

WHITE HOUSE/VA CONFERENCE

EMERGING TECHNOLOGIES IN SUPPORT
OF THE NEW FREEDOM INITIATIVE:
PROMOTING OPPORTUNITIES FOR
PEOPLE WITH DISABILITIES



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Acknowledgments

Mindy Aisen, MD
Margaret Giannini, MD
Steve Tingus, MS, CPhil
Michael Weinrich, MD
Celia Merzbacher, PhD
Dawn Epperson
Terri Carlton
Gloria Winford

JRRD:

Stacieann Yuhasz, PhD, Editor
Jayne Blanchard, Proceedings Project Director
Robert Williams, Graphic Designer
James McAnany, Web Design
Nick Lancaster, Multimedia Manager
Celeste Anderson, Bill Ehart, Lisa Finklea, Charlotte Irby, Judith LaVoie, Neil McAleer,
Marguerite Montes, Ed Motsinger, Arthur Parker, Lloyd Tinker

Dept of Transportation
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NASA
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NIH
FDA
DOE
White House
OSTP/NSTC
HUD
Dept of Commerce
United Spinal Association



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Introduction



Dr. Mindy L. Aisen

Director, Rehabilitation Research and Development Service

Let me start today with a quote from Margaret Mead, who once said, "I was brought up to believe that the only thing worth doing was to add to the sum of accurate information in the world."

When I took my current job at the VA, I saw it as the job of a lifetime. It was a chance to shape research in an environment where rehabilitation research could be conducted to provide desperately needed information and data to drive practice.

The job also had a very important personal meaning. My father was a World War II veteran, and I want to say that he was very proud of me. The most important things in life are love and work, and you get an extra bonus if your work enables others to meet their fundamental human needs.

The field of rehabilitation technology is rapidly evolving. Whether you're a clinician, an engineer, a researcher, an advocate, a consumer, a policymaker, or a combination of the above, you find yourself in a field where today's truth is tomorrow's anachronism.

"Today, more people accept the concept that cure can go hand in hand with care, and technology is absolutely fundamental to these advances."—Dr. Mindy Aisen

Early in my career as a neurologist in neurological rehab, we fought for our place in the rehabilitation field. Our insistence that genuine recovery was a possibility was often scoffed at as offering false hope. But today more people accept the concept that cure can go hand in hand with

care, and technology is absolutely fundamental to these advances. Compassion alone does not drive policy in the real world, and there are more important things than money. So, we have a convergence between financial issues and sharing information within the scientific community.

The engineering community, which is well represented here today, has produced lots of new technologies with lots of gee-whiz factors. Yet access to these new technologies is uneven, because they're expensive and we lack hard evidence that many of them are beneficial. With sufficient information, we will be able to furnish policymakers with the tools to provide necessary resources.



We've come together today—researchers, funders, policymakers, Government leaders—to talk to one another about the need for innovation, the need for collaboration, and the barriers that we can help each other overcome. By the end of these two days, we hope to have forged alliances and to have concrete plans and suggestions to help our community. Thank you.

Bio:

Mindy L. Aisen, MD, was appointed Director of the VA Rehabilitation Research and Development Service in September 1998 and assumed the additional role of Director of Technology Transfer for the Office of Research and Development in February 2000. Dr. Aisen received her undergraduate degree from Massachusetts Institute of Technology and her medical degree from Columbia University College of Physicians and Surgeons. She completed her residency at the New York Hospital-Cornell Medical Center and interned at Mount Sinai Hospital of Cleveland before joining the Burke Rehabilitation Center to serve as Director of the Spinal Cord Injury Service in 1987. Prior to her work at Burke, Dr. Aisen was an attending neurologist with the Albert Einstein College of Medicine Multiple Sclerosis Research and Training Center.



Keynote Address



Dr. Stephan D. Fihn
Acting CRADO, VA

The Office of Research and Development is thrilled that we've been able to bring together so many different viewpoints, all focused on a single critical topic: the potential for technology to improve the mobility, health, and daily lives of our disabled veterans.

The goal of this conference is perfectly congruent with the goals of VA research: To translate scientific and technologic advances into better care for veterans.

It is my great honor this morning to present the first speaker of this very distinguished panel, the Honorable Anthony J. Principi, Secretary of the Department of Veterans Affairs.

Secretary Principi directs the Federal Government's second largest department, responsible for a nationwide system of healthcare services, benefits programs, and

national cemeteries for Americans veterans and dependents, with a budget of \$64 billion and approximately 230,000 employees.

A combat-decorated Vietnam veteran, Mr. Principi served as Deputy Secretary of Veterans Affairs and Acting Secretary of Veterans Affairs under the first President Bush. He subsequently served as counsel to the chairman of the Senate Armed Services Committee, Republican chief counsel, and staff director of the Senate Committee on Veterans Affairs. He was chairman of the Commission on Service Members and the Veterans Transitions Assistance established by Congress in 1996.

Mr. Principi is a graduate of the U.S. Naval Academy. He first saw active duty aboard the destroyer USS Joseph P. Kennedy and later commanded a river patrol unit in Vietnam's Mekong Delta.

During my brief four months as the Acting Chief Research and Development Officer, I've had the pleasure to interact frequently with the Secretary. I have been consistently impressed with his steadfast and unwavering support for research and the poten-

tial it holds to improve the lives of veterans, particularly those wounded in combat.

He has been a vocal and enthusiastic proponent for such research, and this conference embodies that commitment. All of us present this morning sincerely appreciate the Secretary's enthusiastic support, his broad perspective, and his wisdom.

Please help me welcome Secretary Principi.

Bio:

Stephan D. Fihn, MD, MPH, is the Director of the highly successful Northwest VA HSR&D (Health Services Research and Development) Center for Outcomes Research in Older Adults, and he is the head of the University of Washington's Division of General Internal Medicine. Dr. Fihn is also the Research Coordinator for the Ischemic Heart Disease (IHD) QUERI (Quality Enhancement Research Initiative) group that works to improve the care and outcomes of veterans with IHD. In addition, Dr. Fihn leads the Seattle VA's HSR Fellowship Program and has mentored numerous VA fellows and career development awardees, many of whom have developed into prominent VA health services researchers.



Keynote Address



Anthony J. Principi

Secretary of Veterans Affairs, VA

Secretary Mineta, Dr. Marburger, Under Secretary Bond, Dr. Beato, Dr. Justesen, Dr. Brailer, Dr. Aisen, ladies and gentlemen, thank you so very, very much for being part of this important conference. On behalf of President Bush and the Department of Veterans Affairs, welcome to the White House/VA Conference on Emerging Assistive Technologies.

