, spinal cord injury? It can. We've got to see that it will.

Another area where it has happened is the x-ray. Madame Curie developed the physics of radiation. The idea of using this in medicine developed and it just swept around the world in a few years. Last year, we spent over $3.3 billion on x-ray equipment and supplies. You couldn't practice medicine without x-ray. If someone had an injury to your arm and you went to the hospital and they didn't x-ray it, you'd think it was terrible. I could just give you dozens of examples of how terrible it is in chronic disease when you don't get an x-ray. And I don't mean an x-ray picture, I'm talking about analysis as well.

The idea of total hips is rehab in its purest sense. I've met some congressional staff and some senators and congressmen who knew somebody who had hips done, and so on. They would also tell me about themselves; one senator has had two hips done, several have had one hip, or their wives, or their uncles, or their brothers. Almost everywhere I go, they find out that I'm

The electric wheelchair has a long, stormy history. The Federal Government almost ruined our wheelchair industry by inappropriate activity as far as I'm concerned. Still, we've got to make it better. It's far from good enough. Prosthetics is good here but not good enough.

Quads getting around in Washington are seen quite often now. The Undersecretary of Commerce is a quadriplegic who drives a car around.

Orthotics is still not as good as prosthetics for some reason; it's hard to define. For example, instead of using bilateral long-leg braces for cerebral palsey, the hips are controlled with a controlled hip brace. Such a brace will hold a child until he or she is grown and will not need anything. No surgery, just a straight spine. Now we have other devices, electrical stimulation and so on, that are working.

Kinesiology is another area in rehabilitative medicine that should be a lot like electrocardiography in medicine. Force plates and gate strides and that kind of thing are getting into the system so that the disabled can walk properly.

In summary, we have technology available. We need to use it more effectively. That to me is number one. This means that technology for handicapped individuals has to be produced in a profit-making industry. The Government doesn't make wheelchairs. We have to accept this. Somehow it just infuriates me that the VA wants to hold back patents. Patents are almost never profitable.

is still quite momentous. Again, I have to summarize drastically. Our speaker has been at the University of Wisconsin for ten years and I suspect that he's been in many departments and knows many people at that illustrious seat of learning.

I just want to say a few words. What interested me as I went through his qualifications is that his Ph.D. studies are interdisciplinary. That's says a lot to me. And as I look over his resume, I was struck by how many different projects he is and was the principal investigator on--interdisciplinary projects to be sure.

For example, he was the principal investigator for the evaluative services for nonvocal, severely handicapped people. In another vein, he provided engineering services related to the design of commercial production of communications and control aids. Then he was the principal investigator for developing scanning communication aids for the extremely physically disabled children. He was involved in the education of the handicapped directly. And he was involved in field testing and final modification of aids. So you see, his interests range, you might say, from the very basic research on to implementation. He has also worked on the development, evaluation, and dissemination of information on communication aids. That brings in another area--dissemination of information. Very important. I'm very impressed. He has also explored the state-of-the-art of nonvocal communication.

reasons: the size and diversity of the field of communication, and also because of the recent developments--we've seen some rather dramatic recent developments--especially in the area of technology, and also because of its importance in our daily lives.

If I can ask you for a minute to try to imagine doing your job, going about your job, if say, you were unable to walk. Or if you were unable to use your hands. Very difficult. But isn't it more of an inconvenience or handicap than a disability? It's something that can be overcome, certainly something that is not going to stop you from doing your job. Now try to do it if you are unable to see and unable to read to communicate either in the written form. Again, we see that we have a much more dramatic, a much more serious type of disability.

If we go one step further and we are unable to communicate in the interactive mode with the general public because of a severe hearing impairment, we see again that a much more serious barrier is being posed for us.

Now think about individuals who are totally unable to express themselves either through speech or writing. And try to imagine going about your job without the ability to communicate. Of course, it's impossible. If we can't communicate, then we have no community. In Dr. Nichols presentation, there was a quote that said, "What is distinctly human is not inventing the wheel but passing it along." What is distinctly human is the ability to communicate, to interact. Yet there are a large number of individuals for whom communication is denied, or barred, because of a severe physical handicap.

through very careful work and looking at what his abilities are, we can, in fact, provide meaningful direction for these individuals. And as we will see later, even to the point where individuals like Craig are securing jobs in competitive industry.

Now, what's the secret? Well, basically it is focusing on finding out what types of things can be done to facilitate the control that they do have. This second film clip was taken 30 seconds after the one you just saw, and it was the first time that Craig had ever seen this particular aid, this particular approach. What we see is what appears to be a tremendous increase in control simply because his abilities and capabilities are amplified and his disability is ameliorated. In this particular case, we did it by reducing his motion from three dimensions to two dimensions, and providing a surface that he can slide over, do weight bearing, and which provides feedback tension to the muscular system. It also helps to eliminate the need for the co-contraction control. He is here using an aid successfully to spell out his name.

The aid itself is able to accommodate to much more erratic pointing motions than you are seeing here. This is actually rather mild for it. That will be the end of the film clip.

So we're talking about communication, and what I would like to do is talk about the general area, with particular empahsis on communication for the severely physically handicapped.

At the same time, please remember that any time you are able to control an aid, you control 26 letters and words and phrases

We'll like to take a quick assessment of the value and the shortcomings of current technology. Where are we today; what it can and can't do? I think it is important to know its shortcomings as well as what it can do. Finally, we'll take a brief look at future directions.

Figure 1 is split into two parts. In looking at communication we must realize that there are two components to it: a conversational component and a written component. Very often when we think of communication, we think just of the conversational aspects. Now these are important. We need these not only for social interaction, but also for daily living. We need them for education, employment, and recreation. Without this, we are without a good means of interacting conversationally, and we are not going to be able to carry out any of these activities in any meaningful way. And of course, what's left if you wipe all those out?

In addition, for the severely physically handicapped individual, we also have their need to use this conversational mode of communication to accomplish basic self-care activities that we may be able to do for ourselves, but for which they must rely on others.

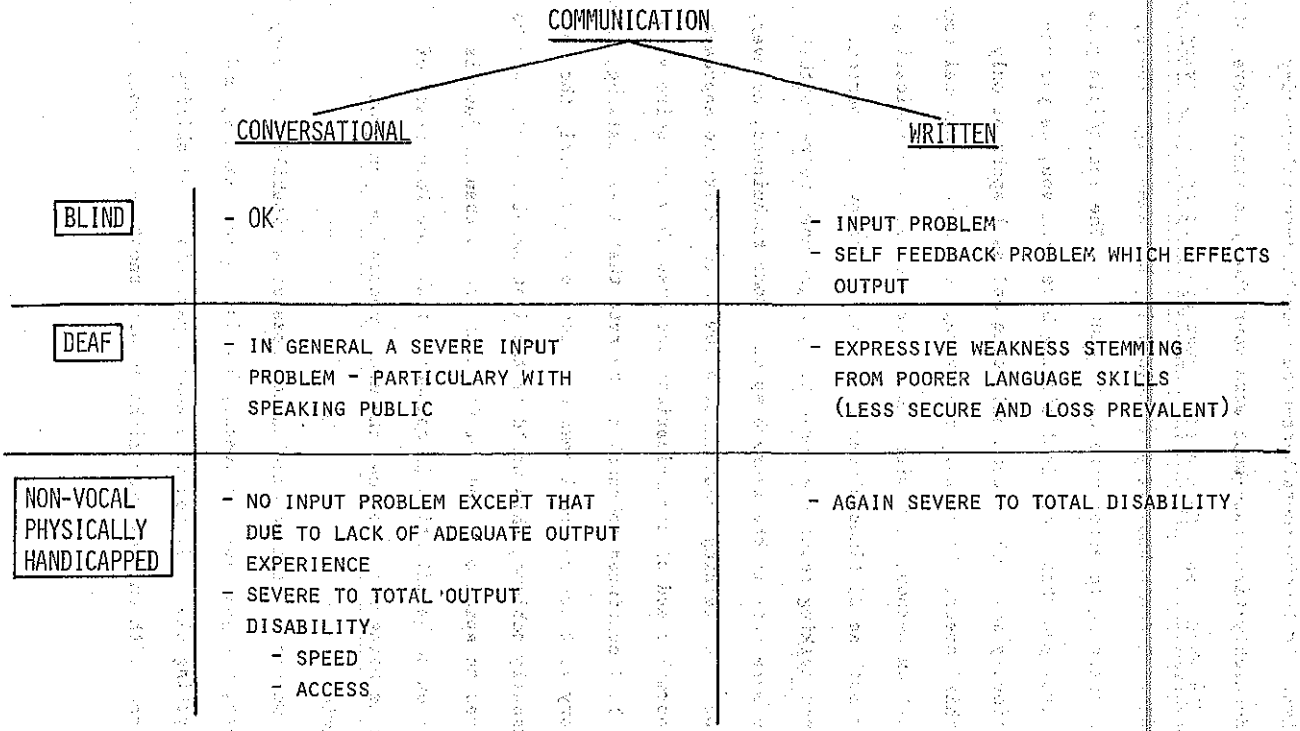
The other component is written communication. And again, this is one that has often been overlooked. Notes to oneself, social, educational, employment, and daily living all require written communications as well as conversational communications. So it is not sufficient just to give a person the means to talk,

especially if they are going to be going anyplace and doing anything productive with their lives. In addition, the individual with the severe communication impairment who has a speed problem will need to rely on written communication even more so. With them it is even more important than it would be to us.

On the bottom of figure 1, we notice, the balance from "conversational" to "written." In our personal and social interaction, the conversational is good enough to cover most of our avenues. But if we are going to get into education, employment, any kind of productive activity--especially that which we are paid for--we find that we rely very heavily on written comment. I'm not saying we don't do a lot of talking at the office; but I mean the kind of work that we're really paid for--unless you are in a manual labor job with which the physically handicapped very often have difficulty. What you are really paid for, generally, is in some kind of productive form, some kind of written form.

The ability to produce written copy as one interacts in the office environment is very, very important. Again, referring to figure 1. For slow communicators we see a shift a little more toward the written. This is important as we look at both the potential and the limitations of speech output aids. The potential is fantastic, but they are in fact not going to be total solutions, especially when we get into the rehabilitation aspect; we need to also provide the ability for written communication.

FIGURE 2


COMMUNICATION
CONVERSATIONAL
WRITTEN
BLIND
- OK
- INPUT PROBLEM
- SELF FEEDBACK PROBLEM WHICH EFFECTS OUTPUT
DEAF
- IN GENERAL A SEVERE INPUT PROBLEM - PARTICULARY WITH SPEAKING PUBLIC
- EXPRESSIVE WEAKNESS STEMMING FROM POORER LANGUAGE SKILLS (LESS SECURE AND LOSS PREVALENT)
NON-VOCAL PHYSICALLY HANDICAPPED
- NO INPUT PROBLEM EXCEPT THAT DUE TO LACK OF ADEQUATE OUTPUT EXPERIENCE
- SEVERE TO TOTAL OUTPUT DISABILITY
- SPEED
- ACCESS
- AGAIN SEVERE TO TOTAL DISABILITY

is left, if they have no ability to interact with anybody else, and they are physically handicapped and have severe disabilities?

However, let me remind you again that these are the same people who with proper aids and devices are now securing competitive jobs as computer programmers in banks, in industry, and securing competitive employment with employers who are not handicapped and do not have any handicapped relatives. And they are doing a damn good job. As a matter of fact, they are pointing up errors in some of the systems that they are working on.

We've seen that the communication problem is both severe and all-pervasive. What I would like now to talk about is some of the intervention approaches as shown in figure 3. I think there are three areas, or three approaches, to intervention in the field of disability. One of them is to restore or to cure. In this, we mean that we want to put the system back as it normally or traditionally is used to achieve a function. For example, in connection with the speech motor control system, we would be going to restoring it so that it could still be used to output and to communicate. This is done through medical, therapeutic, and surgical kinds of treatments. We try to get the disabled individual back to performing essentially the same functions and in the same way as we do it. Now, we are frequently a little bit chauvinistic in this; we believe everybody ought to do things the way we do it, and sometimes there is an overemphasis here.

The next approach to intervention is to facilitate. If we can't cure it, can we brace it? Can we fix it up so that it can still operate? In this approach we facilitate the normal or traditionally used way to achieve the functions that we are used to having achieved.

Prosthetics, orthotics, and strategic kinds of intervention approaches come in here. Let me give you some examples of these. Again, if we can restore, that is certainly desirable. If we can't restore can we facilitate it, so that it in fact works? Glasses are an example of facilitation. We haven't gotten the eyes back to working perfectly, but, by using a rather simple aid, we are able to restore the function. We still use our eyes to see the same way--the normal way--by using eye glasses to facilitate their function.

And the third approach is to augment. Here we provide supplemental or augmentative systems. Now these are in addition to normal mechanisms, in some cases in lieu of, but by and large they should be thought of as an addition to, the functions, the systems we normally use to provide needed functions. We call these augmentative or supplemental kinds of aids.

In figure 4, we have some examples of what these various things look like. We have here the categories "to restore," "to facilitate," and "to augment." I've also broken the intervention approaches into "conversation" and "written" output and input and "call systems," if you will. We'll start out with the restore.

These items on the chart represent the areas technology can currently contribute to. There are a lot of therapeutic and other measures that fall into all three of these categories. In the restored area, we can identify a number of biofeedback aids. These are medical instrumentation and speech motor assessment aids--all things again that Dr. Nickel covered. Better assessment is obtained through using technology; feedback is part of the therapy; and medical instrumentation facilitates the other discipline in terms of their intervention.

In the written output we see the same kinds of things being brought to play. Where possible, of course, this is where we want to be. If we can cure, if we can find the silver bullet, this is what we are ideally looking for.

In the second category, facilitation, we see such things as a palatal lift in communication. Something to lift up the back part of the mouth to allow individuals who have weakness back there to be able to speak in a normal manner. What it does is bring the velum close enough so that the muscles, which, even though very weak, can finish the job and you can still speak in the normal way.

Speech amplifiers and clarifiers are other examples. They will be available some day, but are not today. We are looking at speech recognition and resynthesis. This would allow somebody to say "hello" as best as he could, and through electronics have it come out "hello." The idea is to have something that is

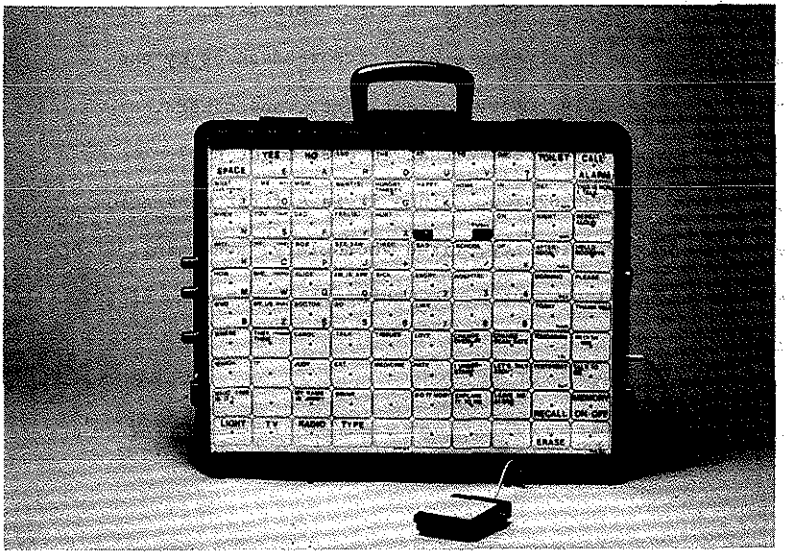
The teletype and computer teleconferencing also fall into this category. In the input category we have audio to visual techniques including auto-cued speech which is a technique which helps augment lip reading. We also have audio to tactile, signing, teleconferencing, captioning and lip reading again.