We begin our deliberations heartened by the remarkable legacy of one of America's most well-known disabled citizens, actor Christopher Reeve, who sadly passed away last weekend. His greatest role, of course, was as champion for those living with spinal cord injuries.

His unrelenting advocacy for, and trust in, the promise of research captured as no one else the attention of the American public, the Congress, and the research and medical communities alike.

Chris Reeve was a source of hope to patients and an inspiration to doctors and scientists. He holds a special place in the heart of the VA. The electrodes implanted in Chris's diaphragm, allowing him to breathe without a respirator, were developed by researchers in our Cleveland Medical Center. Some of these researchers will be speaking to you later on today. Chris's association with VA's spinal cord injury centers of excellence

prompted him to go on record saying, "The whole VA system today is a model for what research can and must be." When I look down the list of accomplishments of various centers and how proactive it is, I just rejoice.

"The New Freedom Initiative is the matrix for tearing down the stubborn residual barriers hindering 54 million Americans from realizing the fullest extent of their potential."—Anthony J. Principi

I am so pleased to see in the audience today Trisha Brooks and representatives from the Christopher Reeve Paralysis Foundation, Lee Page and Tom Stripling of the Paralyzed Veterans of America, Mary Ann King from VA's spinal cord injury strategic healthcare group, and Dr. Vivian Beta and members of the United Spinal Association. My good friend, the late Jim Peters, was its founder and executive director. Jim Peters and Chris Reeve worked together to create and successfully lobby for New York State's spinal cord injury research fund. We all mourn their loss and we draw inspiration from their enduring example.

It's been said that self-reliance is the only road to true freedom, and being one's own person is the ultimate reward. Those words go to the heart of our mandate on behalf of the President's New Freedom Initiative.

We are here today to lay the groundwork for self-reliance and the freedom it will bring to millions of Americans now disenfranchised from freedom of access to technologies, transportation, educational opportunities, home ownership, and

employment opportunities. We are here to improve the lives of Americans with disabilities by helping them in their quest to function fully and freely within their communities. This administration is making good on the promise that this nation will not underestimate or marginalize the abilities of any of its citizens, not in the realms of public service, business, industry, or housing, and not in restaurants, museums, malls, or athletic stadiums.

Our work on the President's behalf will give new meaning to America's unyielding commitment to equal rights and equal opportunity for all. I take very seriously the wide-ranging implications of the President's initiative, because my department has a unique relationship with and obligation to Americans whose disabilities arose during their military service on behalf of this nation.

The global offensive on terrorism demands sacrifices from our newest generation of servicemen and women. Many return home with wounds and injuries that will change their lives forever. My department provides them with cutting-edge healthcare from the research lab to patient bedsides, delivering the newest breakthroughs in medical science. These same profound advances in research and technology are the driving force behind the New Freedom Initiative.

The VA's full-service research system of clinical care, health

services, and rehabilitation research comes together to improve care not only to the veterans community but for the entire American community. The diseases, injuries, and conditions the VA treats are not unique to America's veterans. Many are equal opportunity diseases, injuries, and conditions that also affect Americans at large.

"Chris Reeve was a source of hope to patients and an inspiration to doctors and scientists. He holds a special place in the heart of the VA. The electrodes implanted in Chris's diaphragm, allowing him to breathe without a respirator, were developed by researchers in our Cleveland Medical Center."

—Anthony J. Principi

I can tell you that the VA will continue to bring to bear the full force of our resources to better the lives of all Americans. Ours is a system that encourages patients to achieve maximum self-reliance and maximum independence and to enjoy the freedom they hold. The VA's orthotics and prosthetic labs provide mobility and access to those who could not otherwise walk. Our advances in scanners and readers for the blind help those who cannot see to know the written word and to use the pencil of the twenty-first century, the computer.

My department's Veterans Health Administration is home to the world's most advanced and comprehensive medical records system. Here, technology allows clinicians to rapidly and accurately retrieve the information necessary to provide excellent care and allows time for them to talk with their patients instead of tracking down laboratory or X-ray results.

Our state-of-the-art medical records system forms the basis for a data set that we continually analyze, allowing us to identify the path to the best care. Technology can be assistive, as in the case of the scanning readers for the blind. It can also be transforming. Cochlear implants, for example, enable the deaf to hear. Today, you will hear from VA researchers who are creating retinal implants to enable the blind to see. And VA researchers are working on new solutions for limb loss by developing new technologies. You will also hear about many other examples of our groundbreaking advances during the day. For technology to succeed, it must be invented through dedicated research focused on the most relevant issues. It must also go beyond the engineer's drawing board to be tested again and again and ultimately be disseminated throughout the commercial sector.

We are here today to affirm our faith and the faith of millions of disabled Americans in the untapped potential of technology. But we also understand the

complexities of the process that transforms important, seminal ideas into safe, effective, tangible, and available devices throughout the country. This conference brings together a diverse community with a unifying mission: to make this process less complex and much more responsive. Representatives from industry, academia, consumers, advocates, and the President's administration are committed to making life better for Americans with disabilities. This is a working conference. I expect you will learn from one another and develop the basis for long-term collaborations to make sure certain technologies are available to those who need them.

We must foster creativity in the bioengineering community. To do that, people with disabilities need to be heard so that engineers can work in relevant areas. We must promote communication between the inventors and the commercial sector. And we must ensure industry has the incentives to manufacture important technology.

The New Freedom Initiative is the matrix for tearing down the stubborn residual barriers hindering

54 million Americans from realizing the fullest extent of their potential. If we are to be true to our mission of service and to the promise of the President's investment, injury or impairment will not be equated with dependency. Instead, our citizens will be given the means to realize the force of their human will and the power of their questing minds to overcome the arbitrary barriers of injury or disease and to seize the opportunities and freedoms that are the legacy of all Americans. I look forward to working with each of you as we push back the limitations of physical and mental disabilities.

Bio:

A combat-decorated Vietnam veteran, Secretary Principi served as Deputy Secretary of Veterans Affairs and Acting Secretary of Veterans Affairs under the first President Bush. He subsequently served as counsel to the chairman of the Senate Armed Services Committee, Republican chief counsel, and staff director of the Senate Committee on Veterans' Affairs. Mr. Principi is a graduate of the U.S. Naval Academy, first saw active duty aboard the destroyer USS Joseph P. Kennedy, and later commanded a river patrol unit in Vietnam's Mekong Delta.