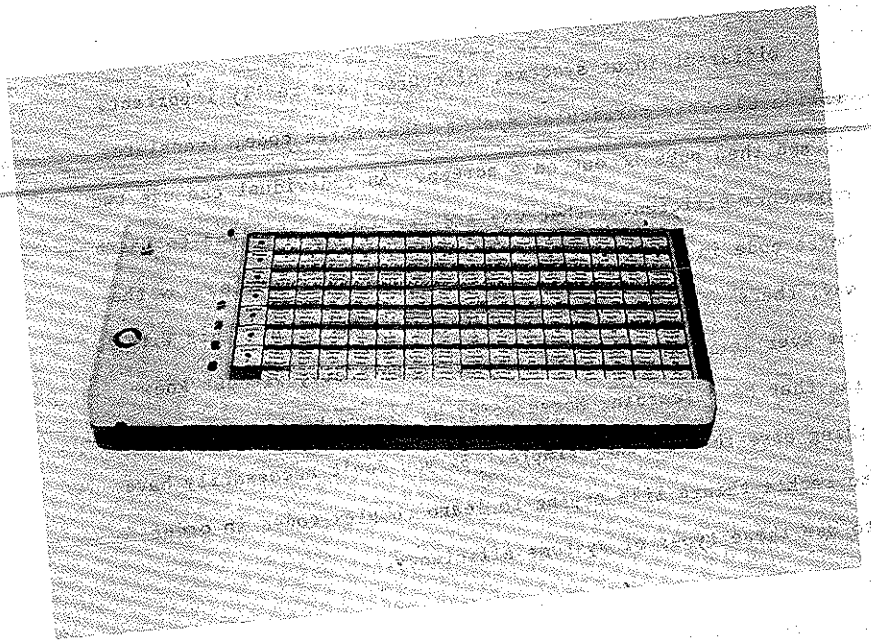
In the written, we see text to speech. And for output we have speech to text for individuals who can output but cannot input. Again, this is something that is being looked at--to have someone dictate and have it typed out for them. On the other side for input we have reading machines which are basically text to speech to allow individuals who are unable to read the text to be able to put it into an audible form which they can then hear. We also see text to Braille. Braille can be displayed off of normal computer terminals and similar devices. We should also note the emergency call systems and remote pages.

This is sort of the level we're at now. Unfortunately, the approach seems to be, first, try to cure. When you give up trying to cure, then we try to facilitate it and see if we can't patch together that way; if we can't facilitate, then we'll give them an augmentative aid if we can find one; otherwise we'll ship them off; after all, by then, our time is used up and away they go.

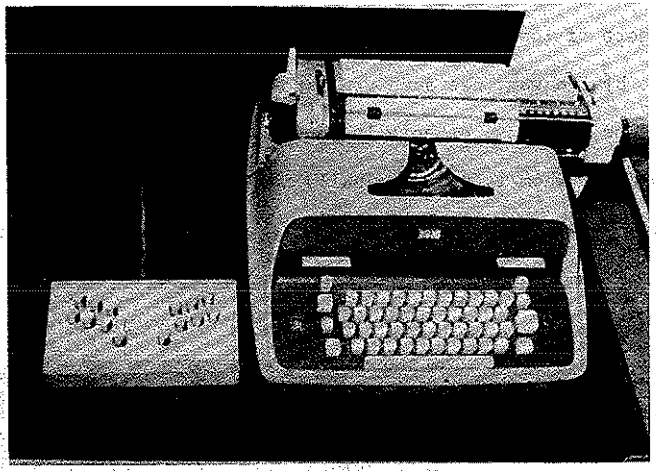
I think the important change we're now seeing is a change in overall approach. Now when a client comes in and you see the person does not have a function we ask, "Can we restore it today?" not, give him the augmentative aid today so he can communicate

Some of the techniques are very simple. Slide A is a zygo communication aid; it is meant to provide individuals who have no means of pointing, a way to point by using a single switch. It uses a scanning technique which is very powerful, but also relatively slow. What we're trying to do is to develop techniques which of course will be faster. These types of aids are the ones that can provide us with the very slow input that we talked about before. But again it is important to have a means of communication and we work for efficiency. This aid also has a 16-element memory in it. With it you can select up to 16 things and later ask it to recall them. The dot will jump to the items in the order that you selected them.



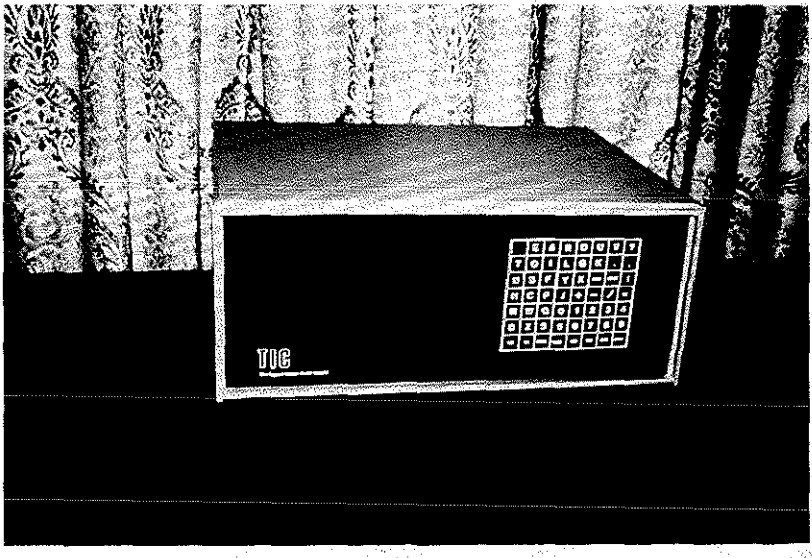


There are different types of inputs. (Slide D) This one by the Cybernetic Institute uses a seven-key input to allow access to a full keyboard.

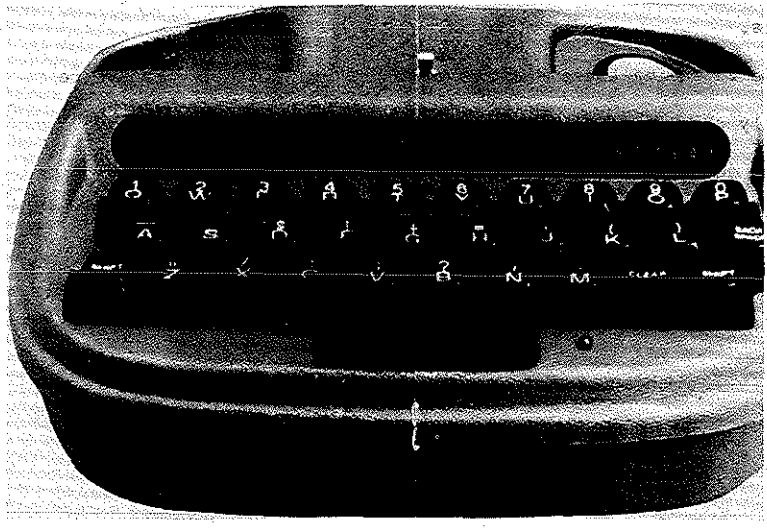


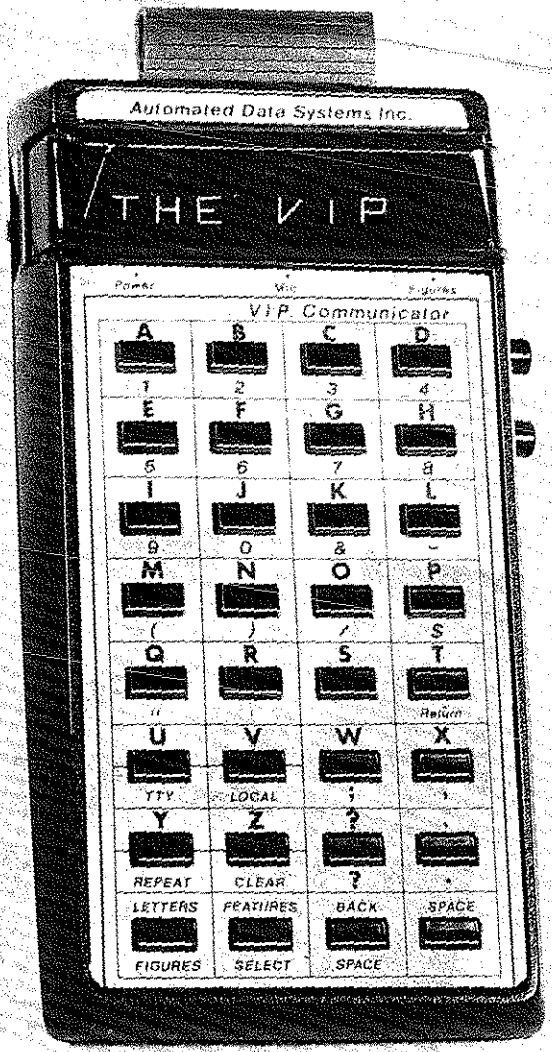
Another approach is to use what amounts to a modified flashlight which is attached to the user's head which he can use to point. This approach has some problems, however, which led to the development of another similar approach which is used in the aid shown in slide F. It's hard to describe so I brought it along and if any of you are interested, you can come up afterwards. This is the one that a young girl recently used while visiting Califano's office--previous office. Basically, the pointer is worn on the head and wherever it points, the little light beam follows it. So the individual, by pointing with his head, is able to indicate the elements on the display that he/she wants and then print them out on a strip printer. The same technology is being used in other ways, so that individuals who do not have good motion with their hands, but have control of their head, can input to computers for these types of things. We also have some individuals now working with space age industries. Pollyhemus Navigation Company is one who is using a system that was originally used in the fighter planes to target enemy targets. You would look at the target, sort of aim your head at the target, and push a button and the computer would know exactly where you're looking. You can also cause other people to look, and so forth. They are now looking at this same technology for use by the handicapped in the sense that a handicapped individual can by just pointing his head reference and output items.

This is the Tufts Interactive Communicator. (Slide G) A lot of work is being done with the eye motion approaches discussed earlier--at Tufts University, as well as other places. This is one of their earlier communication systems using scanning technique and television output.



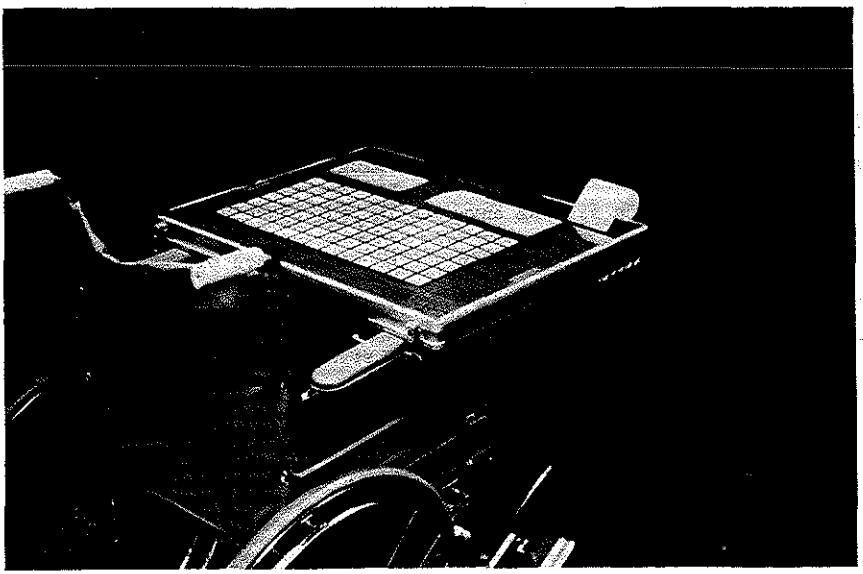
There are a large number of communication aids for the deaf population that can also be used by the physically handicapped population. (Slide I) This one is one used to allow deaf people to talk back and forth over the phone. It is about the size and weight of a ream of paper. The phone sits on the back in a cradle back there and with it of course the deaf can talk back and forth. It's a TTY--short for teletypewriter--one of the first cost effective portable systems, it's about $600 which is roughly around the range that most of them are today.




Automated Data Systems Inc.
THE VIP
VIP Communicator
A B C D
1 2 3 4
E F G H
5 6 7 8
I J K L
9 0 & -
M N O P
( ) / $
Q R S T
" Return
U V W X
TTY LOCAL ; ,
Y Z ? .
REPEAT CLEAR ? .
LETTERS FEATURES BACK SPACE
FIGURES SELECT SPACE

Some aids are getting quite small. (Slide L) The one shown here is for those individuals who use typewriters; this is what essentially amounts to a hand-held typewriter. The device has a keyboard, prints on a strip tape, and comes with or without a key guard. This is actually marketed by TSI but was developed by Canon Company, the ones which make calculators and cameras. The whole objective of this division of the canon company is not to lose too much money. They have gotton into this field to just try and help out and have done some rather nice things like this with really compact systems for the handicapped population. This one has limitations in employment and education, but works very well as a backup to speech. For instance, an individual who can talk, but may not be always understood, can have something which is compact enough to have with him and he doesn't have to haul something large around. He can have it when he needs it.

This is an example of a more advanced aid. (Slide M) Here we begin to look at the severely involved individual and the fact that conversation isn't good enough. We need conversation and written communication as well as control. This one was developed at the University of Wisconsin and provides the ability not only for visible output, but on the right you can see it has a miniature printer, page printer, built into it to allow the individual to do written copy. It will also work with full-page printers or T.V. screens so you can also hook it up to modems and use it over phone lines with other handicapped individuals or with computers; it has also been used to control wheelchairs. Individuals like Craig, whom you saw in the first slide, can use aids like this to interface to almost any electronic device as well as to their own environment for controlling their own environment.



like dimming and brightening their light, turning on the appliances and things in their houses using modifications of these same systems.

These are the kinds of things we're seeing. There are, however, three dangers right now to cost effective application in terms of the handicapped, as listed in figure 5. The first one we need to look at is the inappropriate application/recommendation. Right now, in the field, what is becoming available is far ahead of the number of people who know what is going on and know how to properly apply it. It is always going to be that way in a newly emerging field but we need to get out of this situation quickly.

The second problem we have, is that a lot of the tools we have need much improving. A lot of them have come up by the bootstrap. Many have been designed or applied without adequate support. Many of them were developed by people not in big centers but off by themselves, especially in new fields. A lot of additional work needs to be done to refine them over time.

We have to be very, very careful because these things are generally ineffective as a single function application. You can't go in and say this individual is multihandicapped and I'm going to work on communication and get him a conversational communication aid and walk back out. He's not going to be able to do a damn thing with it. He's not going to be able to do anything in the classroom, he is not going to be able to do anything better on the job site. We have to be looking at a total coordinated team effort for rehabilitation process.

Unfortunately, we're finding people who are familiar with one or two aids running out and trying to apply them. I think some more work needs to be done in terms of trying to coordinate the rehab process and, as Dr. Nickel was saying, get the rehab engineer in on the team so that the aids can be understood better, as well as the human factors. You can't only understand the aids and you can't only understand the client. We need teams; we need to look more toward that model.

Going right along with that is the third point. Too often the device is perceived as a solution rather than a tool in the solution. Too often we see individuals given an aid and pulled out of therapy instead of the aid being a tool for them to develop effective communication. There has to be a large number of strategies and other things developed along with any aid or device.

These are three dangers that I see to a cost effective application. They are to me a danger to the whole field. If we start applying aids and they don't pay off, then the whole thing is going to reverse on us. I think that support has to be directed or turned in those directions of applying aids and devices as well as just in developing them. Again, this one is a tough one to nail down. Service delivery is funded locally and research is funded federally, but who is going to fund everything in the middle? That is the big problem as we see it at the present time in this field. I see it as a very definite danger if it's not covered and covered well.

FIGURE 6

COST BENEFIT CAN COME FROM 4 LEVELS

4 AREAS FOR ACHIEVING COST BENEFIT

1) REDUCED CARE/SUPERVISION

2) INDEPENDENT LIVING SITUATION

3) EMPLOYMENT - SHARING OF COST OF LIVING

4) FULLY INDEPENDENT - PAYING TAXES

effective aids, the number is few today. The devices have only been around for a couple of years; in many cases the individuals are actually on the job with the promise that the aids are on the way--and they sometimes never show up. So we are finding employers compromising themselves and having difficult times as a result.

One of the R&D problems is that technology can run up to $10,000 for an individual. That just stops people cold, when they hear that. Divide that out over ten years, however, and it turns out to be like $1,000 or $500 for $5,000 worth of equipment. We're finding that educational systems which the children are being put into cost about $2,000 to $18,000 per child per year, depending upon which situation they are in. Yet they are still unable to speak, or write or interact or really take any kind of advantage of the educational system at all without some mechanism to speak and write. So we appear to be pouring money down the tubes, in some cases as much as half a million dollars per child, because we can't spring $5,000 to give them a way to communicate and write. This is a real problem.

Another area that has been identified is the problem of therapy versus aids. I don't know how to solve this problem; let me just pose it to you to think about. Let me illustrate. We had one individual in the VA system who they had had on speech therapy for two hours a day for six months. I think it cost about $40 per hour. That's $80 a day for 6 months. (AUDIENCE REMARK: "Plus $200 a day to be in the hospital--you forgot that.") Yes.

Again let me say that the aids are not seen as alternatives to, but rather, tools that should be brought in while the person is in therapy. If we can develop the original or normal communication channel along with them and then find that we no longer need them, great. But in the meantime we have functional communication and the therapy needed to help use them better.

In summary then, basically, I see the funding, the cost, the lack of trained personnel, the view of aids as solutions, and the applications too late, or as we talked about, in single function manner--where we just work on one aspect instead of total whole things, as being the greatest barriers to this field. These and perhaps our own shortcomings in understanding what these individuals are capable of doing. Thank you.

KORNBLUH: I hope you won't think me ingenuous if I take a minute to say that we're living in an exciting decade, a decade filled with many problems and, I hope, many solutions. I couldn't help but think, as I listen to our first two speakers, that we may have to think in terms of devising some taxonomy, some overall classification--like Gregory Mendel did in the field of biology. Perhaps we need a similiar type of person to come in and deal with problems of the handicapped and begin to make a grand taxonomy of both the techniques, aids, devices, equipment, even the kinds of people who work with the handicapped. I started to make a list of kinds of people and I came up with over 15 or 16 types comprising the handicap community. Now, what I guess I'm trying to say is, I

He was responsible for many researches dealing with the physically disabled in a multitude of disciplines. He was Director of Research and Development for the American National Standards Institute on the accessibility and usability of facilities of the physically disabled. He has been a lecturer and consultant throughout the United States and several foreign countries. And, as with our other participants, he has authored many books and articles and edited many bulletins and contributed to many books as well as contributed to an encyclopedia on the aspects of rehabilitation.

He is past president for four terms and a director of the National Paraplegia Foundation. And again, he has received many local, state, national, and international awards. Just let me give you a couple of examples: the W. F. Folks Award, highest award of the National Rehabilitation Association for professional achievements and services and the distinguished service award of the Illinois Council on Exceptional Children for "his leadership."

He got a special citation from the American College of Sports Medicine. He is also a charter inductee into the Hall of Fame of the National Wheelchair Athletic Association.

I'd like to now give you Professor Dr. Timothy J. Nugent, who will discuss the role and place of environment facilities in the area of handicapped studies. Please.

The first of these is the telephone company. Twenty some years ago, with the origination of the effort at standards that would make environmental things accessible and usable, they argued against it. Their argument, at that time, came largely from the Eastern Seaboard where they said telephone booths couldn't be eliminated because:

> (1) they are used mostly by gamblers who wouldn't want to be overheard--and that is a direct quote; (2) people who had speech difficulty or who spoke foreign language would be embarrassed if they couldn't be enclosed in a phone booth. We know that the new hearing boxes that existed, even in those days, precluded anybody hearing your conversation if they were standing right next to you.

Another industry that objected vigorously was the elevator industry. I had to finally embarrass them in those days because they refused to put controls horizontally. In the carte blanche way, and this is typical when new things come into being, they said well, people envision going up and down, not sideways. They thought that was an intelligent argument. So I took a photograph of a two-column keyboard that had 82 stories, I think it was in the building, and of course they went up to 41 and then came down to 42. I asked them if they envisioned going up and then dropping rapidly to the next level. And of course, they were embarrassed by their own argument.

say very readily in our community, where we've been doing this for over 35 years, that the greatest benefit is accrued not to the individual with the disability, but to the general public--in many ways. Time doesn't permit me to explain that.

I think another thing that was pointed out is that we shouldn't lose sight of the individual and the need to develop the potential of the individual by hiding behind technology. I have seen technology exercised for the sake of technology only and literally destroy individuals in the task.

I have seen technology be unique, clever, ingenious, but not really result in the introduction of the individual disability to a more social and more interacting situation. At the same time we have the problem that Gregg identified. When new things come into being, many professions find it hard to accept them because they think it is going to displace their essentialness, such as therapists that deny or clinics that deny a piece of technology, but emphasize therapy. The two must work hand in hand and they have not. That, I believe, is one of our shortcomings.

When we began mainstreaming in the regular schools, faculty and administrators in special schools thought it would put them out of work; the truth is we need far more of them now that we are actually "mainstreaming"--a word which I kind of dislike--than when we had them all herded together.

the real problem for the patients or individuals that we're serving or supposedly training. We must learn to look beyond the institution in which we work; we must look beyond our own professional discipline, our own categorical concepts; we must look beyond the limitations that we have placed on disability which unfortunately have become a self-fulfilling prophecy far too often. I think human beings are capable of doing far more than most of us give them credit for being able to do.

Years ago when the concept of developing standards on accessibility and usabilty came into being, we had people seeking membership on our committee for one reason only by their own admission; they wanted to destroy the effort or deter any forward motion. I won't mention the agencies and the industries. Now we have quite the opposite, which is good. Except there is some abuse and some misuse, which hopefully I will remember to identify later.

We must distinguish, in general terms, those things which technologically and sociologically apply to the individual and those things which apply to the environment in the sense that they can become requirements for a standard. We must distinguish between what is needed and what is desired. I would emphasize that a performance standard for mobility of all of us might be that each of us should have the right to own an automobile, or that each of us should have the right to travel freely and independently. It would not be that each of us should have the right to

I see no justification at all for any Federal subsidies to industry or to manufacturers to develop those things that are needed by the public. Those with disabilities are a significant segment of the public in numbers and potentials, in value and worth. They are larger than any other one segment of our population for whom we've ever had legislation and social action. I don't think we should subsidize those things that would otherwise come about naturally with good programming.

I am very disturbed in one area of concern, and I'm going to be specific in this instance. One of our major areas of concern now is transportation. I am disturbed first with General Motors Corporation, which sold me General Motors buses in the early and mid-fifties, and which knew full well what we did to make them accessible and usable to all people. Our buses are a system that's been running for 29 years. You and I can walk in the front door in four seconds; a person in a wheelchair, including an electric wheelchair, can wheel in the same door also in four seconds.

The buses have come all the way to Washington many times to facilitate White House Conferences, Paraplegia Foundation meetings, PVA meetings, and the like. They served everyone from age 2 to age 102. The man who sold me those buses is now the manager of General Motors Bus and Coach Division. How simple it would have been, with all the investment in their new vehicles, to have integrated this into the scheme. Overnight the problems of

handrail. Then, it's stable and secure. That same ramp on a bus that has a 14 inch high floor, by law, would have to 14 foot long, because the maximum pitch allowable is one and twelve. Consider where you could exercise that.

I want to emphasize four points to those of you who get into nitty gritty problems. No panel, even this one, can cover everything completely. If you will concern yourself with the purpose for which something is being done, the intent of that specific effort, the performance requirements of that particular effort, and the functional concept of the use of that effort by people, you can solve a lot of problems that may not be written into specifications.

Manufacturers have made some very worthwhile contributions; however, some manufacturers may have done more harm than good. I don't know the answer to obtaining integrity and to commitment; but I think it is important that we try to recognize the difference.

On the problem of transportation, I would stress one thing, namely, the entire system must be accessible to be meaningful. I think the entire system can be effectively supplemented by dial-a-ride and various other programs that evolve; however, I cannot see any of those limited specific systems ever meeting the needs of the population throughout our Nation. This is particularly true when one considers the variety of uses and traffic patterns and the threats that the energy crisis makes on these kinds of efforts.

I think the technology exists in public transportation. I think we are behind in the game because of the investment General Motors and others have made in their vehicles and because of the Federal money that has been expended on other things, none of which are coming into being.

I think all of us are also guilty, and I think these are the things that must be considered. We argue against the operators of mass transit and we argue against agencies and Government bodies saying that mass transit is important to people with disabilities so they can:

(1) go to work, which means earning money; (2) so they can go shopping, which means spending money; and (3) so they can participate in the social and recreational activities of the community.

Then on the other side, we have a carte blanche requirement that disabled persons either get on free or at half fare by virtue of disability. It should not be by virtue of disability, but by virtue of economic status. It's our overplay at times, in the types of identities we make, that actually deter us from our own goals. There are people in wheelchairs in this very room that are probably making as much as I make, and perhaps more. I know some people in wheelchairs that make $150,000 a year; they are very successful people. These assumptions and this carte blanche approach to environmental facilities problems, rather than defining them, are very problematic.

So often, action on behalf of those with disabilities in buildings, at facilities, and in transport, is deterred and deferred because people talk about safety without truly understanding it.

Now I have a handicap. I made a note here and I cannot read it. Another area that has caused a real problem is in transportation, and it goes back to what I said about manufacturers' bandwagon approach. I know of two cities that invested very heavily in making their transportation system accessible and all vehicles have been idle for the last six or eight months. Also, within the last three weeks, one of my friends from one of the cities sent me a report saying you can abandon the idea, because they can prove it doesn't work. And that happens to be from our home State, Gregg.

The truth of the matter is that the thing I alluded to earlier, the haste with which it was done, was out of concern for proper application and utilization. However, it resulted in buying things that had not been field tested from manufacturers who had not done their homework. The failure of the effort, as far as I'm concerned, was preclusive.

The next area of environment which is all-encompassing, of course, is the man-made environment, or the built environment, including outdoor areas, recreation areas, and the like. I will say to you without any reservation, there is no building or facility in the world, regardless of the appearance desired by the owner, designer, or builder, regardless of its purpose, intent,

Now it is one thing to develop a standard on electricity; it's it's another thing to develop a standard on plumbing; it's still another thing to develop the all-encompassing standard on the total environment where we touch upon all those things. To get agreement on all those things is really having your head in the clouds, because it just can't be achieved in that fashion.

A standard does require concensus. A standard then becomes the basic reference for codes, which may vary in different parts of the country because of changing climates, changing topography, or changing or different legislations in existence. For instance, some States have statewide zoning codes and some States don't; some leave it to the community. There are all sorts of variances. But there is a tremendous economy in arriving at a mutually agreed-upon standard and then referencing it in codes, particularly when that standard requires revision and change as sociological and technological changes happen.

Sometimes knowledge comes into being because, without any additional cost, referencing that particular standard brings about change in every community, every State, automatically--without all of the money that has been unnecessarily spent in the rewriting and replicating, just for the sake of signatures.

Standards are basically prepared as performance requirements. Now when one deals in a simple, specific standard, we could say that wall must resist a certain flame and a certain temperature for two hours. It's a performance requirement. The reason that

Now these are the areas of concern that are very problematic and need to be emphasized more than a measurement or a specification. There are conflicting regulations within our Federal Government that sometimes cause great problems in the realization of the accessible environment.

Another area that I think requires some mention is that of enforcement--meaningful enforcement. I think that, unfortunately, some people are placed in positions of enforcement too rapidly and before they fully understand the total problem, and particularly the functional aspect of it. They thereby cause considerable reaction and opposition. I went through an industry where the vice president of a particular corporation said, "In the first half a day we have saved $250,000 over what one of the inspectors said was necessary--just by being concerned about function and performance."

I'll give you one simple example. A Federal authority once said: "If a door was not 32 inches clear, you would have to tear out the walls and put in all new door jams." Now that means tearing out the walls, throwing away the doors and door jams that are there, buying, building a new wall, and putting in a new door jam. And he was adamant about it. However, the same door with an offset hinge that cost $3 was more than wide enough. Unfortunately, he wasn't concerned with function and performance; he was concerned with specification and had not been challenged to think in the dimension that I am trying to emphasize in this particular instance.

Through such symbols, a blind person can identify location, the designation of buttons, say on an elevator, but so can the foreign person who doesn't speak the language. It's also easily discernible by the person who has sight. So there are many areas where technology can still be exercised and applied in a meaningful way to make the environment better.

Our real task now is involvement in industry, developing our own perspectives, and rewarding initiative rather than subsidizing those areas where there has been total inactivity. I think, perhaps, one of the best things to come out in recent years is the tax incentive, which basically says, you might receive a break from our Government after you have shown to me that you've done something.

I see the time, and I'm just going to stop here.

KORNBLUH: Thank you very much. I'd like to spend about 15 or 20 minutes interacting and ask you to address questions either to the entire panel or to any specific member of the panel and to ask you to speak fairly loud--I would appreciate it. Does anyone have any comments, questions, please?

QUESTION: I'm Suzanne Brainard from Control Data Corporation, and I'd like to address my question to Dr. Nickel. You were speaking about some of the disadvantages of some of the interaction with the private sector. What do you see as the perceived disadvantages other than the whole concept of profit-making?

At Rancho we have every ward open on a patio that is level. There is no ramp. They wanted to put in all kinds of fancy fire doors and things. It would have cost us over $1 million, that kind of thing. So overregulation is a real thing that I have talked to. I think that collaboration with private industry is just an absolute must. And it behooves you, I think, to take advantage of research that is going on in the different agencies better than you have.

And I'm not speaking to any firm specifically. I'm talking about anybody. Maybe you have a comment on that, Gregg, because you're involved in that totally.

DR. VANDERHEIDEN: Well, I can't say anything except to reiterate what has been said already. I think the safety question is another one. If the steelworkers and bridgeworkers and everyone else had to go through all these same safety things that the handicapped go through, we would not have any high-rise buildings or any bridges. A person has to be able to decide his own risk level and the handicapped have protested and said: "We have the right to die in a fire."

Basically, the comment was made appropriately with respect to buildings and things. If there is a big fire on the bottom, the people on the top are not going to get down, and yet, we don't shut down the big buildings; however, the handicapped have been turned out of jobs and everything else because they can't use the elevators and because the elevators go to the basement in case of fire. They also can't use the stairways, so we can't let them up there. Things like these are not uncommon.

DR NICKEL: You don't think; you know. Government is not going to make wheelchairs--never has. It made submarines. They started contracting those, and the Brooklyn Navy Yard closed down because they can do better at Norfolk; there they have a private company. They never made an airplane; they used to make rifles but they don't any more. They used to make shoes, but they don't any more. So I don't see anything in the horizon that the Government is going to make wheelchairs or any other device for handicapped persons.

DR. VANDERHEIDEN: The one thing the Government does have is a whole bunch of patents and rights to things they are afraid to release, perhaps because they are afraid somebody is going to make a buck on them.

DR. NICKEL: This is almost an infuriating barrier. Some bureaucrats feel that literally everybody is a crook that wants a patent. I see that constantly. The VA now, by regulation, had really choked it down and it's been opened a great deal. But I think it needs to be opened widely--open patents so CDC doesn't get the sole source, but that's not what you're after.

QUESTION: Vernon, I'm glad you corrected the efforts of the VA, because the Government patent policy does vary from agency to agency.

NICKEL: Right. I should add that NASA has a beautiful track record in the space program, and so did the Atomic Energy Commission. That's the kind of open Federal program that we need.

particularly with the reading machine technology. We're talking about devices which cost often between $5,000 and $20,000. The possibility of individuals or the families of individuals assuming the cost of these devices, I think, as a blind person, is out of the question. My income is probably as good or better than the average blind person. Yet, I am not going to spend $20,000 on a reading machine I would enjoy using. What I think is vital is to get the products better marketed and to get the prices down. Also some means of supplementing the ability of individuals to buy much needed rehabilitation devices is really in order. Would any of the panelists have any suggestions, other than third party means, for purchasing rehabilitation devices?

DR. NICKEL: If you break your leg today, God forbid, and I were practicing in this town, I could put you in the hospital and spend an enormous amount of money--as long as it was well spent: discipline, surveillance, and all that good care. Somehow this has to get into the technology that we've talked to already. Another example, you don't pay for your airport if you fly an airplane. That comes from tax money. That is how I see the problem.

But there is such a double standard between acute and chronic medicine here, that it's just ridiculous. If you have a heart problem, I can get you a pacemaker, spend an enormous amount of money, and nobody questions it; if you need a pacemaker for

funding to work with the people, but they cannot get any tools. So they are faced with a problem. It is not a problem that the therapists are causing and it is not an invasion of territory problem. It is a problem with history, it is a problem with evolution, and it is a problem with Federal regulations. You go through and see what can be covered with third-party payers. It's only in the very recent writings that we begin to see inklings of aids and things being applicable. And I think this is the place that particularly needs to be looked at and explored and worked on.

Probably from the Federal legislation on down, the aids will begin to be something that is a viable expense area. As to alternatives to third-party payers, I think as the Federal Government begins to pick up on these, so will insurance companies begin to pick up on them and other kinds of things. The third-party payer is anybody besides the person who is handicapped, if insurance companies are third-party payers, fine. No, I don't have any great ideas as to where the money could come from. From the standpoint of loans, where an individual needs it for employment and rehabilitation, he could get it. If and when he is rehabilitated he could at least make a contribution back. I don't know if he could pay it all back.

VANDERHEIDEN: I really think it is an excellent area. I also think it is a reflection on the tax policy of others for blindness and things like this. There are a large number of disabled individuals more and more going out and making their own way. I think it is very interesting when the Government does not provide money to somebody, but simply takes so much away. Then you don't lose all those dollars administrating the money to take it away and then give it back.

I think that is another good area outside of third-party payers if you will; that is to allow tax writeoffs of other than medical equipment. Also some of the things that people get for their homes because they are handicapped more and more can be classified as medical equipment. We have a large category of things that are great for lazy Americans and greatly benefit the handicapped individual.