Norman Y. Mineta (left) and Anthony J. Principi (right)



Keynote Address



Dr. John H. Marburger III

Director, Office of Science and Technology Policy (OSTP), Executive Office of the President

Thank you, Mr. Secretary. And thank you and the organizers of this conference for inviting me to say a few words this morning.

Two broad trends are occurring in society that are good news for all of us here today who are interested in emerging technologies for people with disabilities.

The first trend is a marked elevation of awareness of the needs and capabilities of people with disabilities throughout society. Accommodations that were required under the Americans with Disabilities Act (ADA) of 1990 have had an enormous impact on the architectural and design standards for a wide array of buildings and workplaces, products and services.

These new designs and practices make daily life easier for everyone, including people with disabilities. But they have also

helped to create an attitude of awareness. We see it everywhere, in the curb cuts and in the new accommodations in public buildings and in private places of business.

More and more, people today are aware that there is a large population among us of people with disabilities who need to be incorporated to the fullest extent into society at large in order for us to remain economically competitive and vigorous as a nation.

“Targeted medicines that reduce or eliminate side effects, new materials for strong but lightweight mobility devices, and distributed autonomous sensors are some of the ways technology can enhance the lives and daily activities of people with disabilities.”—Dr. John H. Marburger III

The President’s New Freedom Initiative, announced in February 2001, pledges full enforcement of the ADA, identifies new

areas of need, and establishes important new programs that will accelerate the transformation of the systems of everyday life to accommodate people with disabilities. The cumulative effect of these and other Federal programs, reinforced by a growing number of advocacy and assistance programs for people with disabilities, is a mega-trend amounting almost to a revolution in society’s expectations of the physical capacity of all its members.

It’s getting easier for people with a wider spectrum of physical disabilities to live their lives. As this audience is aware, however, much more needs to be done to realize the President’s vision of tearing down the barriers to equality that Americans with disabilities face today.

The second significant development is an even more profound recognition in an area sometimes inadequately called “information technology.” The impact of miniaturization of electronic components in the 1960s and ’70s, followed by powerful, inexpensive computers in the 1980s and ’90s, has been far deeper, broader, and faster than anyone could have predicted three decades ago.

High-bandwidth wireless communications, cell phones, global positioning devices, and incredible small-scale computing power are not just stand-alone applications but part of an interacting system of devices and processes that have transformed our environment for living and working.



GPS

There's the Internet, of course, which is easy to define as a set of wires and computers, but whose function in society has become so diverse as to defy description.

These revolutionary technological advances can offer real improvements in the quality of life and care for people with disabilities. Already available are products that incorporate advanced information technology for managing medical records, miniaturized electronics, inexpensive sensors used for information processing, enhanced connectivity via telecommunications, and the Internet. These and other emerging technologies, such as nanotechnology and biotechnology, promise advances that will assist everyone, not just people with disabilities.

Targeted medicines that reduce or eliminate side effects, new materials for strong but lightweight mobility devices, and distributed autonomous sensors are some of the ways technology can enhance the lives and daily activities of people with disabilities.



Targeted medicines

President Bush's administration is making investments to take advantage of these emerging technologies. We are investing in the whole range of applied sciences and related technologies needed for basic understanding of specific disability issues. And we are investing in the technology infrastructure needed for the continual development of new disability-related products.

The nation's research and development (R&D) investment in assistive technology is not collected systematically across agencies, but we know federal spending in this area has been increasing. Key agencies that support assistive technology R&D include Health and Human Services (HHS), the National Science Foundation (NSF), the Department of Veterans Affairs (VA), the National Institute on Disability and Rehabilitation Research (NIDRR), and the Department of Education (DOE).

In addition to research aimed specifically at disability and rehabilitation, Federally funded research is scattered throughout the Federal R&D portfolio, including \$132 billion in the current Presidential request for science, breaking all records for R&D spending.

Examples of funded programs in these agencies with applications to assistive technology include robotic research by NASA, lightweight battery research in the Department of Defense (DoD), and nanotechnology research at the National Science Foundation (NSF) on materials that are many times stronger yet much lighter than steel.

The challenge is to link research results and relevant technologies to specific products and to raise awareness among providers and consumers of their availability. It doesn't help if the technology is there but not incorporated into products that serve the disabled populations.

The President's New Freedom Initiative includes proposals for increasing research on and access to assistive and universally designed technologies, and it is part of the responsibility of my office

to bring together this diverse set of capabilities within the Federal agencies and encourage them to talk to each other and share information about the possible applications of their work to these critical needs of society.

The Interagency Committee on Disability Research, for example, authorized many years ago by the Rehabilitation Act of 1973, promotes coordination and cooperation among Federal agencies conducting disability and rehabilitation research programs. Representatives from more than 30 agencies regularly participate in this interagency group. The current chair, Steven Tingus, is also the director of the National Institute on Disability and Rehabilitation Research (NIDRR). Among the committee's goals is the coordination of government-wide activities in support of the New Freedom Initiative and in particular to prioritize the immediate assistive and univer-

sally designed technology needs of the disability community, as well as foster collaborative projects between the Federal laboratories and the private sector. The committee is essentially an intergovernmental counterpart of the Center for Applied Special Technology (CAST), one of the sponsoring organizations for a conference on aging that occurred earlier this year.

I'm very pleased to be part of this initiative, and I am encouraged by the tremendous reaction to efforts to bring people together and focus on these issues. I look forward to seeing even more results as a consequence of the enormous investments that this administration has made in technologies, many of which can be turned to advantages for people with disabilities.

Thanks again to the Department of Veterans Affairs and other organizers of this conference for

bringing this diverse group together. I look forward to seeing the results of this conference.

Bio:

John H. Marburger III, PhD, was born on Staten Island, NY, grew up in Maryland near Washington, DC, and attended Princeton University (BA, Physics, 1962) and Stanford University (PhD, Applied Physics, 1967). Before his appointment in the Executive Office of the President, he served as Director of Brookhaven National Laboratory from 1998, and as the third President of the State University at Stony Brook (1980–1994). While serving as a Professor of Physics and Electrical Engineering at the University of Southern California, Marburger contributed to the rapidly growing field of nonlinear optics, a subject created by the invention of the laser in 1960. He developed theory for various laser phenomena and was a cofounder of the University of Southern California's Center for Laser Studies.