Environmental controls cost about $1,000 and up. Until they came out with this one for $40. For $100 you can get a system that runs about seven or five appliances or something--that kind of thing. Now the only problem you have is how you decide if someone is really handicapped or they are not really handicapped. So I think there are going to be some definitional problems, and this it is a definite area to explore.

QUESTION: I think that Fran has raised an extremely good point and that is the difference between medical deductions and tax credits. I'm a schooled accountant and very few disabled

people are really qualified to the point of getting medical deductions when you consider the prerequisite. Consider their income level; the fact that they must file the long form and three percent for tax credits. I think Representative Guyer has two bills in Congress right now on buying devices for the deaf. He calls them credits. In other words, this is a full dollar returned for the investment that the person puts out and I think one of the problems obviously is administration. I think you just referred to that, Gregg. Just how you qualify for it? We have that same qualification test on our income tax every day. Tax credits over medical payments do offer some incentive for the individual.

KORNBLUH: I'd like to change the focus a little bit and take the prerogative of being the conference moderator and ask a question of the panel. My title is Specialist in Information Sciences and Future Studies. One of the things I do is try to look ahead, five, ten, fifteen years. It seems to me and some other people feel that in the decade of the 1980s many of our educated young people will be underemployed, and unemployed. I would like to ask a question of any one of the panelists. There are certainly opportunities for education in medicine and in education and special education for the handicapped; there is also beginning to be an opportunity for a major in rehabilitation engineering. What about other areas and majors? What if young people in business schools or other specialist schools wish to aid handicapped individuals--how could they do it? For example, I know of no areas and no schools that give a man or woman

DR. NUGENT: There are precedents already for agencies buying some of the expensive equipment; they buy Opticons and they may buy the talking calculator. I think it is a matter of gradients; it's a matter of equipment being around long enough to prove itself and the justification of the need being established. Then the agencies do pick up. They've even started to buy some of the target automobiles and control equipment which are extremely expensive so that people with disabilities can drive independently. I think there are precedents there, I think it is happening.

Caution has to be exercised and I think that, if we do rapidly subsidize some of these things, the costs will remain up there when they shouldn't. I can remember the big calculators we had years ago and how expensive they were. Now I can find one paper thin that will do ten times more and it costs from $15 to $16. The volume is there, but there is a whole gamut of problems that should be addressed.

FRAN LAUDER: I'm from the White House Conference on Handicapped. The question I wanted to ask is, I guess it is semantics, is this. Lots of these devices and technologies are known as medical appliances. This is a complicated question. It was mentioned that people with disabilities may engage in all kinds of employment. Statistics say that many of them are not employed. The first time I needed a wheelchair maybe it was a medical expense, the next time I needed a new one. I sort of needed it like a new pair of shoes, or if I need some new gadget for my car. But you see there is no place to put it on your tax except under medical expense. . .

your ear or eye, I can't get it for you. This is an evolutionary thing that is actually occurring.

VANDERHEIDEN: One thing that needs to be separated is the development and the manufacture and distribution of aids and the Government's role in that and also the Government's role in helping the individual secure aids. If you support on the product end, then you are in a sense pre-selecting the aid. If you support on the person end, then what you do is give them a little better purchasing power, and you still let the natural economic forces and the competition and the best article survive, if you will. But I think some differentiation needs to be made there.

I don't think that all companies, especially small companies, are able to always withstand all of the R&D that it takes to get something out and do it right. You can always do it wrong and get it out, yes, and that is part of our problem. I think that NSF and the small business funding that they do helps in this area. I do agree with you that some means of providing some financial support to the people needs to be divided. Earlier I made the comment that we can get therapy funded, but we cannot get aids funded, or something like this. This is not a problem caused by therapists; as a matter of fact, the therapists are often the ones seeking the funding of the aid. It's not that the therapists and the aids are seen as invading their territory. On the contrary, the therapists are sitting there going nuts because they can get all the

QUESTION: I think our mutual friend Jim Bliss at Telesensory has written an article in the International IEE Journal about two years ago in which he said that the laws must be changed to permit risk capital to be spent with profitmaking organizations. We're getting a little of it now, but it's subterfuge. We contract with a nonprofit organization that deals with a profit organization and the two or three levels of control in there makes it impossible for a profit-making organization to arrive at the results.

One last item; I'm not speaking of Control Data and I'm not speaking of AT&T. The people who are producing things in Vanderheiden's area are not big corporations, they are small people who in the past went bankrupt. The guys mortgaged their homes, and sell their wives and children in order to produce a product that didn't survive in the marketplace because no one wanted to put money into it. So I think, really and legislatively, we've got to recognize that profit is with honor, if your you Biblical students will pardon the pun, especially in Morristown, New Jersey, it's got a good reputation. But I still say that is one of the problems I see that we have got to cut through some of the old concepts and despite the fact that some of my colleagues in the past have been associated with gamblers, I'm willing to take a risk.

QUESTION: I agree with a lot that's being said. The Government shouldn't get into the business of making wheelchairs, but particularly with the technology Gregg was discussing and

The people there have to assume a certain level of risk. They put up with a lot of inconveniences to go into buildings because of being handicapped. If they are willing to accept additional risks in order to be able to go out and do things, I think this is not only good, but it is going to be necessary. Of course, there is a problem with getting ahead of yourself. There is a problem with going out to develop something and trying to get it into the field quick. If you don't get anything back on it, you may go bankrupt. So you get something into the field quick, and it's not too good; thus, by hurrying, you can mess up.

There are a lot of difficulties that private industry has. The number of people in the handicapped community is a huge population, but it is so variant. There are so many different types of disabilities, that it is hard to mass market anything in the area of the handicapped. Yet products are still marketable.

We are talking now about semi-customed technology, which is a technology from which you make a whole bunch of products and customize after they have been purchased. For severe and multiple handicaps I think this is the only way we're going to be able to go. But it is an area that has just started to be looked at. We really don't have anything in that category, except one or two aids at this time. So these are some of the problems that I see. If private industry is not involved, I don't think it is going to go anywhere.

DR. NICKEL: If I implied that I have criticism of interaction with private industry, I don't think I meant that. I don't mind criticizing, I don't mind saying that either. But there is no other way. We have to work with private industry. There is actually no other way.

QUESTION: What are some of the things that are stopping us? Is it private industry?

DR. NICKEL: I think Dr. Nugent was right. Some of them jump too fast and start promoting. There has been a lot of that promotional bit which is very bad. All kinds of gimmicks. And I think that Congress has been subjected to some of that by some of the researchers. I've heard the term "dog and pony show" used frequently, when they bring gadgets that have never been used on humans and imply that they are now functional. Another problem is this problem of overcontrol and safety. Dr. Nugent, I totally agree that safety has been wildly exaggerated.

I was very much involved with the problem of accessibility of the handicapped in the California schools--specifically the Downey school district, where Rancho is located. The problem was fire. There has never been a child hurt in a fire as far as we know in California schools since 1880 and that was where somebody lit a fire and others caught their clothes caught on it, that kind of thing. There has never been a school fire in the district that hurt anybody. Yet, they were stopping handicapped people in wheelchairs from going to schools that were totally acceptable.

There are some areas that I would like to see explored. For instance, elevator controls are still very problematic to us. They are problematic because each keyboard is unique to that particular elevator and that particular building. One may be four buttons, another one may be 100 buttons.

For some time now, a colleague and I have advocated that with a little effort and a little ingenuity, you could take the standard keyboard that's on a pushbutton telephone or on the calculators or the things that have been demonstrated here which a blind person becomes very familiar with, and have one keyboard that would be true in every elevator, whether it was four stories or 100 stories. With the economy of a printed circuit behind it, it would save money for the manufacturer and be readily usable for all people. Now the industry has thrown a lot of objections up to it and there are a lot of problems; but I don't think they are real. I think real problems have real solutions.

I think another area of concern is that many times we focus too closely on a given problem or a given population. We don't realize that if we broaden our viewpoints, we might very well solve the problems of several groups of people. Let me give you one example of a problem that we're working on in a very cooperative way with several agencies, including the elevator industry. It concerns international symbols that can be tactiled.

that's preferred rather than saying it should be built out of concrete block is that if we say concrete block and the next week somebody comes along with a better product, we preclude the use of that better product, and therefore destroy the very purpose we had in mind.

Now, unfortunately, when we get into something as diverse as a standard on accessibility and usability in all public facilities and buildings, incorporating all causes and manifestations of disability, along with the general public, we have to translate some of the performance requirements into specifications. This is where we run into trouble. Again, because people don't want to do their homework.

As an example, we emphasized over the years that if you cannot turn a faucet with your fist clenched; in other words, if it meant requiring you to grab and have a forceful grip on a round knob, or something like that, that was not acceptable. And of course the translation was that, well, the lever handle is acceptable. And it is. However, can you believe that a Federal inspector and a State inspector, when a company came up with something that was absolutely perfect for the disabled that required just a little touch to activate the water, and built into it was environmental concerns, refused to approve it for a whole system of buildings in that State. Why? Because it didn't meet their translation to a lever handle.

or function, that cannot be accessible and usable to all people without loss of the architectural facility, without loss of space or function, and with very little, if any, extra cost. And this is not hypotheses, this is something that has been proven or demonstrated many times over.

I don't know what concept the architect of this building had in mind; it's a beautiful building, of course, rich in its possessions, but it certainly was not designed for functionality, accessibility, usability, or even safety. In fact, you couldn't get into this room without having to negotiate steps from any entrance. I'm not too sure I understand the logic of that.

Again, the technology exists to achieve a totally accessible and usable environment; that there is need for more technological research is very evident. I think there is one other thing that we have to recognize and that is, no matter what we do there possibly will be some people we cannot serve; some will not be able to use the environment in a normal fashion. But even they will benefit from anything we do accomplish.

I think it is important, if I may, to distinguish between a standard and a code, because this is something which comes up time and time again. A standard is something which is mutually agreed upon by those people who are most:

(1) knowledgeable about that given subject; (2) who would be most affected by that given area of concern; and (3) who would be responsible for implementation and enforcement.

We went through one period with one system where the people who needed the financial break the most were the people who had the hidden disabilities that were not evident; those with mental and emotional problems, whose economies were really adversely affected, originally didn't qualify.

I think that another deterrent, and I'll hit this again when I get to buildings, is our overconcern for safety. I might as well put the two together right now. I don't know how many times I've been involved in litigation across the country or been called upon in other roles, where the real deterrent to not doing something was the assumption of how hazardous it was to do it--hazardous because this person was in a wheelchair or he was blind or something else. These are faulty assumptions. The first assumption that is faulty, of course, is the assumption that people with disabilities are not able and willing to take the same risks that all of us take. The second assumption is that safety is achieved just through design when all of the evidence shows that more often than not the cause of injury is the behavior of individuals in a hazardous situation. In other words, the hysteria that results.

And so it is with practically all of our designs. It's ridiculous to believe that where you have three or four banks of elevators serving a 100-story building, and an explosion or a severe hazard where be on the 50th floor, that there would be any means of egress to those on the 100th floor--even with all our precautions.

So I stress again, the entire system should become accessible and usable, supplemented by, perhaps, door-to-door transportation or dial-a-ride; it has been some 20 years ago that we did research on door-to-door transportation on our campus. With the minute efforts that were made to making transportation systems accessible, various arguments came up such as: "it would slow the system down," "it's impossible to facilitate," "the cost would be prohibitive." The cost would not be prohibitive if we began where we should begin, that is, with the manufacturers of the basic units. It is prohibitive when you have to buy a total unit and remove the stairwell, restructure the undergirding of the bus, and reroute all of the linkage for controls; but it's not difficult with all the things we've done in manufacturing, to conceive of a door that would be wide enough initially and route all of the components in such a way that they would not have to be removed and paid for, literally, twice.

We did this. We took films of middle-aged people; you are always in danger when you identify people, but I have to give you some perspective. Middle-aged and elderly people were filmed entering and leaving conventional buses. We had a stop watch on the screen and the time was 15 to 17 seconds. Then we showed that same person getting on our bus using the lift mechanism and it took four and one-half seconds. Following that we showed a person in an electric wheelchair getting on in four and one-half seconds. So it wasn't a true argument at all; but it did defer action.

accessibility and usability in our transportation and mass transit probably would have been resolved. I am willing to say this openly because I said it in their presence at Senate hearings in the past. And I demonstrated it. The truth of the matter is that the lift mechanisms that have proven effective in transportation over these years cost only $2,000. But the cost of modification to the buses that come off the line is something like $13,000. That's what puts it out of reach.

Somewhere we failed in getting our message across and I use that as a very explicit example of the role that industry and manufacturing can play. I can assure you that a bus will come onto the market that will do the job--hopefully soon.

I am equally distressed, and this is not the way to become popular in Washington, with the apparent waste in this area of endeavor by our own Federal Government. In spending millions of dollars to lower the floor a few inches, it still doesn't get the person in a wheelchair or a severe ambulatory person to the floor of the bus. I was particularly disturbed, and made it known, when that bus had a ramp on it. If you will take just a few minutes' time to picture that one curb is this high, and one curb is that high; they range from nothingness to eight to ten inches.

One sidewalk may have only five foot clearance and the other may have 20. The standard for safety and function of a fixed ramp on a fixed building is one and twelve, and it requires a

own a Rolls Royce or a Mercedes or a Cadillac. This is where we enter into confusion from time to time.

Some of the difficulty that we encounter in the program of accessibility and making the environment totally usable, of course, is that we not only are dealing with all aspects of the environment, all trades, all professions, but we are also dealing with all causes and all manifestations of disability. Occasionally, what is good for one disability may be problematic to another. At least that's the way some people advance these things. But I can tell you too, without reservation, that there is not that much of a conflict and that these things can and have been easily resolved. I would mention that the manufacturer, industry itself, holds the simple resolution to many of the problems of accessibility and usability.

If certain things can be manufactured as modular products, thereby eliminating all the opportunities for decision or indecision or errors in construction, we could come up with far better, far more economical and far more accurate components in construction. Again, the precedent is there. The majority of bath units going into homes today are the fiberglass units--they are the one piece units. There is little chance for the individual builder or tradesman or subtradesman to foul up the procedure. Such answers exist in many areas of our concern which would result in economies, simplicities, and better standardization. At the same time, I envision a sense of anxiety and haste.

So we run against these attitudinal barriers and more often than not, I hate to say, they come from the professionals that you would most hope would readily support some of the technological and sociological change. And, I don't free our Federal Government of this one bit.

I think our Federal Government has wasted so much money on self-perpetuating research and loses sight of purpose, and intent, and performance requirements, and functional concepts. It just disturbs me. There is one world of difference between responding to the needs of people and overreacting to the political pressures that grow out of the needs of people. Unfortunately, I think it's the latter that we see the most in recent years.

We cannot separate the various disciplines as they relate to our need to make our environment accessible and usable; we cannot separate the application of technology whether it be in the clinic or in support of the communicative needs or skills of an individual. I do think that we must emphasize more of the total application of all good things in our professional preparation of medical doctors, physical therapists, occupational therapists, and the like.

I think it is very shortsighted that most of our medical people and associated health science people are trained in the clinical setting and immediately work in the same or similar setting without ever having been challenged to find out what is

Now what I'm trying to say is two things. When we talk about changing the environment to be accommodating to all people, we are not only talking about the technological aspects, we are also talking about the sociological change. Technological change happens much more rapidly than sociological change.

You build a better mousetrap and advertise it properly, and you'll sell it. But in this particular subject we are involving all aspects of the environment, all aspects of construction and manufacturing, of design, and of utilization. We are touching upon everyone's lives in a way that we must; at the same time we're advancing technology, we are very concerned about sociological change. This means a change in the thinking of everyone in this room and everyone that isn't here.

It means developing a readiness on the part of communities, of governments, and of individuals. I would say to you that all of the technology exists already to make the environment accessible and usable to all people. Don't misinterpret this as saying that there isn't room for more technological development. That time will never come. But to think that we have to wait for more technology to make the environment accessible and usable for all people is faulty.

The solutions do exist and the need is for proper application. The benefits, not only to individuals with disabilities but the benefits to all people in all of society, are immeasurable and were mentioned in a different way earlier. In fact, I would

DR. TIMOTHY J. NUGENT: Thank you very much, Marvin. I am very pleased to be here and particularly pleased to share this particular day with my good friend, Dr. Vernon Nickel, and someone I've known and heard of his work, Dr. Gregg Vanderheiden. Gregg also comes from my alma mater which is nice.

I would second everything that has been said earlier, and I would emphasize two things. First, the results of all of the efforts that concern environmental changes should allow for accessibility and the usability by all people, including those with all causes and manifestations of handicapped. We cannot achieve this without emphasis on rehabilitation technology, and communication technology, and without a tremendous emphasis on the development of the individual and the mechanisms that support the individual so that he can use that environment.