Keynote Address



Norman Y. Mineta

Secretary of Transportation, DOT

First, I want to acknowledge the leadership of Anthony Principi, not only at this conference, but especially in making certain that people with disabilities—often disabilities they acquired in the service of this great nation—can participate fully in American society.

This is a very impressive group that you have assembled. I am very, very proud to be associated with all of you in this endeavor. It really shows the level of commitment by President Bush and across the administration in advancing the President's New Freedom Initiative.

The goals of the President's initiatives are very near and dear to me personally. Fourteen years ago, as a member of Congress, I had the honor of developing the transportation portion of the Americans with Disabilities Act (ADA).

It was the culmination of decades of efforts on the part of many of you in this room, and the results have been heartening. President George H.W. Bush signed that legislation into law, and with its passage, we have seen doors that were once closed begin to open, and a decade later, another President Bush has challenged us to go to the next level, to connect people with disabilities to services, jobs, and opportunities. At the core of the New Freedom Initiative is the President's

deep commitment to tearing down barriers so that every American has the opportunity to live a full and independent life.

Top leaders across the Bush administration are working hand in hand toward that goal. At the United States Department of Transportation, we are responsible for a critical link in the chain, because before you can enter an open door, you have to be able to get to that door.

Virtually every day at the Department of Transportation, we are working to make our national transportation system more accessible. And while we still have a long road ahead of us, our progress is significant.

Today, more than 90 percent of the nation's bus fleet is ADA accessible, and 82 percent of our nation's key rail stations are user-friendly for disabled passengers.

In aviation, we have reached settlements with a number of air carriers that were not providing the required in-cabin space for stowing a folding wheelchair, were not supplying appropriate assistance to wheelchair users, or were refusing to provide transportation to disabled individuals.

As all of you are very well aware, last February, President Bush issued an Executive order directing Federal agencies that fund transportation services as part of their human services programs to coordinate their efforts.

Some 62 Federal programs offer transportation services to connect people with programs like job training, health care, and education. But often they present a confusing, inefficient maze to

the very people who need them. Requirements are different, and scheduling is not coordinated. We are changing that.

Last month, I had the privilege of convening the first meeting of the Coordinating Council on Access and Mobility. This senior-level cabinet group is overseeing President Bush's Executive order. We are working across the government to apply some common sense and to coordinate our services so that more people will be able to get around more easily.

- 1 to 2.3 million American households own at least one vehicle that has been modified to accommodate a driver or a passenger with a disability.

- More than 90 percent of the nation's bus fleet is ADA accessible, and 82 percent of our nation's key rail stations are user-friendly for disabled passengers

Now, many of you may be familiar with the United We Ride program, our national initiative that supports the President's Executive order. The vision is one-stop shopping, where a customer can call a single number for a ride, regardless of where they are going or which agency will provide the funding. Technology is key to achieving that success. It is a

tool for helping agencies to coordinate; for improving scheduling, reservation, and dispatch services; and for helping those individuals who need a ride to know what their transportation options are and how to find the ride that they need.

We see examples across the country of transit systems putting technology to work to better serve the disabled community. Systems in Corpus Christi, Texas, use technology and software that electronically records, logs, and routes a customer's trip request.



Crosswalk with countdown

This automated system communicates with computers onboard the vehicles to determine the best pickup point and drop-off time, based on the rider's request. As a result, the wait times are down and the costs are also lowered.

Other transit systems are providing on-vehicle audio announcement, accessible traveler information, and flexible routing to make it easier for passengers

with disabilities to use conventional transit services. Now, this is just the tip of the iceberg. Many, many more ways exist for technology to remove barriers that once limited mobility for people with disabilities.

Personal Digital Assistants (PDAs), such as Palm Pilots, are being programmed to be personal global positioning systems. These systems can identify stops, bus numbers, and specific route information.

Researchers in the rehabilitative community are developing PDAs with preloaded pictures of the environment and directions so that people with cognitive disabilities can "see" their route and get reminders when they need them.

Audible pedestrian signals and talking bus stops can allow those with visual impairments to travel more safely and to be able to travel independently. Pedestrian detectors can adjust signal timing at traffic lights to accommodate slower-moving pedestrians, such as the elderly and people with mobility impairments.

Our National Highway Traffic Safety Administration (NHTSA), within the Department of Transportation, is researching adaptive devices for people with disabilities so that they will be able to provide better and safer control over automobiles.

Today, some 1 million to 2.3 million American households own

at least one vehicle that has been modified to accommodate a driver or a passenger with a disability. Technologies on the horizon promise even greater freedom of the road for those with disabilities. I envision enormous applications from our Intelligent Transportation System in aiding research into crash avoidance systems.

Perhaps it is an outgrowth of my background in California's Silicon Valley. I am a believer when it comes to technology. I see technology rewriting our assumptions about how people with disabilities will travel.

Let me close by expressing my deep appreciation for all of you taking time from your own busy schedules to devote two days to this conference, and to Anthony Principi, to the White House, and to the Department of Veterans Affairs for their leadership so that all of us can focus on how these emerging technologies will be able to bring new freedom to Americans with disabilities.

Together, we will continue to break down barriers so that people with disabilities have the mobility to enjoy all of the rich opportunities that this great nation has to offer.

May God bless each and every one of you, and may God continue to bless the United States of America. Thank you very much.

Bio:

Prior to joining President Bush's administration as Secretary of Transportation, Norman Y. Mineta served as U.S. Secretary of Commerce under President Clinton, becoming the first Asian Pacific American to serve in the cabinet. He is the first Secretary of Transportation to have previously served in a cabinet position. Before joining the Commerce Department, he was a vice president at Lockheed Martin Corporation. From 1975 to 1995, he served as a member of U.S. House of Representatives, representing the heart of California's Silicon Valley. Mineta and his family were among the 120,000 Americans of Japanese ancestry forced from their homes and into internment camps during World War II. After graduating from the University of California at Berkeley, Mineta joined the Army in 1953 and served as an intelligence officer in Japan and Korea. He joined his father in the Mineta Insurance Agency before entering politics in San Jose, serving as a member of the City Council from 1967 to 1971 and as mayor from 1971 to 1974, becoming the first Asian Pacific American mayor of a major U.S. city.