There is no beginning and there is no end to this particular subject. By this I mean there is no discipline in existence that can escape a responsibility for making the total environment accessible and usable to all people. The most severely disabled person can live in a normal environment and do all things quite independently when the environment is accommodating, including people without arms or legs.

I think we've come a long way; but we have so much further to go. I'm going to use one or two examples of some of the arguments we received years ago; I'm using these examples because they have now become good working partners in the effort to make things accessible and usable.

hope all of you have been stimulated, as I have been, by listening to our two speakers. I'm sure that will eventually contribute to growth in solving problems in the areas thus far addressed. I can't help but say that the Congressional Research Service is also beginning to take notice of the need to keep abreast of some things our speakers talked about.

Why don't we have coffee and in about 10 to 12 minutes, return to our seats, please. We have at least 40 minutes for our next speaker and that will bring us to 10 minutes to 12, and I would like to leave 20-25 minutes for questions and answers.

We're now about to enter another area which is both separate and overlapping with respect to technology for the handicapped individuals. Our third guest will concentrate on environmental facilities technology.

Currently he is the Director of the Rehabilitation Education Center, and Division of Rehabilitation Services at the University of Illinois in Urbana, Illinois. Again, I'd like to just briefly tell you some of the things he has accomplished and which impressed me. He was the founder of the first program of higher education for the severely disabled in 1948. He was also founder of Delta Sigma Omicron, the national rehabilitation service fraternity in 1948. Because I like sports, I was impressed with the fact that he was founder of the National Wheelchair Basketball Association in 1949. Needless to say, all of these prorams have grown tremendously, and I think they are still flourishing.

So we're talking about $300 a day for six months. Still, they could not buy him a $300 aid. Some of the costs are "in the system" and some of them are not. This is the kind of thing we see and it is frustrating both therapists and handicapped individuals.

There is also a serious problem. I call this "the skeleton problem." If you do therapy and nothing happens, there's nothing left behind. It's gone. There's nothing to account for or haunt you. But if you place an aid and it doesn't work, what are you going to do with this thing now. It's going to sit around and haunt you. Your administrator is going to jump on your back; "you've got a whole closet full of old aids." What should happen to them? It's just like your glasses. When your glasses aren't any good, you just throw them away. But what if you had to keep all the old glasses that clients outgrew? What if you had to stack them up in a closet? And the next time you had a client who needed glasses, they would say, why don't you go and get one of the stacked out of the closet and use those? You can see the problem.

So we have a problem! What do you do with the spent appliances and what do you do with the ones that don't work out or are outdated? I think this is part of the problem that we're going to see in terms of transition to using technology.

The cost effectiveness comes in here as well. The cost to place these aids to provide disabled persons with effective communication can greatly increase the benefit of therapy when non-aided therapy is not effective in providing functional output.

poverty level, plus $20,000 it takes for all the other needs and expenses that they have.

Perhaps we ought to be looking at the Government sharing the cost and paying for some of them and allowing the individual to still take home a decent paycheck. The individual can move out of what turns out to be incredibly expensive housing situations, such as our institutions, and both parties win. On the last level, of course, we have the fully independent person paying taxes and hiring his own people to take care of them.

We have them among individuals who are nonvocal, nonambulatory, and nonmanipulative. After, we expect these individuals will stay in the home where the parents will take care of them. But as they get older, you're talking about somebody the size of you or me who is totally unable to get himself up and down. Parents very quickly become unable to care for these individuals and they end up back in the total care situation anyway, along with some very unhappy parents for having to have to "abandon" their children. This occurs simply because cute little kids grow up to become adults who are physically incapable of taking care of themselves without assistance. We need to find ways to help these individuals take care of themselves or move into semi-care situations.

So there are cost effective ways of applying technology on several levels. No cost benefit studies have yet been done or even attempted with these severely handicapped individuals. Part of the problem is that although we do have some individuals with

Cost benefits! Yes, as we see in figure six, there are genuine cost benefits at a number of levels and not just for employing these individuals. This is true for the deaf, the blind, and the physically handicapped. Since these levels may be easier to visualize for the physically handicapped, let's look at these for a moment.

In the physically handicapped, we can see it even without moving to full employment. The cost to care for a physically handicapped individual runs from $25,000 to $30,000 per individual per year. You are talking about individuals who need total care. Now if we can provide them with the ability to reduce the need for total care and they begin to care for themselves, we can save a great deal; first, by reducing the amount of care and supervision that is needed; secondly, by providing the ability to move out into independent and semi-independent living situations. True, these are expensive. However, if we can compare them with what it really costs to have them in the institutions, the difference is unbelievable. The problem is we are afraid to look at what it costs in the institutions.

Third, we have employment and sharing of the cost of living. Here lies a problem we see often. As soon as the individuals begin to make any money, they lose all their support. And if it costs $20,000 a year for them to live, in terms of their medical and all of the other hardship related expenses, it's real tough to go out and pick up a $40,000 or $30,000 a year job so that they have $10,000 to live on; or let's say $27,000 to live on,

FIGURE 5

3 DANGERS TO COST EFFECTIVE APPLICATION

1) INAPPROPRIATE APPLICATION / RECOMMENDATION

2) INSUFFICIENT AS SINGLE FUNCTION APPLICATION

3) DEVICE SEEN AS SOLUTION RATHER THAN TOOL IN TOTAL REHABILITATION PROCESS

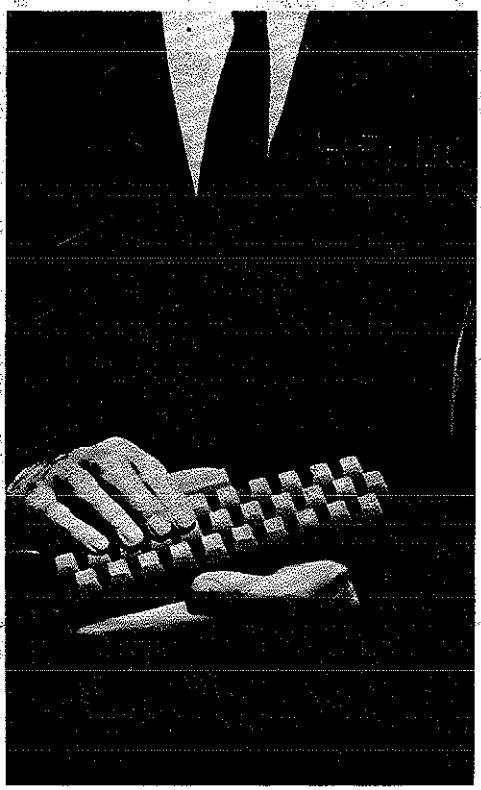
QUESTION: what is the possibility of getting this into production?

This one is commercially available today from Telesensory Systems, Inc. We did this through the Government, specifically the Bureau of the Handicapped of the former Department of Health, Education, and Welfare. It has a marketing program which helps move ideas from the laboratory and connection platform into the marketplace. This is one of their first aids that BEH put through that system and is it now commercially available through Telesensory Systems, Inc., which, by the way, is paying the Government a royalty on it as well. So there should be a feedback to the Government and I think the Government can end up with more money back than they ever put into the actual development itself.

There are other advances we'll be seeing of course. Sears has now come out with a control system actually developed by BSR in England that allows you to control the things in your house from a little hand-held unit. You can point it at a control unit, and control those modules which you can plug anywhere in your house. You plug your lamp into the module amd plug the module into the wall anywhere. Then sitting anywhere in your house you can control any of the lamps or appliances in the house that are plugged into these modules. All you need to have is a little control unit plugged into the wall near you and it sends signals right over the wiring. You can also put a jack on the side of communication aids and individuals like Craig can be operating various things


Canon
CANOLA

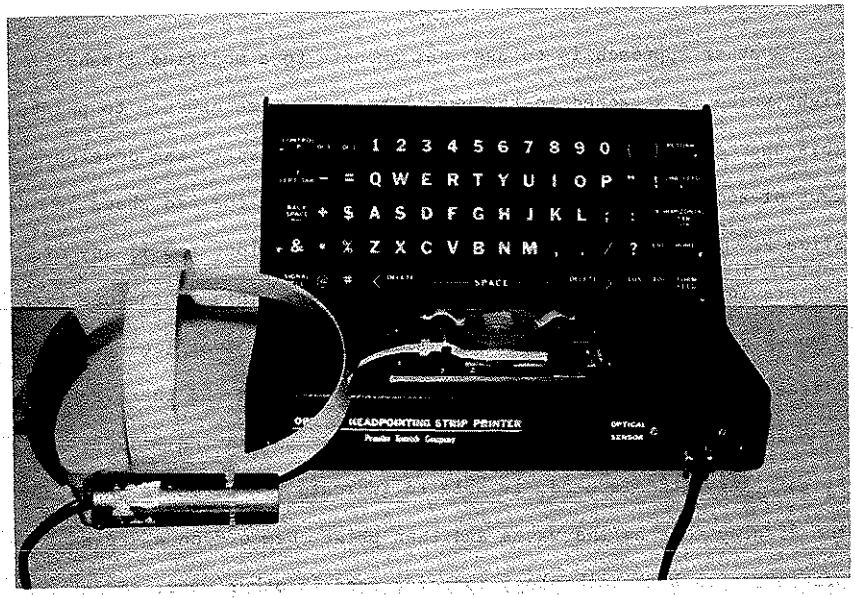
This slide shows another communication aid. (Slide K) This is meant for an individual who is not able to speak, but who has rapid hand motion. Looking at the human factors, we see in his pocket, the word "hello." The individual types and the message goes across on his lapel. There is quite a difference in humanness between having the display on his lapel versus down in front of him. The effectiveness, the eye contact, and the feeling are really quite striking. What we're doing is finding, as we'll mention later, that we're getting better in technology. We are doing more for these individuals, not so much because of advances in technology, but because we're learning more about how it should be properly applied and how to effectively implement it.



With technology, however, we're finding that these are getting smaller and smaller. At the present time I have a teletype system on me even though you can't see it. Not only the deaf individual can have one that is noncumbersome, but also the individuals who are close to him or her--a deaf wife or a deaf friend. You could have a teletype with you and call them and talk with them. Here is the modem and also the teletype. (Slide J) This is an entire TTY system with phone modem so you can communicate over the phone and yet you don't have to have the large cumbersome units of yesterday. It will easily fit in your briefcase or in your pockets.

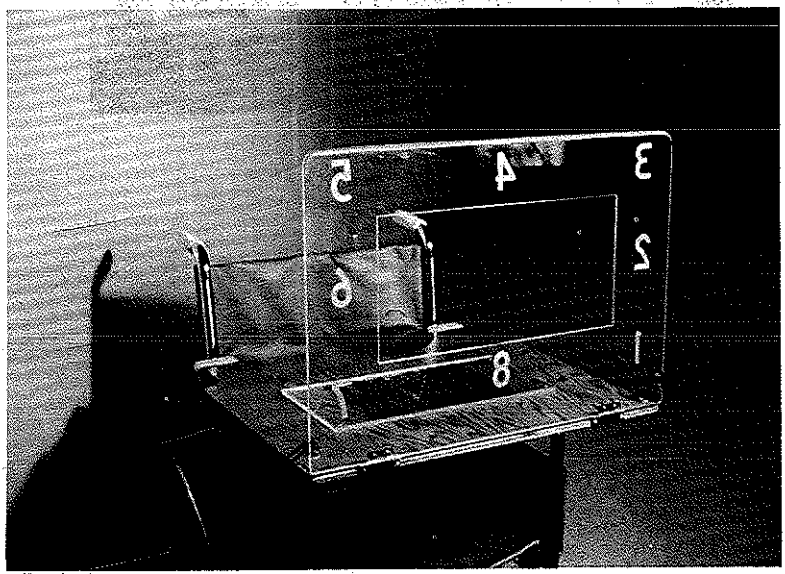
We're seeing these kinds of advances being made; where we're not only able to do things, but we're able to do them in a way that is meaningful and in a way that is effective. Individuals can not only have the capability, but have it in a form which will work and will be functional in the job site and in their lives.

A large number of switches are needed to interface two individuals. (Slide H) Fortunately, we're finding that we are going away from the one-switch input systems. We are finding that it is much more important and effective if we can provide them with abilities to control things in graded fashion, i.e., not to hit a switch, but to be able to pick out a large number of items as we're talking about with these head pointers. The speed factor we're talking about can be as much as ten times faster. You saw what three times faster meant a few minutes ago.


1 2 3 4 5 6 7 8 9 0
Q W E R T Y U I O P
A S D F G H J K L
Z X C V B N M
SPACE
HEADPOINTING STRIP PRINTER
OPTICAL SENSOR

This is an eye-gaze communication chart that was developed by an engineer for his friend. (Slide E) It sparked a lot of excitement about the use of eyes for communication. It is now leading to about a fourth generation research in a number of places where eye movements are used for communication--individuals can just sort of look at what they want and it will print out.

This, by the way, has some great potential. The "eye look" also has some problems, especially when you get to the severely handicapped for whom it was originally intended. Many of them have ocular motor problems which are more complex than we originally thought.



Different input systems, of course, are really important. (Slide C) This particular system takes Morse code, translates it and then puts it out on a screen. An individual can use two movements efficiently that way and yet nobody else has to learn Morse code in order for the individual to communicate. By the way, there are techniques for the individual to use this without ever learning the code; or more accurately, without knowing that he's learning Morse code; he thinks he is learning something else that is very simple. So you don't necessarily have to tackle things like trying to learn complex codes in order to use these types of systems efficiency.

(Slide B please.) The handivoice is one of the vocal output aids; there is the slide and I'll let you also hear it. It is a direct selection aid; you point to the items and it will speak them. (Voice of mechanism: Surprise. I am using an artificial voice.) Now some of you may recognize that as being the same voice as the Kurzweil reading machine uses--and it is. It's from the Votrax Corporation. It is the only portable speech synthesis aid that is commercially available right now. Speech quality is being improved through a number of things and we're very happily seeing the public sector finally getting enthused with speech output. It seems to be catching on fire and now that we have some of the larger corporations from the private sector working on the problem. We'll probably be seeing even more rapid advances; although we are already seeing some very significant advances by the Kurzweil Company, Telesensory Systems, Inc., and others.

QUESTION: Can you relate that to cost right now?

Yes, the aid is about $2,200. Since it is a first generation aid, some things like flexibility, fixed vocabulary, and things like this need improvement. But again, things that we are seeing will rapidly change.

today and then begin to work on facilitating and eventually on restoring as much as possible.

The importance of having communication from day one is very important. In the past it has been something that has been as much as two or three years down the road and we tend to give up. Now we begin working on speech and looking at some of the other ways of providing communication at the same time. It's like when we break our leg. We use crutches; we may use a wheelchair first, then crutches second, and back on our feet third. We're not saying when we use the wheelchair that we're never going to be able to walk. We're just saying I can't today. Then we immediately begin to use the augmentative or supplemental aids today to help function and work back toward trying to achieve the final goal. This approach is something new in the communication field and there are problems implementing it, which is something we'll be talking about in a few minutes.

What I'd like to do, if we can at this point, is to show you a couple of slides. I assume most people here are familiar, or have seen, the reading machines for the blind. So could we have the slides on the nonvocal techniques to give you an idea of the kinds of things we're talking about that are possible today.

The field of nonvocal communication technology is something that has just sprung up in the last eight years; it has been really applicable to the handicapped and effective only in the last two or three years. It's that new a field.

familiar with his speech, understand it, and then put it into better form so we can understand it.

For an individual with a hearing impairment, a hearing aid falls into this category. Again, we are using the normal mechanism in the normal way with some kind of assistance devices.

For output, we have the writing aids, dampers, prosthetics, and orthotics which can facilitate the individual's physical efforts. On the input side, we have glasses, magnifiers, and closed circuit TV's that are used with individuals with visual impairments.

Again, if we can facilitate it, fine; if we can't, then we have the augmentative kinds of approaches. And here we have speech synthesizers. Now to be functional for the conversational needs, it would have to be portable and therefore we would refer to "portable communication aids" versus "stationary aids." We may also refer to non-portable aids as writing aids or some kinds of stationary interaction aids, but not necessarily communication aids per se.

There are many nonvocal communication aids here. Signing also comes under this category. It's not a hardware technology, but it gives you an idea of where signing would fall into this general scheme of restore, facilitate, augment. The system of signs is not the normal system that you normally use to communicate with; it is a system that can be used to augment or supplement, to go along with the speech system for output for individuals who have a hearing and/or speech disability.