Dr. Marburger (left) and Secretary Mineta (right)



Keynote Address



Phillip J. Bond

*Under Secretary of Commerce for
Technology, DOC*

Secretary Principi, Secretary Mineta, Dr. Marburger, Assistant Secretary Brailer, friends, it is good to be with you and a real privilege for me this morning to be representing Secretary Don Evans, my boss, who has a deep and abiding personal interest in this subject. On his behalf, let me welcome you to the start of this conference.

In February 2001, the President launched the New Freedom Initiative. Close on the heels of the announcement, we began to work on that initiative from the Department of Commerce standpoint, trying to do our part to bring this promise into reality for so many Americans, to support the development of assistive technologies, and to promote the expansion of the U.S. assistive technology industry. In fact, in 2001, we launched an effort to survey the emerging industry of assistive technology. We completed a two-year survey,

culminating last February in the announcement of an eight-point initiative by Secretary Evans to work on assistive technologies. We're now busy implementing all eight points of that initiative. Our departmental efforts in support of the New Freedom Initiative really boil down to two main thrusts: speeding the transfer of new technologies for individuals with disabilities and also boosting U.S. exports. We are the Department of Commerce, after all. The fundamental reason is that not only do jobs come from new assistive technologies for use both here and abroad—jobs for folks with disabilities and those without—but that with more sales comes more R&D, which leads to new innovations, new products, and new advances.

Promoting exports becomes a way to promote the new technology. In fact, my job description as Under Secretary basically is to try to encourage technology for the benefit of the U.S. economy and its citizens. This past July, for the second year in a row, we hosted, along with our friend Troy [Justesen, Acting Deputy Assistant Secretary, Office of Special Education and Rehabilitation Research] and his office at the Department of Education, a policy forum and

exhibition to commemorate passage and enactment of the Americans with Disabilities Act (ADA). Our theme was "Technology for All Americans," and I see a number of familiar faces here from those conferences. The aim was to talk about and look at technologies that would help Americans fulfill their dreams, because technology is really best when it moves beyond the merely cool gadget or gizmo and really empowers and enables people to fulfill their potential. As we promote assistive technology development, we want to make sure these new technologies work for all segments of American society. And so at our conference we had more than 40 exhibits by leading companies, government agencies, and associations that serve the disabled community.

We had a full day with terrific exhibits. We highlighted some of the advances. We discussed barriers to making more technology available and accessible. We explored further, deeper cooperation among those in the community, in industry, and in Government. Today and tomorrow, thanks to Secretary Principi's leadership and that of Dr. Marburger, we hope that those themes will be fleshed out more completely.

We hope you'll produce some substantive suggestions that all of us on the Government side can look at. For instance, on R&D, what can we do with the advanced robotics and materials Dr. Marburger talked about? What can we do with the affordable bandwidth that the President wants to see available to all Americans by 2007? What can we do in the workforce and in education as we open up whole new vistas to educate those with cognitive or learning disabilities with new technologies? What can we do in technology delivery, moving it out of the lab and into the marketplace? What can we do in transportation as Secretary Mineta talked about? All of these can have such a dramatic impact. Think all of these questions, and your work in the next two days serves to underscore another critical point: how unique the assistive technology community is.

“Our departmental efforts in support of the New Freedom Initiative really boil down to two main thrusts: speeding the transfer of new technologies for individuals with disabilities and also boosting U.S. exports. We are the Department of Commerce, after all.”—Phillip J. Bond

All too often in the past, assistive technology has fallen through the cracks between medical devices and information technology, instead of bringing the two fields together for the benefit of, and cooperation with, the community so that we can figure out how to deploy it and use it best. This can no longer be. Assistive technology is simply too important to our nation to allow it to continue to fall through the cracks. First, let's fully recognize the unique character of it, the importance of it to our economic growth and productivity, and that a large segment of our society can contribute more and wants to contribute more. Certainly, the President sees and understands this. It is what motivated him to move on the New Freedom Initiative so quickly after coming into office, recognizing that the development and distribu-

tion of new assistive technologies is critical to our economic security, to our society, and even to our national security—in short, assistive technologies are a real national priority. We're committed in this administration to making sure that no child is left behind as he or she looks forward to being a part of the strong current of American society. We also want to look forward to working with all of you to deepen and expand what we already have done, to reach out and engage more with industry—we've talked about that a little bit—and also to promote awareness across the culture.

I think it's probably true today that nearly every American family has been touched by someone who's disabled in their extended family. We need to promote that awareness across the culture and then continue to work for those untapped markets, as I said, because not only does it enhance economic security but it promotes innovation. Commerce will be trying to do our part in building out the initiative using our foreign commercial service to help U.S. commercial companies sell assistive technologies around the world. At the National Institute of Standards and Technology, we'll be looking to unlock new technologies that can create new instrumentation and new standards that can lower cost and make assistive technologies more accessible—in short, an America in which we really, truly have opportunity for all. We can look forward to a day when we have not only no child left behind, but no citizen left behind. Congratulations, and we look forward to working with you.

Bio:

Phillip J. Bond was sworn in as Under Secretary of Commerce for Technology on October 30, 2001. His primary responsibilities are to supervise policy development and direction among the Office of Technology Policy (OTP), the National Institute of Standards and Technology (NIST), and the National Technical Information Service (NTIS). His experience in the private sector includes serving as Director of Federal Public Policy for the Hewlett-Packard Company, a position he held immediately before joining Commerce, and serving as Senior Vice President for Government Affairs and Treasurer of the Information Technology Industry Council. He is a graduate of Linfield College in Oregon.



Keynote Address



Dr. Cristina V. Beato

Acting Assistant Secretary for Health, HHS

Good morning. I want to thank Secretary Mineta, Dr. Marburger, Secretary Principi, and my colleagues at the Department of Health and Human Services (HHS).

I'm here on behalf of Secretary Tommy Thompson. It's my great pleasure to be participating with you this morning on this historic occasion.

Our President strongly believes that every American has the right to an opportunity to contribute their God-given talents. In order to do that, he proposed the New Freedom Initiative to break down barriers and to create collaboration, not only within his own Executive Branch but also between levels of Government and public/private partnerships.

With the leadership of President Bush, the New Freedom Initiative has instructed our department,

Health and Human Services, to give high priority to improving the nation's response to disability issues in our many programs that support direct services, as well as our medical research that helps prevent and ameliorate disabilities, especially in policies that can shape the options available to disabled individuals and their families.

We are committed to creating more opportunities to provide care in the home and in the community in which you live. Our department translates President Bush's compassionate agenda into action.