FIGURE 4

OVERVIEW OF CURRENT TECHNOLOGY IN THE 3 INTERVENTION APPROACHES

(FOR COMMUNICATION)

	RESTORE	FACILITATE	AUGMENT
CONVERSATION			
OUTPUT	- BIO FEEDBACK AIDS - MEDICAL INST - SPEECH MOTOR ASSESSMENT AIDS	- PALATAL LIFT - SPEECH AMPLIFIER - SPEECH CLARIFIER - SPEECH RECOG/RESYNTH	- SPEECH SYNTHESIZERS (PORTABLE) - NON VOCAL COMM AIDS (PORTABLE) - (SIGNING) - TTY - COMPUTER TELECONFERENCING
INPUT	- MEDICAL INST	- HEARING AID	- AUDIO TO VISUAL (AUTO CUED SPEECH) - AUDIO TO TACTILE - (SIGNING) - TTY - TELECONFERENCING - CAPTIONING - (LIP READING)
WRITTEN			
OUTPUT	- MEDICAL INST - BIOFEEDBACK AIDS	- WRITING AIDS - DAMPERS - PROSTHETICS/ORTHOTICS	- NON PORTABLE NON-VOCAL COMM AND TYPING AIDS - SPEECH TO TEXT - BRAILLE FEEDBACK DISPLAYS ON PRINTERS, TERMINALS ETC. - VOICE FEEDBACK DISPLAYS
INPUT	- MEDICAL INST	- GLASSES/MAGNIFIERS - CLOSED CIRCUIT TV MAG	- READING MACHINES (TEST TO SPEAKER) - TEXT TO BRAILLE - BRAILLE DISPLAYS
CALL SYSTEMS			- EMERGENCY CALL SYSTEMS - REMOTE PAGERS

FIGURE 3

INTERVENTION APPROACHES

RESTORE

RESTORE THE SYSTEM NORMALLY/TRADITIONALLY USED TO ACHIEVE A FUNCTION. (CURE)

- MEDICAL/SURGICAL
- THERAPEUTIC

FACILITATE

FACILITATE THE SYSTEM NORMALLY/TRADITIONALLY USED TO ALLOW IT TO STILL PROVIDE THE FUNCTION

- PROSTHETIC
- ORTHOTIC
- STRATEGIC

AUGMENT

PROVIDE SUPPLEMENTAL OR AUGMENTATIVE SYSTEMS TO HELP PROVIDE FUNCTION IN CONCERT WITH NORMAL/ TRADITIONAL SYSTEMS

- AUGMENTATIVE

problem. If-I-were-to-talk-at-even-one-third-normal-speed-you-would-quickly-tire,-and--what were your thoughts right there, ah! He's finished! No. He's not! I just spoke at one word every 1.5 seconds. I don't know if you noticed it, but even right there, I was starting to accelerate as we went on. The incredible pressure from you that I can feel sitting here from you, as you unconsciously say, O.K.! come on! come on! as I spoke at only one-third speed. Right now, the average speed in a nonvocal communication person, even with the new technologies communicating, is as much as 25 times slower than that of the average person. I'm not talking about the worst case; right now, we're in that stage were this is the average speed. Some techniques, however, and we'll be talking about them, allow us to "start to approach" the normal speed of communication; but even they are quite slow.

If I continued to speak at the rate that I was talking, which is very fast for nonvocal communication, but not nearly the speed we usually achieve, this would be the last panel I would ever be invited to speak on. And for no other reason than it just is too slow to be effective in communication. You lose track of what is being said, because the mind wonders and you grow impatient.

We can see that communication loss as a disability is very severe, not just for employment, but for social affairs, and everything else. If you take away a person's total ability to interact with anybody, you might as well shoot that person. What

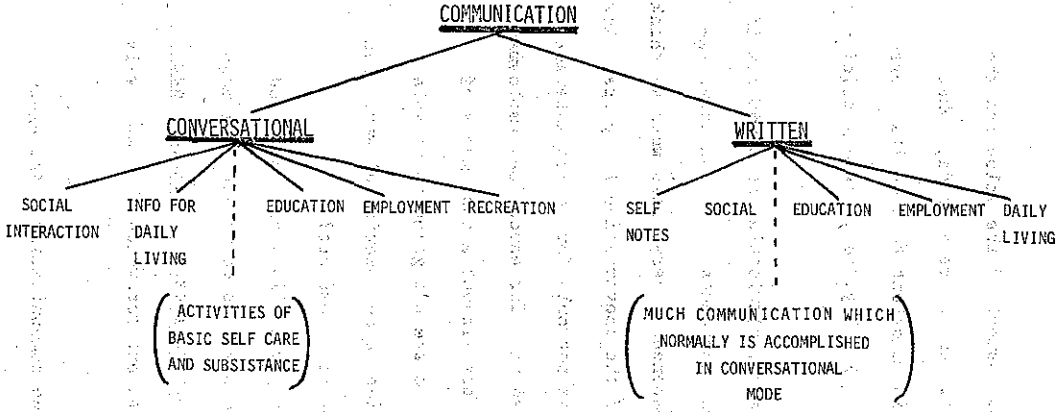
In terms of communication, figure 2 shows we have three major populations that I will be going over today: the blind, the deaf, and the nonvocal physically handicapped. The blind and deaf are probably much more familiar to you, and I'll be covering them in less depth and detail; in the question section, we can bring them back up if you wish more detailed discussion on any aspect.

Conversationally, the blind have no severe problem. In written, they have an input problem and self-feedback problem, which also affects output in some ways. If you can't see what you are doing, you have some difficulty in providing output. But again, not terribly serious; but definitely something that needs to be looked at. The input problem, of course, is very significant.

In deaf, we have a severe input problem, particularly with the speaking public. And again, we have an expressive weakness that can stem from poor language skills. Now, this is intervenable, but we see some more severe communication problems here in terms of the ability to interact. We'll talk about the approaches in a few minutes.

With the nonvocal physically handicapped, we have no input problem, except there is some input difficulty due to the fact that we do not have good output. It's always a little difficult to attain most language skills; there are inevitably some delays and problems. But we have here a severe to total disability in terms of output. We also have two other aspects. All of our intervention programs introduce both a severe speed problem and a severe access

FIGURE 1



	CONVERSATIONAL	WRITTEN	
PERSONAL/ SOCIAL INTERACTION	85 - 95%	5 - 15%	
EDUCATION EMPLOYMENT PRODUCTIVE	20 - 40%	60 - 80%	
PERSONAL/ SOCIAL (FOR SLOW COMMUNICATORS)	50 - 70%	30 - 50%	

to communicate. This same interface approach can be used to allow the individual to control 26 elements of the environment, 26 aspects of a machine, the mobility, etc. We'll also take a brief look at that.

We only have 40 minutes, so all of these will be brief looks, but hopefully we can give you a feeling for the kinds of things that can be done and the direction in which we are now headed.

The points that I would like to be covering this morning are: 1) the impacts of the disabilities in this area (and I think, you got a feeling for that from the film clip); 2) the diversity of disability types and the approaches to solving their respective communications problems, and 3) to define and delineate, and to clarify the different ways of approaching these problems. Some of my comments may be extentions of Dr. Nickel's excellent comments, in terms of cure and intervention.

We'll talk about the levels of intervention. Then we'll briefly scan over the state-of-the-art to give you a feeling for where we are today, both in terms of state-of-the-art and "state-of-the-mart." I thank Dr. John Eulenberg for that term. I think it is as important, or more important, to know where we are in terms of what's available to the handicapped than it is to know where we are in terms of what we can see if you go to the conventions and conferences and look at papers of what kinds of things could be done but are not available.

I would like to show a short film clip here to show you an example of one such individual. We talked a little bit earlier about the triage, about breaking the population down into those who we have ways of serving, those that can pretty much shift for themselves, and those for whom we have not yet developed good intervention approaches.

The severely physically handicapped individual used to be in category three. What we're finding is that through the proper and appropriate application of technology, we're taking category two and stretching it down and down and down (or up and up and up, depending upon how you want to look at it), so that it is encompassing more and more of this population.

This is a short film clip of an individual who had cerebral palsy. Craig is about 14 years old when this picture was taken. He normally spends his day sitting on his hands to keep himself stable. In the school system they had managed to develop for him a basic a "yes" and "no." He would pound once for "yes" and twice for "no." He had no means of really communicating or interacting. He is totally speech impaired and, in terms of his writing skills, he had none. When he grabbed a primary pencil he broke it right in half. Even when he was put near specially adapted typewriters, he was unable to use them. And yet Craig has had his IQ guesstimated as high as 140.

Where is he going to go; what is he going to do? Well, we didn't use to have any answers; but what we're finding is that

He also has a long list of honors. Two of them I think are especially worth noting. He received the Isabel and Leonard W. Goldenson Award for Outstanding Research in Medicine and Technology relating to cerebral palsy in the physically handicapped in 1978. And the other one I think I'd be proud of, if I had, is the Man-Made Environment Award from the United Cerebral Palsy Association in 1977. I also counted the number of his publications. He has 17 major publications, at least, plus nine papers he has presented. The average is probably more than two a year and he's just getting productive, I suspect.

Also what impresses me as I go through his vitae is that he has run so many workshops. I like people who have run workshops. He ran national workshops on nonvocal communication techniques and aids, early education of children with exceptional needs, language development of young children workshops, and development of communication skills workshops. Indeed, I'm proud to introduce our next speaker who currently is both teacher at the University of Wisconsin and Director of the TRACE Research and Development Center for the Severely Communicatively Handicapped at the University of Wisconsin.

Please, Gregg.

DR. GREGG VANDERHEIDEN: Thank you. The area that I will be talking about today is communications. It is actually a subset the area that Dr. Nickel has been talking about in terms of rehabilitation. I think it has been set aside or separated for three

They want to almost stifle activity by calling--and I see many bureaucrats here--everybody in private industry a crook. I've heard this frequently. They think that all these people who are doing all this kind of stuff are just somehow a little crooked. Making a profit on wheelchairs is just not right. It just doesn't make sense. I believe, you have to accept the fact that we are in a profit-making world. And thank God we are.

So these are some of the things I see that we have to get hold of. This is where Federal intervention can play a profoundly important part. They have to look at things the way they are, not how they would like them to be or how they think they might be. Thank you very much.

KORNBLUH: Thank you, Vernon. I would like to mention your ending dealing with Federal intervention. We will discuss as one of the issues in our last session, the roles of the private sector and public enterprise. In this connection, I would like to introduce a future panelist and a past panelist who are members of the audience, Joe Heil (would you stand please). Joe is with Disability Services unit of the American Telephone and Telegraph Company and Joe will be on our panel on November 16, representing the viewpoint of private industry. Seated on the right side is Elizabeth Pan. Elizabeth spoke on information resources at our last sesson. I'm delighted to have both of them attend the second meeting. I just took the personal vitae this morning of our second speaker. While it isn't quite as thick as our previous speaker, it

an orthopedic surgeon, and they tell me of somebody who has had a total hip done.

We used to have essentially nothing for these very disabling and painful hips until something developed that was a total collaboration of the surgeon and the engineer. This is a long story in itself, but it's a superb example of what I've been trying to talk about. So what I've been trying to say here is you can put your little kid on your knee.

What is distinctly human is not devising, say the wheels so much as passing the idea along. Robert Osborn in the Smithsonian in 1973 discussed a speech of Sir Peter Meteroir, the Nobel laureate in immunology, who, incidentally, had a stroke and was not well cared for. I happened to be involved in some of this later. He's a superb man. He's back directing the Research Council in Britain. But he understands what rehab engineering is all about. It can take little girls who would otherwise be on crutches because of congenital deformities of the foot, and permit them to walk. This is rehab at its very best. You can just imagine the difference in the lives of these little girls. It is phenomenal.

A bicycle in 1936 was good engineering. We have had good engineering of bicycles for many years now.

I saw President Franklin Roosevelt on his wheelchair. It's still in the museum at Warm Springs. Miserable engineering. And relatively speaking, wheelchairs are still miserably engineered.

So we've got a new man on the team. There was an NIH study about ten years ago and the man who headed this study was Jack Irving, who was a physicist who was head of research at North American Aviation. They surveyed the country and wondered why it was so difficult for engineering science to be brought into the medical environment. And I'm not talking just the M.D., I'm talking the whole gamut of medical environment.

It was a very interesting study because there was a great difference in philosophy between the scientist engineer and the medical type community, or the medical scientist. Again, when I say medical, I'm not talking M.D., I'm talking M.D., nursing, physical therapy, speech, vocational, and so on. Now the engineer has a very different background. He wants his parameters defined, he wants to go to his shop and write out the specs, and so on. So you need a new bridge across the Potomac. They do some stress studies and soil studies and flow studies, and then they go to their shop and come back with the whole thing all worked out. This is what they are doing and I saw this with the metro here.

So this is what the engineer has been trained to do. But you don't learn to do this in the medical field. And so there is an enormous difference. And this is what the new programs of rehabilitation and engineering centers are trying to get together--the academic engineer and the academic medical people. And again it's quite different than we in medicine think of the engineer.

So what will modern technology do to chronic diseases? Now a disabled person wants better. Or he wants to limp a little less. If you did that kind of a workup on heart disease, you'd be thrown out of the hospital from an eighth-story window. It's such a contrast. Now modern technology will make diagnosis more accurate. Then we want to get better treatment. We see many examples of that, in the Hippim plant we'll be talking about in a little bit, in the wheelchair, or in the prosthesis. Then the next question, how do we evaluate it. That is the toughest one. Because in acute medicine, with few exceptions, evaluation is built right into it; it's a solid part of the discussion and planning. That's just as much needed in chronic disease.

I'll say again that chronic disease is as academic as acute disease if we make it so. It just infuriates me when a professor of medicine at (I almost said the university) says that chronic is unacademic.

This is the key to what I'm trying to say. We're talking about fundamental engineering--we will go into that for a minute--which should and will attract the clinical, the economic, social, and political base that is absolutely essential.

Now, what do we mean by engineering or rehab engineering. This is probably an unfortunate choice of words because engineering in the medical system means something quite different. When I was in the operating room and the lights were not adjusted,

want it. You don't want anything to go wrong when you are having your appendectomy or open reduction of the fracture. This is the kind of discipline we need to develop in chronic disability.

Here are some of the reasons why space age technologies are going to make the improvements that I've been suggesting. Almost all our young people are trained in a scientific method, and they see the bacteriology, and they see the blood chemistry, they see the respiratory gas analysis in the intensive unit, and they like what they see. They are attracted to it. And they should be; it's good. That's one of the main reasons why they are unattracted to chronic disability; because we have not yet applied the scientific method to it.

Now we laugh--I notice you are smiling at this thing--I think you know what it means. We are bowing to this golden calf. And I think that's probably all right. So if we're going to bow to the golden calf, let's put a golden calf of research in chronic disability that will attract the young medical student and the young nursing student.

I'm not mentioning physical therapy, occupational therapy, and some of the others because they essentially deal only with chronic disability. But we shouldn't forget that the first line of intervention in any disability, is the physician-nurse combination and the acute hospital, and so on. Thus, the other allied health personnel are left with less than solid ground to build on. That's how I see this.

incredible document of large magnitude concerning the impact of musculoskeletal conditions in the United States. Now, if you add neuromusculoskeletal and then you add sensory motor, then neuromusculoskeletal is much larger. But the volume of neuromusculoskeletal problems in the United States exceeds $20 billion a year. The amount of research is miniscule. Miniscule! Further, a lot of it has been very badly applied.

Hemaplegics alone are over two million in the U.S. I know of only one chronic stroke rehabilitation unit--there may be others, but I don't know of them. The treatment of stroke in most places is to get rid of them in two weeks. A major medical school in this country gave a special prize to their chief resident in medicine who was finishing his five-year program as having let in the least number of strokes for that year.

The rehabilitation program of strokes is probably the most lucrative of anything you can imagine if we practice some of the things we're talking about. Don't take the person who has got chronic lung disease, and has been senile for ten years, and then has a stroke and put him in a rehab unit and think you'll get somewhere. He needs compassion and good care. But for God's sake let's do take the 35 year-old person with an aneurysm who is aphasiac or dysphasiac and somewhat hemoplegic and not let him develop all the deformities and all the social rejections and all the things that we know about. The care of stroke

The middle group is the one we needed to concentrate on. The milder ones don't need all the expense of the things we're talking about. We would have dissipated our resources. But the most severe cannot use them either. We don't have the resources to do all the things that we might want to do, but for God's sake, let's do it for the middle group who can really benefit.

The state-of-the-art of rehab is poor, believe me it is. We've got to face it. So we've got to have the same discipline, the same quality control in chronic disease as we have in acute disease. I think the two areas that this applies to more than any other is the nursing profession and the medical profession.

I recently met with a national group of rehabilitation nurses and compared to operating room nurses, compared to nematology, you are in a different world. There are some good ones in it, but there isn't the support of the nursing profession for rehabilitation nursing. As far as I know, there is only one graduate program in rehabilitation nursing in the country today. I think this is very bad. There again, the Federal Government can play a key role and already has played a key role in preventing this area from developing. They have supported neonatology; they have not supported rehabilitation nursing.