Across the Department of Health and Human Services, our 2005 budget proposal includes more than \$75 million in support of the New Freedom Initiative. The President has also proposed that the money follow the individual rebalancing initiative.

Other initiatives at HHS include a \$1.75 billion, five-year Medicaid demonstration program to help Americans with disabilities transition from nursing homes or other institutions to community living. Whether you are a parent struggling with a disabled child or an older person with an elderly

parent who is disabled, I know the pain your families share and how much people want to be independent. The demonstration program will help States and communities achieve a more equitable balance between the proportion of Medicaid spending on institutional services and on community and home services. This is where the action takes place. It's in the communities. It's not in Washington, DC.

The demonstration program helps States design flexible financing systems for long-term supports that allow the funds to go where the individuals are and to help provide the most appropriate and preferred settings for disabled people in their community.

The President also has proposed the Living with Independence, Freedom, and Equality Account Savings Program. This program costs nothing to the Federal Government. The accounts will remove barriers to independence, community living, and participation in the labor force for Medicaid-eligible individuals with disabilities. Folks with disabilities want to contribute. We need to make sure the barriers are torn down so they can.

The President's 2005 budget also includes a number of other investments in the New Freedom Initiative, including the innovative TT-III Medicaid demonstration. It will offer respite services to caregivers of adults with disabilities. It will also offer respite services to caregivers of children with severe disabilities, home and community-based services for children residing in psychiatric residential treatment facilities, and a proposed \$18 million in 2005 for demonstration projects, with \$327 million proposed over five years. Communities know best how to tailor solutions for themselves.

"We as a country spend more resources on healthcare than people in any other industrialized nation, and we get the right treatment only 55 percent of the time. For our minorities, that's even less. Think how much better our recordkeeping will be when healthcare catches up to banking, journalism, veterinarians, and auto services."—Dr. Cristina Beato

The President's New Freedom Initiative is a comprehensive approach to disabilities. It's from cradle to grave. The President understands prevention. Many disabilities that occur as a result of war—especially in the realm of head trauma—may be preventable. Many of those disabilities that are the result of diseases are also preventable. Many of them are chronic. This department works very, very strongly putting prevention mechanisms in place.

Treatment and medical devices, pharmaceuticals, new technology—you've heard a lot of this here today. Translating that into communities and everyday living is where we all need to help and come together as a community.

This President is committed to using the full force of the Federal Government to keep that investment going; to use the incredible technology

that we have in this nation, whether it is in medical devices, pharmaceuticals, or assisted robotics; and to apply that technology so it can help our citizens.

Our Office of Civil Rights continues its compliance programs to protect the rights of individuals with disabilities under the Americans with Disabilities Act (ADA), with an emphasis on the right to be served in the most integrated setting under the Supreme Court's Olmstead decision. The Department of Justice, along with HHS, works through alternative dispute resolution whenever possible to resolve complaints.

Make no mistake: As we talk about research and development, I want to bring this up because incredible strides have been made. This is the first President ever to support stem cell research. Stem cell research using the adult stem cell has resulted in incredible new advances in heart disease, which can cause disabilities. This is the first President in history to propose stem cell research and support it, as well as the development of regenerative medicine for diseases like blindness and macular degeneration.

In our department, as of February 2001, Secretary Thompson took the step to create the Office of Disability, headed by Dr. Peg Giannini, whom I'm very happy to introduce today. That happened because of the President's New Freedom Initiative.

The Administration on Aging (AOA), also part of our department, continues to support family caregivers, by far the largest source of care for elderly and disabled individuals, through our National Family Caregivers Support Program. And the Center for Medicaid Services (CMS) has joined the AOA to develop one-stop aging and disability resource centers.

Disabilities also happen in the mental health arena; it's not just physical disabilities. Our Substance Abuse and Mental Health Services Administration (SAMHSA) is developing an action plan

for carrying out the ambitious recommendations of the New Freedom Commission on Mental Health.

“Healthcare has the potential in electronic information updates to produce savings of 10 percent of our total annual spending, which is close to \$1.5 trillion.”—Dr. Cristina Beato

As to our Indian Health Services (IHS), there are disparities in our minority population when it comes to disability services and access. IHS is collaborating with SAMHSA to support persons with disabilities, particularly in our Native American groups that have high affliction rates associated with drug and alcohol abuse.

Our Health Resources and Services Administration (HRSA) mainly serves our rural communities, which also have a disproportionate lack of access to many of these treatments. HRSA provides \$25 million to support medical services for children and youth with special health needs to ensure access to a family-centered medical home for our children.

At our Office of Women’s Health (OWH), we are addressing the disparities concerning women with disabilities. The OWH is in the process of developing health education materials and tools to facilitate a better understanding

of the health and health behavior of deaf girls, building on two years of work to better understand deaf culture, particularly where deaf girls get their health information.

In collaborations between our Office of Disabilities and Office of Women’s Health, experts are meeting to examine progress and various recommendations regarding women with disabilities and to identify the gaps so that we’re able to take steps to remove them.



Woman with disability

As I’ve mentioned, and you’ll hear much about today, breakthroughs in science and technology are emerging every day. While virtually every other sector of our economy is charging ahead into the twenty-first century, it’s sad for me to report that the healthcare industry has a lot of catching up to do to benefit all Americans.

For example, we can all use ATMs around the world, from Bangkok to Moscow to my home state of New Mexico. You can get money and find out what your balance is from your checking account. But if you show up in my emergency room in Albuquerque,

even 50 miles away from your home, and you’re unconscious, I have no clue as to what your allergies or medical conditions are. I would have to scramble to track down any sort of medical record on you.

In the media, editors can layout entire newspapers on a computer, saving time and money, allowing them to get the latest news in the paper every day. Yet so much of the money people spend on healthcare goes to maintaining and losing redundant paper records.

If you have a pet, or get maintenance services from Jiffy Lube, you get an electronic reminder to update your pet’s shot schedule or schedule your next oil change, all across this country. But few people ever get such reminders for their children’s immunizations.

We as a country spend more resources on healthcare than people in any other industrialized nation, and we get the right treatment only 55 percent of the time. For our minorities, that’s even less. Think how much better our recordkeeping will be when healthcare catches up to banking, journalism, veterinarians, and auto services.

Ladies and gentlemen, I’m happy to report that under President Bush and Secretary Thompson, we’re charging forward in the delivery of healthcare by building a new health information

infrastructure to include electronic health records and a new network to link health records nationwide.

Not only will we do better, we'll also avoid medical errors and we'll be able to accomplish four goals:

1. Bring information tools to the point of care.
2. Build an interoperable health information infrastructure so that records follow the patient, allowing clinicians like myself access to critical health information to help you when we need to make treatment decisions with you.
3. Use health information technology to give consumers more access, involvement, and responsibility in their healthcare decisions.
4. Expand the capacity for public health monitoring, which in the age of bioterrorism is critical, as well as quality of care measurements and bringing research advances more quickly into medical practices.

Healthcare has the potential, through electronic information updates, to produce savings of 10 percent of our total annual spending, which is close to \$1.5 trillion. We can sure take care of a lot of uninsured people with that.

Technology enhances productivity, expands functionality, and improves quality of life. It has been my great pleasure to represent our secretary, who's out traveling, and to represent this great President. May God bless you and bless our great nation. Thank you for all your work.

Bio:

In her capacity as the Acting Assistant Secretary for Health, HHS, Cristina V. Beato, MD, serves as the principal advisor on health policy and medical and scientific matters to the Secretary of HHS, oversees the Office of Public Health and Science, and supervises related programs and activities within the Department. In addition, she is a rear admiral in the U.S. Public Health Service Commissioned Corps. Board-certified in family medicine, Dr. Beato has dedicated her professional life to improving the health and well being of individuals, families, and communities. She emigrated from Cuba in her childhood and went on to receive her undergraduate and medical school education at the University of New Mexico (UNM). During her medical residency, Dr. Beato instituted the first formal medical community outreach program for abused, neglected, and abandoned children at the All Faiths Receiving Home in Albuquerque.



Dr. Beato (left) and Secretary Principi (right)



Keynote Address



Dr. Troy R. Justesen, EdD

*Acting Deputy Assistant Secretary,
Office of Special Education and
Rehabilitation Research, DOE*

Good morning. Thank you, Mr. Secretary. I bring greetings from Secretary Rod Paige at the Department of Education. He wishes to extend to you his apologies. He's on travel as well. He asked that I come here and bring his greetings and share with you some of the achievements of the Department of Education (DOE) with respect to the New Freedom Initiative (NFI).

Before I do that, in thanking my colleagues here at the front of the room today, I would be remiss and probably punished tonight when I get home if I didn't introduce my brother, who is the Associate Director for Domestic Policy at the White House and the New Freedom Initiative adviser to the President, Tracy Justesen, in the back there.

In a quirk of fate, Tracy has the job I had before coming to the Department of Education. So, I think the President wanted to

see the same face in the Domestic Policy Council. But he doesn't, because I'm the better-looking of the two.

The New Freedom Initiative, ladies and gentlemen, is basically broken into four main components: increasing access to assistive and universally designed technology, increasing access to educational opportunities, increasing access to the workforce, and increasing access to community living.

The Department of Education has responsibilities for all four of these components. Most aptly, and it's my privilege to be the first to announce it here, the House and the Senate last week passed the Assistive Technology Act of 2004, which will be before the President for his signature.

The Assistive Technology Act is one in which the Department of Education has taken the lead since its original creation in 1988. Both the National Institute for Rehabilitation Research and the Rehabilitation Services Administration will be assuming the lead in implementing assistive technology for individuals with disabilities across their lifespans.

The Assistive Technology Act gives us unprecedented opportunities

to build new foundations in assistive technology where the act has not gone before. We have the chance to work with our colleagues across the administration in a variety of Federal agencies to promote assistive and universally designed technologies for people with disabilities.

Principally, we've done a great deal of work with Phil Bond and Ben Wu from the Department of Commerce. And we look forward at the Department of Education to building that strong alliance and making sure that the R&D efforts in assistive technology move those products to the hands of people with disabilities.

The New Freedom Initiative fosters educational and workforce opportunities for people with disabilities. We at the Department of Education, under the President's leadership, have seen an increase of more than 75 percent in special education and rehabilitation services for people with disabilities since the President took office in 2001.

Seventy-five percent of this increase also represents an opportunity for young people with disabilities, as they move from educational experiences to adulthood, to realize the successes and the vision of

Secretary Mineta's efforts on the Americans with Disabilities Act (ADA) and the President's efforts on building on the ADA for the New Freedom Initiative. This is a wonderful, historic reflection of our investments in special education-related services.

Our opportunities in building community living and accessible environments for all people with disabilities are also a fundamental component of our work at the Department of Education. But we realize that we should not be working on the NFI's four tenets alone. We look forward to continuing our work with all Federal agencies, with consumers in the field, and with researchers and practitioners, making sure our efforts—the multibillion dollar efforts we have in the Office of Special Education and Rehabilitative Services—reflect what consumers with disabilities need and what they want.

Our achievements in building on No Child Left Behind and the soon-to-be reauthorized, hopefully, Special Education Statute for Children and Youth with Disabilities are our opportunity to work with our partners, to work with you, and to work with researchers, advocates, and the individuals with disabilities, making certain that the New Freedom Initiative is a reality and not just a concept.

-An estimated 54 million Americans have disabilities.

-About 6.9 million young people receive special education and related services in this country every year.

Along those lines, this President has signed what I can count to be more than five executive orders implementing various provisions of opportunities for people with disabilities under the New Freedom Initiative. This historic achievement, reflects his personal attention to the needs of increasing opportunities for all people with disabilities. Today, we have an estimated 54 million Americans with disabilities. These numbers continue to grow. We look forward to building on the

adequate needs and services that we provide at the Department of Education for people with disabilities throughout their lives. We have 6.9 million young people who receive special education and related services in this country every year. We are furthering the great successes we have made in educating all children, including children with disabilities, but also ensuring that as these young people grow up and move into adulthood, the workforce, and into independent community living, they do so as fully and equally as they possibly can, together with their peers and colleagues without disabilities.

Secretary Paige joins his colleagues, Secretaries Principi and Mineta, in bringing you his congratulations on the achievements you have made to improve the lives of people with disabilities. As a person who sits here and uses assistive technology, my personal thanks to each of you in the room for increasing the opportunities, removing the barriers, and making the New Freedom Initiative a reality for my colleagues and brothers and sisters with disabilities in this great country. Thank you very much.