So we're dealing in the neuromuscularskeletal system and the sensory system. We're dealing, for our discussion now, with something extracorneal; we're not dealing inside the eye, or inside the

large tuberculosis hospitals then and they are almost totally empty now, as you all well know. With our population increase, we'd have ten times as many, because care even at its best, of chronic tuberculosis, was not good; many of these people would stay in hospitals for years. That has totally dissipated. While tuberculosis is relatively a small problem in our country--it's a potentially serious problem. The main problem is the immigrants who are coming in with active tuberculosis. Some things can happen, and did happen to make tuberculosis a relatively minor problem. The influx here was better science, triple drugs, and much more. It was also better social care and better milk control.

For those of you who don't remember it, tuberculosis was a number one public health problem for years. Many of your relatives were very sick and may have died of tuberculosis. The application of space age technology, the main crux of my discussion, is going to make the difference in my opinion; and it already has started to do so to a very significant degree.

An example is the wheelchairs in the room today. A few years ago, there were essentially no wheelchairs such as these, and those of you in wheelchairs could not have come to meetings such as this.

And the last one is triage, which is an approach to prioritize disease in order to better determine need and place of treatment. Acute medicine has done this superbly well. I mean triage is practiced rigorously. It is practiced rigorously in acute hospitals.

How do you subdivide? Well, you can subdivide by regions, such as the spine, such as the low back problem, or you can subdivide by major disability which is more diffuse; that is more like a spinal column injury. The pattern has not yet been totally established and probably there will be two methods of division as it evolves. I've given you probably the two best examples that are clearly defined as the regional subspecialization versus a disease entity subspecialization. Other examples would be like cerebral palsy, and the other would be like hand disability. These are the evolutionary trends that have not yet been really established.

There is also the need to delegate and upgrade allied health professions. The two professions that have failed most miserably in the chronic disabilities is the medical profession and the nursing profession. And that is really the start of most of this. I think both medicine and nursing have not fulfilled their rightful obligation to this category of diseases and category of problems.

Most medical students have a very low regard for chronic disability. I recently was on a panel in one of the very major medical schools in our country and the chairman of medicine, a very distinguished physician, made some very scathing remarks about chronic disability in that it did not deserve or didn't achieve academic excellence, or could not achieve academic excellence. He kept using that word, "academic excellence." I think I really

In the Veterans' Administration this drifted rapidly into what is now called medical research, more the NIH mode. Gradually the care of the physically disabled receded. We'll be talking about some of the causes for this. But it's a very proud background for the physcially disabled that this was the real beginning of a research program. I feel it's one of the most successful programs that ever nas existed. It was a phenominally successful program because in a very few years it turned around 180 degrees from a real mess to a first-rate type of activity that involved many disciplines: better surgical care, better postop, better psychological care, better rehabilitation, better prosthetic care, better job placement, and so on.

You may be surprised to know that it was generally considered the fate of the amputee in America that he would be an elevator operator. And some of you have probably seen some of the old elevators going up and down with an amputee sitting on the chair. This was the state-of-the-art at the end of World War II. This has just changed so much, it's hard to remember it.

What is rehabilitation? There are many definitions. Dr. Jacqueline Perry, my associate of many years, I think has the best one. She includes medical care, all the allied health, all the application of technology, the psychological, the educational, the environmental, and the occupational, and the vocational. So you make the best with what you got. I think this is the best definition and this is different from curative medicine.

DR. VERNON L. NICKEL: Thank you, Mr. Kornbluh. It's a real pleasure to be here. This has been, for several of us in this room, an interest for many, many years; we see things starting to fall into place. It is my opinion that modern science, or science and technology, or space age technology is going to be not only the means of supplying devices and technologies to patients, but will be the magnet to attract the quality of care that chronic disabilities deserve.

Now, why did I come to Washington? Well, this is an interesting phenomena for people like myself; all my friends ask me and have differing comments about what they think is the reason. My reason was that I have been very interested in the application of science and technology to the physically disabled. This was an opportunity that presented itself to be the director of a new program that the Veterans Administration has started aimed at supplying such technology to the physically disabled.

The original beginning of long-term research in the Federal Government was essentially what we're here about today. President Truman had a friend, George S. Allen, the Allen of the Washington Merry Go-Round column, who suffered a jeep accident in Europe during the war. With the interest of President Truman and Mr. Jack Northrup of Northrup Aviation, and others, they decided to improve the care that was so very bad at that time.

I had the privilege of seeing this very famous patient entirely as an observer, not as a participant. I heard that this famous man was in the hospital with this injury, so I went over and saw him.

On November 1 we covered educational technology and information resources technology--we had two speakers--and today we will cover the other three technologies with our speakers. On November 16, in our last session, we're going to address the implications, the impacts, and the consequences of the issues that may stem from these five technologies--in other words, what issues will arise from the use, misuse, and nonuse of these technologies. In the background material you will see nine issues in paragraph form. I'm going to choose one issue and leave it to the audience to select two or three other issues that they want our distinguished panel to discuss. We'll have five panel members--perhaps six.

I'm not going to talk about what we did last time. There will be a committee print published on these proceedings. We hope to have the proceedings published sometime in February 1980. I've been asked to stay well and work hard to get it out, and I'm going to try to do just that. We will include what I call connective tissue. It won't simply be a transcription--although that will be 90 percent of the committee print. There will be some introductory and background materials and we'll try to package this material for maximum utility.

It's really a genuine pleasure and an honor to be seated in the center of the distinguished speakers we have today. I would appreciate your holding your questions until the question and answer period which follows the conclusion of the three talks. If you feel you may forget the question, I suggest you to mark it down

Environmental Facilities Technology for Handicapped Individuals

Environmental facilities technology concerns physical and sensory means for overcoming environmental barriers--both natural and man-made--by handicapped individuals which limit access to buildings, facilities, and means of transport without sacrifice of their function and without addition of major costs for redesign or initial design including:

- Specialized emergency warning and information display systems including flashing alarms, audio signals, and video screens at mass transit facilities;
- Accessible public mass transit systems and individual transit systems, including dial-a-ride, specially adapted minibuses and vans, and ambucabs;
- Special signs incorporating textured surfaces, illustrations, and braille writing;
- Architectural barriers and their elimination at places of work and at home, including redesign of household appliances and modifications to work tools, and equipment and workplaces;
- Accessibility and usability of recreational facilities; and
- Vehicle accessibility and driving aids, including lifts, transfers, ramps, elevators, and automobile controls.

ESSENTIAL DEFINITIONS AND DISTINCTIONS

Rehabilitation Technology for Handicapped Individuals

Rehabilitation technology relates to the residual capacity of a human and the replacement capacity of machines, systems, and artificial materials so that the latter become--as nearly as possible--natural extensions of the human and always under human control such as:

- Prostheses either externally worn or implanted in proprioceptive or sensory systems;
- Ortheses which are aids designed for support, posture, and/or control;
- Travel and positioning aids for the blind such as radar canes, pathsounders, sonic guides, light probes, sonar sensors, and obstacle detectors;
- Materials designed or treated to prevent tissue trauma, cool the body, and resist fatigue;
- Synthetic replacement of defective tissue;
- Multipurpose and multicontrollable wheelchairs; and
- Environmental control devices and systems such as adaptations for employment accommodation.

This technology would also encompass exercise methods and modalities as well as early warning diagnostic tools such as the automicrobic system, automatic metabolic analyzer, gait analysis by biotelemetry, medical data acquisition unit, compact blood analyzer system, and the implantable programmable infusion pump.

SESSION # 2

NOVEMBER 6, 1979

impact on handicapped, and perhaps go to your data base for a long time.

DR. PAN: Probably for as long as we can see because, as I said, I really do not see a monolithic system that will have every thing in it. What I talked about was the need for linkage, a need to coordinate available systems, not combine them in one great big one.

QUESTION: I think there is some experience that we have that can shed some light on the question that has been raised here. In the very early days of information technology for scientific documentation, there was a great deal of urgency, just as there is now, to try to retrieve information on what we now call space technology.

In those days, however, space technology almost didn't exist. There came to be a recognition that one could not get access to information about this primative technology until the discipline matured. Similarly, in areas like "effects of chemicals on the environment." As that discipline matured, it became possible to retrieve information; but still only insofar as the discipline was mature was it possible to get information on that subject without having to go through the circuitous process that we do, for example, at the National Bureau of Standards, where we now have something over 200 on-line data bases.

DR. PAN: In other words, previous research done on a particular area.

QUESTIONER: Research done on a practical source, if you will. It's not research in the sense of technological devices but it's a new institutional device. That's what I was saying, it ought to be added, I think, to any comprehensive system.

DR. PAN: Yes. Well, I will be very glad to agree with you if what you are implying is that not all of our knowledge is research based. That there are other things that we need to know that does not come from research. Where to get funding is one kind of knowledge. When it comes to what research has been done in a particular area, there are systems now available that can tell you, but the problem, as I pointed out, is that you have to go from one to another to pick all the knowledge up. It's all segmented.

QUESTIONER: In this area of institutional soft technology, I think the Government needs to expand its delivery system and put the consumer into the chain of flow of information and also put program officers into a continuous chain. They are discontinuous at present.

DR. PAN: Perhaps so.

QUESTION: Suzanne Brainard from Control Data Corporation. One question, through this conversation, has come to my mind. Is there not a gap between determining what kind of information should be disseminated and some sort of an evaluation process

rate that you pay talking at 180 words a minute? I happen to think so. Mother Bell hasn't given us a break on that yet. But those are issues.

The other issue is, should the telephone company, or the Government, or someone, and I would say probably private industry could very well afford to do so, make the device--the TTY, the microcomputer, or whatever--available to deaf customers at an equitable cost and on parity with its other phone users. As a matter of fact, the telephone company has now, or has had for several years, the capability of a very low cost touchtone telephone that can activate and give you a hard copy of an alphanumeric message. There are a number of devices that could be put into play if we could find a way to pay for them.

KORNBLUH: I'd like to add that in our third session a member of the panel is from AT&T. I anticipated this kind of question. Some of these types of questions have already been asked of this person--many by me. So if you attend on November 16th, I think you might get some additional insights.

Incidentally, I'd like to continue, but those of you who want to leave, don't feel embarrassed. Please do leave, but I think we have a few other questions. For five more minutes, do we have any other questions?

QUESTION: I'm from the White House Implementation Unit. I'd like to address my question to Dr. Pan. It seemed to me that

DR. PAN: Yes, I would agree with you wholeheartedly that any system that tries to be everything to everybody is doomed to failure from day one. I did speak of knowing your user and recognizing the channels and the modes that they use in seeking information as the basis for designing any service or any system that would deliver information to that user group.

There is a significant difference between how disabled people may find information that they need to cope with their disability as opposed to how a researcher finds information on a subject he is researching.

Those data bases that you mentioned primarily are for researchers, are for academic people, lawyers, professional types. They contain the kinds of information that these groups need to do their work. The physicians for MEDLINE, the educators for ERIC and so on. What is there for disabled people?

KORNBLUH: You had a question you wanted to ask?

QUESTION: Dr. Frank Ligro. I would like to let you know that I'm giving a proposal at a meeting of NRA; last September I also gave a proposal. The proposal was made to help handicapped groups; one was the deaf and the other was the blind. The deaf problem was on using the phone system, so I asked the blind people if they are interested in working with us as TTY cooperators for the deaf. The deaf can benefit from them because right now we have four TTY services.

And as we seek those solutions, we are not only seeking them for the benefit of the handicapped, which is very important, but also for the total society.

It's a very interesting proposition. I'm sure if Mr. Bell had not developed the telephone, somebody might have come along. His main interest in the whole research that led up to the telephone was his interest in the problems of the hearing impaired. And certainly the concepts of intelligence testing, which is not very much in vogue today, has certainly has been an important aspect of the educational community and I think it may even come back in vogue. And that came from our look early on into the programs for the mentally retarded. We may have abused it, but we can abuse anything.

KORNBLUH: In my own experience, I think there is no question that spinoff and serendipity will occur. In other words, we'll have transfer of technology, I suspect, from the nonhandicapped to the handicapped. As we make adoptions to the handicapped, we'll get retransfer of technology from the handicapped back to the nonhandicapped and so forth and so on purposefully and also through serendipity.

History is replete with people who have made discoveries and money through serendipity. You can sit around a table and talk about things a long time and not get needed insights. You may actually have to actively do things and trust that luck will occur.

We may get a letter in our office, or a phone call asking: "How do I get my stepfather into a rehabilitation hospital?" His doctor doesn't know anything about rehabilitation, you see. Well, you can't give out doctors' names, but there are all kinds of information that we get in the private sector and sometimes we know the answers and sometimes we go to someone else. It's your linkage I'm concerned about.

DR. PAN: It is a complex problem because there are many players involved and many hidden agendas. However, there are efforts beginning, and I think that it has to start with the coordination at the point of research, the point where new knowledge is created. If that can be coordinated, then we will have a chance of being able to coordinate the dissemination of that knowledge.

NIHR has a mandate to coordinate all research that is relevant to handicapped people. And I for one would hope that their role for coordination would be extended towards the coordination of research dissemination. It is also true that NIHR cannot, or even the entire public sector cannot, do it by themselves. It requires that we all cooperate.

QUESTION: Russell Kirsch from the National Bureau of Standards. I'd like to point out a strikingly similar thread that ran through three of the talks that we heard today. Starting with Congressman Brown when he pointed out, at first

and technology, which the bulk of our citizens understand poorly or not at all, the widespread availability in both schools and homes of inexpensive computer facilities could just possibly play an important role in the continuance of our civilization." Thank you.

KORNBLUH: Thank you very much, Frank. Those of you who would like to leave, feel free to do so. We are going to spend another 10 or 15 minutes asking questions of Dr. Withrow and Dr. Pan. If you have a question, just identify yourself and address the question to either or both of our guests, please.

QUESTION: Don McNeal, Corporate Manager for Science and Technology Data to Handicapped, National Science Foundation. I'd like to expand and support Dr. Pan's statement with regard to the importance of research utilization and I'd also like to add the thought that it's not just a transfer of information. Research utilization to me also involves the development and manufacturing and distribution of these products, and that really isn't going to happen unless you get the projects more involved. Just providing general information is not necessarily going to accomplish that. I think we need to provide some information to manufacturers with regard to market data; I think we need to provide tax incentives to companies; I think we need to limit the cost of product liability, which is keeping a lot of manufacturers out of the market right now; I think we need to help them out as far as product evaluation is concerned to get many of these devices through the FDA approval stage, as well as to

In summary, I think that I have talked about three prime things. One, the technological devices that enable the handicapped person to transpose their sensory or physical handicap amd more nearly participate in the normal world because of it. The issues there are: how do we find the resources and how do we establish the standards that will enable us to make those accessible to all people. We are, as many of you know, hoping that in 1980 we will have 20 hours of prime time on PBS, ABC, and NBC for hearing handicapped people in a caption format. Who will buy the decoders, what kind of tax break will be allowed, what kind of assistance will be needed, and how can we assure that all people who need the decoders and can benefit from that system will indeed have it? These issues certainly pertain to many other kinds of things that we have mentioned before, such as the readers for the blind, and so on.

The second area is the one of learning technology in the classroom. We need to be sure that all of our Federal laws do not prohibit the use of technology in the classroom; rather these laws should allow technology to be considered as one means of meeting the objectives set forth for the children that the laws are intended to benefit. I must say that I think the educational community in general has been very resistant to accepting it. We need to spend time, effort, and money in retraining people who are already in the classrooms. If it is not possible for them to change and adapt to the new technologies, then we may need to take steps to help those involved deselect the teaching profession.

These things are possible. The dream is how we will put them together. Will the educator move and take each thing and assemble it and put it into the educational system? I think that some of the issues that we're confronted with is how to change the educational system. We know that it will not change unless teachers and the school administrators are part of that change. We know, also, that technology is powerful enough that it may take place in the home.

It seems to me that if we are leaders, that we will modify our own thinking so that we can get the educators to participate in modern technology. The schools are one of the last places to have that participation. Your local bank has it. It's time the schools participated at a much greater and much more emphatic level.

I remind you, as the other speakers have reminded you, that many of the innovations that come about for the handicapped have benefitted our society in general. The typewriter, as you probably know, was invented for physically handicapped people. Alexander Graham Bell, inventor of the telephone, was a teacher of the deaf and was looking for an amplification system. One of his trials and tribulations at the beginning, hard as it is to believe today, was that people thought who on earth would want to talk to somebody else.

And of course the telephone system is the basis of our whole electronic communication system today. We have to ask ourselves

recent study that HEW did in terms of the home computer, video disc, and the whole new array of microcomputers, it was discovered that the affluent or the privileged are getting more privileged. Why? Simply because they are using these information and communication tools and have a whole new community of educational experiences available to them.

This is true also of the educational toy market and the computer toy market. They are very, very successful. The "Speak and Tell" System of Texas Instruments Corporation is certainly one of the more popular ones. Many of the "Simon Says" types of toys that hit the Christmas market last year have had outstanding sales records.

Why have those been successful? They have been successful probably because the marketeers have put them together in very attractive packages. They are relatively expensive as far as toys are concerned. Also, they are at a child's motivational level; they wisecrack with the kids. Many of them have voices and, in effect, enter into a dialogue.

Mr. Gardner, in writing in the November issue of Psychology Today talked about his experiences with his own children. He thought the electronic toys were fads, probably the grandparents bought them, and he said they were the only toys that his kids ever had. When the battery died, they came and pounded on his desk and said, "You've got to go out even though it is three o'clock in the morning and get me new batteries for this thing."

talk, time and time again, about technology doing what technology can do best and humans doing what people can do best.

Technology can become an infinitely patient tutor. A number of years ago when I was in Illinois working with Robert Stepp from the University of Nebraska, we developed a series of interactive eight millimeter films for emotionally disturbed handicapped children. One of the beauties of that particular system was that the teacher never tired; no matter how many mistakes the child made, the teacher was still a very pleasant person on the film.

The filmed "role models" could do it over and over again without people--the learners or the teachers being exasperated. More importantly, the children did identify with the film children and the film teachers.

Let me share one example with you because I think it is exemplary of the level that the children identified with the film teacher. We had one series where we were going through a cafeteria. We were trying to enhance vocabulary and language about breakfast. We always shot our films from the child's or learner's viewpoint so you had your tray, you got your tray, you saw somebody else's hands moving the tray down the counter, and so on. The teacher, who is the counter lady, would say, would you like some eggs, would you like this, and so on, and place that on the tray. The child used a mechanism which recorded his or her responses and, for research purposes, we had a hidden camera and photographed the child. Further, we split the screen so you could both see what the child was saying and see the child's reaction to this particular learning module.

Now we have had for years a promise of what I'm calling learning technology--what everyone else calls instructional technology. It has promised the moon and sometimes it has delivered the "tar pits." So we have a lot of people who are disillusioned by it. But I think right now we are in a period of time which is in tune with cost of technology, the reliability of technology and the learning process itself. Yet, we find that the educational community today is not spenting more proportionately on technology than it did 20 years ago.

Over the last 20 years we have very consistent figures showing that the educational community spends about 1-1/2 percent of its budget for textbooks, filmstrips, computers, and what have you. However, there is an interesting shift over the 20 years. Twenty years ago the educational community spent 95 percent of its support money on textbooks and five percent on everything else. Today the expenditure is 65 percent on textbooks and 35 percent on other technologies.

If you go into schools, especially in your elementary schools, you will find that there are filmstrip projectors, audio tapes, and even some portapack video cameras and recorders. We are using them. Now, the more technology we use in the classroom, the more likely the handicapped person is to be assimilated in that average educational program. The reason for this, and I think Elizabeth alluded to the reason in her presentation, is that technology, in a sense, removes some of the barriers.

The information communications system is one that can transcend some of the handicaps. For example, if we use computer teleconferencing, we can transcend time and space. We do not need to

We need to develop a system of distribution and assistance for all handicapped people that is equitable. I'm sure I don't have to tell people in this room that the various systems we have--ranging from some of the health services, to vocational rehabilitation, to services to crippled children, and a variety of other assistance programs--vary from State to State.

A few years ago, Congressman Roybal asked the Bureau of Education for the Handicapped to look into the distribution of hearing aids--a technology that has been around for a very long period of time. In our study we found, for example, that California, Illinois, New York, could be considered to have very high levels of professional involvement and quality programs but had very, very different rules and criteria. A child in California, for instance, could be issued binaural hearing aids. A child in Illinois, based upon perhaps equal professional judgment, could only have monaural hearing aids. Illinois provided maintenance for those hearing aids. California and New York did not provide maintenance for those hearing aids.

In a lifetime of education of a hearing-impaired individual--about 18 years or more--the parents of that hearing-impaired individual could have a bill from $2,000 to $4,000 for hearing aids. That's a sizable investment for the capitalization of hearing aids and their maintenance.

Certainly some of the more exotic aids that we've described are going to cost more than that. What standards, what principles will we establish on a national basis? I've mentioned California,

of implanting a hearing aid into the brain that enables the hearing impaired person, not to receive hearing as normal persons do, but to get auditory signals. Those kinds of techniques, as far out as they seem, are certainly in the developmental stage; eventually, in some format, they will be brought to a marketing or distribution stage.

The costs of devices are also going down very, very rapidly. To get a voice synthesizer for a mute individual five or ten years ago would have cost in the thousands of dollars. I think in subsequent programs you will hear of developmental work that will make those devices and systems for the handicapped available for hundreds, rather than thousands, of dollars. There are other techniques that are being developed. For example, Marvin talked about the eye-blink operating device. Any kind of voluntary body movement can act as a switch. If you only can move your big toe or if you can have only a very gross response that you have physical control over, you can activate a typewriter or CRT and thus form a means of communication.

In Massachusetts we have experiments where very, very severly paralyzed children are now communicating via computers. These are children who have never had expressive communication before--17, 18, 19 years of age. There were lost in institutions and had a total dependency until they were able to have interfaces with these particular computers that allow them to communicate with the community and with other people.

time in school is $3.25. Big difference! With satellite transmission, cable companies, videotape, videodisc, we are rapidly allowing programs to be delivered on demand at the time and the place that the viewer wants them to be delivered.

In Seattle, HEW is supporting a demonstration project with a cable company that allows you, in effect, to call up the cable company and have your program scheduled when you want it within their library of programs. So if you miss a program that is scheduled, you can still get it and have it literally sent out to your house at 3:00 on Sunday morning--if you wanted it at that time. In fact, the technology that is available to us today is extremely important in terms of its utilization with handicapped and with all people.

Despite my questioning about the public schools and whether their time may not have expired, they are the only places that we now have universal education. It's important therefore to think about the "Education for All Handicapped Children's Act," because that act, in itself, is bringing some interesting pressures upon school systems.

The school systems have always talked about--at least in this century--handling children on an individual needs basis; but, for the first time, the educational community is faced with the problem of actually putting their actions where they have been talking. That act, as important as it is in terms of assuring the rights of all handicapped children to a place in school, is equally, if

Frank is now Chief of Educational Technology Development for the U.S. Office of Education. He has written a number of books and interestingly enough, he has produced and directed quite a number of educational films. I would like to point out that Frank has pioneered in interactive media for both handicapped and non-handicapped learners. Frank, if you would, please.

DR. FRANK WITHROW: Old habits, as we all know, change very, very slowly. I daresay that in this audience, many of you, I suspect, are informed about technology and even work in technology. Probably, many of you will go back to your offices and homes and do business very much like you have done in the past.

Frequently, information technology is available to us--sometimes down the road, sometimes in our offices. The key to change, however, is access to that available technology. If you do not have access to it, you will not learn how to use it. Further, you will not learn how to become an effective member of the new information communication society that we're rapidly moving to.

Technology, especially new technology, inevitably changes the way we think. Print, for example, in the fifteenth century enabled us to store and transmit knowledge in linear formats. It organized knowledge for us and it allowed us to transpose time and space. We no longer had to be in the presence of the master teacher, or the master scientist; they could write it down. Print can be transmitted geographically and you could hand that knowledge down from one generation to the next. Print was a marvelous world-shattering technology that changed all of mankind after it came into being.

technology which assists disabled people in their use of data processing equipment, will be delivered through TECHNOTECH, a technology system developed by CDC. The software is already available and the telecommunications network is international in coverage. Within a year, we have the beginnings of data base technologies for disabled people--something the rehabilitation community has been discussing for as long as I have been working in this field.

What we have here is a situation where the private sector has felt that there is a sufficiently large market to justify the funding for the development of an initial data base which can be expanded if it is successful. That's the point; for this venture to succeed, the rehabilitation community, particularly the public sector, and the potential users of the data base have to be involved. Are we going to work together to insure that the product will be useful or will the public sector create still another dissemination mechanism marked, "for disabled people only"? The answer, it would seem to me, is clear. Government cannot afford to ignore the resources of the private sector much less compete with it.

In the last 40 minutes or so I have touched on a number of points related to the dissemination and utilization of rehabilitation research results. If I have to select three points that are to me the most significant, they would be the following:

(1) The Government, especially NIHR, should give a higher priority than is given currently to activities such as the repackaging of research results, their dissemination,

let me be the first to say that my training as an information scientist precludes me from being entirely objective on this question. Moreover, I have said that this was my opinion, not a documented fact.

I do have two reasons for arriving at this allocation: First, I believe that both research and research dissemination and utilization are equally important. Research does not make a difference unless it is used and it is not used unless it is disseminated. It's as simple as that. Second, as one who has conducted both kinds of activities, I believe both are equally complex and equally costly.

Well, some of you might say, "Can we afford to do all this?" I realize that for me to respond by saying that we cannot afford not to do this, is not particularly helpful, no matter how sincere I am in this belief.

It doesn't take a clairvoyant to realize that during the next decade we are not likely to see a great deal of increase in government funding for human services in general, and services to disabled people in particular. Those of you who may be more optimistic than I, might accept the statement if presented as a worse case situation. What if we don't get any more funding for services to disabled people, what can we do? I would look for an answer in the direction of greater efforts to cooperate with the private sector. Who knows more about effective dissemination and marketing of information products than publishers, for example? Or about creating demand

of the Bureau of Education for the Handicapped, the Office of Civil Rights, and other HEW-funded research relevant to rehabilitation.

A great deal of research is conducted by agencies outside of HEW: the Veterans' Administration, NASA, NSF, etc. Each of these programs has its own dissemination mechanism. A user who is really interested in covering all the available knowledge on a subject has to access perhaps a dozen different systems.

The same user who has learned over the years to rely on a particular service for information all of a sudden may discover that service no longer exists because the grant which made that service possible was not renewed. Most of the information and utilization projects funded by NIHR are funded as R&D grants or contracts. Yet, except in some cases, when we are trying out different approaches, providing information services is not research.

The point is, ladies and gentlemen, the lack of integration of research efforts results in unproductive segmentation of the knowledge base making retrieval from such a base a challenge that most of us as potential users of that knowledge base can do without. The funding mechanisms used to provide information services, add instability to a situation already made complex by the lack of coordination.

So where are we at this point? So far, I've talked about what we are and what we are not doing in terms of the dissemination and utilization of rehabilitation research results by the public, by disabled people, and by service providers. I've called your attention

On the basis of the knowledge we gained from this survey, we drew up the requirements for an information system to meet the needs of rehabilitation service providers. These requirements are: (1) to maintain a central repository of research reports and other literature on subjects of concern to the rehabilitation professionals; (2) to develop a computerized data base from which information can be selectively retrieved by geographically dispersed users; (3) to serve as a link to other formal information systems including other computerized data bases which contain relevant information; (4) to package information on specific issues for specific target audiences; and (5) to develop a network consisting of organizations which provide information services in order to achieve better coordination and enable resource sharing.

These requirements became the basis for what is now known as the National Rehabilitation Information Center. NARIC is now in its third year of operation from its headquarters at Catholic University. The computerized data base containing bibliographic descriptions of 4,000 research reports can be accessed through terminals connected by telephone lines to a computer in New York. Copies of the full text of documents are available from NARIC in hard copy or microfiche upon request. NARIC also performs literature searches of 150 data bases accessible through System Development Corporation, Lockheed, and Bibliographic Research

So far, I have talked about what we are doing and what we have failed to do in terms of disseminating information to the public and to disabled people. Let us now turn our attention to the category that I called "service providers."

Service providers include researchers, educators, doctors, nurses, therapists, counselors, engineers, and others too numerous to list here. Again, what we have here is a diverse group bound together by its common interest in providing services to the handicapped people. The kinds of information service providers need are determined by the kinds of work they do. Counselors are interested in effective placement techniques; program administrators are concerned about evaluation and planning; rehabilitation engineers want to know how to design more efficient devices, and so on.

Service providers rely primarily on three sources for information for what they need to know: their employers, formal information systems including computerized data bases and the informal network of colleagues who share the same work concerns. Compared to our knowledge of how disabled people seek information we know a great deal about how service providers obtain information.

About five years ago, I directed a study that examined the information-seeking behavior and preferences of rehabilitation service providers. We interviewed administrators of service delivery agencies, counselors, legislative staff at the Federal and State levels, educators, and researchers. We found that the most frequently voiced complaint made by the rehabilitation service

information resources published by the Clearinghouse for the Handicapped lists over 250 private sector organizations and 50 federally funded operations which provide information to one or more disability groups. This listing does not even include information services at the State and local levels, perhaps numbering in the thousands.

Should we conclude from these numbers that disabled people are getting the information that they need? There is no apparent lack of services, if numbers mean anything. But what about the fact that of the 422 action items identified by the White House Conference on Handicapped Individuals, 34 deal directly for the need for more information dissemination to disabled people? That would indicate a high priority. Even a cursory review of PL 95-602 would reveal how many times the word "information" or its equivalent appears. These expressions of perceived need lead one to conclude that existing information is not getting through to disabled people.

In this case, one can ask why we're not getting through. I posed this question to a colleague who is legally blind. Her answer, which will be included in committee print, is too long to read here, but I would like to quote from it. She says:

> Information that is disseminated within the rehabilitation community may never reach me because I'm simply unaware of its existence. Unless I'm a vocational rehabilitation client, or work as a counselor, I may be quite unaware of such devices as low-vision aids. Numerous publications which could be of assistance to me are out of my reach. I am, however, aware of the local library, newspapers, television, and radio. These are the most readily available sources of information for me.

It is obvious that our most effective means of reaching the public are the mass media. It is equally obvious that the key to accessing the media are the people who work in the media. They are the ones who should be the target of our dissemination efforts. After all, they can only present what they know.

Disabled people, and the organizations which represent them, are doing the most in terms of disseminating information to the public by accessing the mass media. Government's role is more indirect. For example, NIHR has funded research on attitudinal barriers. It also funded other projects, such as the development of a how-to-do-it mannual to assist consumer organizations in their efforts to access the media.

Let's now look at the dissemination of rehabilitation information to disabled people. The estimates of the number of disabled people living in the United States today range from 10 to 45 million, depending upon who is counting. Notice that we don't even know for sure how many disabled people there are. This number, whichever number you choose to assume, includes people with physical as well as mental impairments, adults as well as children.

Some disabled people are disabled from birth; others are disabled by a traumatic injury or disease. There are disabled people living in rural areas, urban areas, suburban areas; some work in mainstream jobs, others in sheltered workshops; most are unemployed. Some reside in institutional settings; a growing

What kinds of information about disabled people does the public need? The public does not need specific information about disabled people as much as it needs positive images about them. Positive images influence our perception of each other's humanity and our understanding of the common human thread that ties us together, disabled and able bodied alike. We are all the same and yet we are all different.

What we don't know, we don't understand; what we don't understand, we often fear. Fear breeds prejudice and builds barriers. Portrayals of disabled people which show them coping with everyday situations help foster an understanding of mutual human bonds. This understanding can lead to the acceptance of disabled people as human beings with the same survival needs as any human being. Acceptance in turn can open the doors that provide entree into the mainstream of life: jobs, home in a community, educational opportunities, and legal and civil rights.

Recently there have been a number of television programs which illustrate what I mean. "Like Normal People" which is based on a book by the same title, written by Robert Myers, a Washington Post reporter who has a mentally retarded brother, tells the story of a mentally retarded couple who wish to marry and live as independently as possible in a community. Another example is a story of Kitty O'Neal, a stunt woman who is deaf.

The point is, ladies and gentlemen, if research is going to make a difference in the lives of disabled people, research results have to be disseminated and used.

Getting research results disseminated and getting them used are two different problems. Dissemination is the precondition for utilization, but does not of itself ensure it. The appropriate analogy is getting the horse to water and then getting it to drink. We know a great deal more about information dissemination than we know about how to promote its use.

What I would like to talk about today is what we are and are not doing in terms of the dissemination and utilization of rehabilitation research results. By "we" I mean, collectively, the Government, specifically, NIHR and the private sector including consumer organizations. In the context of this paper, dissemination refers to storage, retrieval, and distribution of information and products, particularly R&D reports,to their users. Utilization includes repackaging of reserch results for specific audiences.

For example, a research study of some technological aid would produce a research report that is probably of interest to researchers working in the same or similar subjects. A counselor, on the other hand, would have little use for the research report on this technologocal aid, but would be interested in a brief description of the aid in terms of its functional utility to disabled people, its availability, and price. The consumer would find the same information about the aid useful, but it is more likely to receive this