Bio:

At the time of this speech, Troy R. Justesen, EdD, was delegated the functions of the Assistant Secretary for the Office of Special and Rehabilitative Services (OSERS) at the U.S. Department of Education. He is also the Acting Deputy Assistant Secretary at OSERS. Prior to this, he served as Deputy Executive Director of the President's Commission on Excellence in Special Education and worked as a policy analyst in the Director's Office of the Office of Special Education Programs. In the mid-1990s, Troy served more than three years at the U.S. Department of Justice working on enforcement issues under the Americans with Disabilities Act (ADA) of 1990. He also worked at the Utah State University-University Center for Excellence in Developmental Disabilities Education, Research, and Service on issues involving children and youth with disabilities, including assistive technology, personnel preparation, and special education. He holds a BS in education and an MS in special education, each from Utah State University, and a doctorate in education from Vanderbilt University.



Keynote Address



Dr. David J. Brailer

*National Health Information
Technology Coordinator, HHS*

Thank you, Mr. Secretary, Secretary Mineta, Dr. Marburger.

Ladies and gentlemen, it's a privilege to be here with you today. I applaud your leadership, and I am very happy to be part of this.

A year ago, I was actually in a research center in San Francisco and was asked to participate in a report called "The Emergence of the Bionic Man." And I thought: this is very interesting. This report was about the profound convergence of implantable devices and other assistive technologies that incorporated information technology and wireless transmission.

What we discovered was a future that is not far out. Frankly, many of you know much more than I about this convergence and the ability of these technologies to change lives. Since I have come to the Government this past year, I have seen it already happening

in the Veterans Health Administration (VHA) and in other parts of the Government. These technologies have already improved healthcare and transformed lives, yet I think that we are at a position where these technologies can clearly bring us to another era.

I want to step back, though, because the other speakers have talked about this very clearly. To me, what underlies this—and this was the purpose of the President's April 27 Executive order to bring about the Health Information Technology Strategic Plan—is the need to think about how we use technologies today and in the future to enable a market for healthcare services where consumers have better choice, easier mobility, and the capacity for taking more direct control over their healthcare consumption, and therefore over a major part of their lives. This strategic framework, which Dr. Beato very eloquently summarized earlier this morning, lays out what we believe to be the key elements that are needed to bring healthcare to the point where we not only can take advantage of the great advances we've heard about today but also set a basis for moving forward.

We have the ability to make health information a key aspect of the therapies that happen daily between doctors and patients. Today, there are two elements that I'd like to present to you and challenge you to think about during the discussions.

The first is the concept of telemedicine. We've made great strides in bringing advances that make all of us more capable, as well as making people who live with disabilities more mobile and more independent. Telemedicine has also brought healthcare to peoples' homes and to the workplace.

Many aspects of care delivery today don't require the physical proximity of a doctor and a consumer, but some things clearly do. We will continue to build on the work in the Department of Commerce and the Department of Veterans Affairs today to develop the capacity to make telemedicine the norm in healthcare.

This is not just true of people living with disabilities, who face challenges getting into healthcare facilities. It is true for everyone who consumes healthcare due to many inherent challenges with getting to the point of care.

To advance this goal, we are developing the design for a Health Information Network. You no doubt have heard about this. The network's goal is very simply to be able to move information securely between doctors, hospitals, laboratories, and pharmacies so that when any person moves through the healthcare system, their information will move with them, if they choose.

I encourage you to give us guidance in thinking about what is it that telemedicine should do. What questions should it address? How can it move forward? Because we're poised to be able to do this.

Second, we must address the question of evidence. You've heard some discussion this morning about prevention. One of the great capabilities of technologies that collect information from the home, from the point of care, from the pharmacy, and from the laboratory is the ability to help us understand the root causes of illness or injury, as well as the right medical responses to the condition, how long it takes for certain treatments to be delivered, how much they vary, and whether or not those variations matter.

If we don't design this data collection into the kinds of systems that are being built over the next decade as a result of the President's Executive order, we won't be able to address the questions that will empirically advance the ability to deliver new treatments or new preventative mechanisms to deliver new treatments or new preventative mechanisms. We're doing this with clinical trials today. A tremendous effort is underway in the National Institutes of Health to improve and accelerate clinical trial discoveries so that we can take those findings directly into practice and translate them so that doctors are able to access medical evidence and know what treat-

ments are most relevant to patients they serve. This is something that goes beyond the formal clinical trial. It encourages and builds upon the empirical experience of natural experimentation. To capture these experiences and outcomes over time is incredibly data-intensive.

But we need your guidance today. To realize our vision for a healthcare system that is truly consumer-centric, we need very much to know what you think are the key questions and considerations we should be addressing in this particular area, because it is a still-emerging, cutting-edge field.

Thank you very much for the opportunity to be here. I am very proud to be part of this, but we have a long way to go. I encourage your deliberations today, and I look forward to talking with you more about information technology in healthcare.

Bio:

David J. Brailer, MD, PhD, was appointed the first National Health Information Technology Coordinator by Health and Human Services Secretary Tommy Thompson on May 6, 2004. Dr. Brailer is one of the nation's foremost authorities on clinical data sharing, local health information exchanges, and the use of peer-to-peer technologies in healthcare. Previous to his appointment, he was a Senior Fellow at the Health Technology Center in San Francisco, a nonprofit research and education organization that provides strategic information and resources to healthcare organizations about the future impact of technology in health care delivery. Dr. Brailer recently completed 10 years as Chairman and CEO of CareScience, Inc. (NASDAQ: CARE), a leading provider of care management services and Internet-based solutions that help reduce medical errors and improve physician and hospital-based performance. Dr. Brailer holds doctoral degrees in both medicine and economics.



Panel Introduction

New Freedom Initiative: Technology Meets Reality



Dr. Mindy L. Aisen

Director, Rehabilitation Research and Development Service

This panel is entitled “New Freedom Initiative: Technology Meets Reality.” We have a very interesting group of people speaking to us today. Amazing technologies are available now, and our distinguished speakers can tell us about them.

We will also discuss making the clinical application of those technologies possible for people with disabilities. So, the process has to go from idea to prototype, to testing, then clinical testing, to developing evidence of benefit that justifies expenditures of resources and, simultaneously, to finding a commercial champion to take it over.



LOKO System

On our panel today are:

- Steven J. Tingus, MS, CPhil, who is the Director of the National Institute on Disability and Rehabilitation Research (NIDRR) in the Department of Education.



- Eric Dishman, PhD, from Intel Proactive Health Research.



- Alfred E. Mann, founder of the Alfred Mann Foundation and the CEO of many important companies that make technologies that enhance the lives of many Americans and many veterans.



- Dinah F. B. Cohen, Director of the Department of Defense Computer/Electronic Accommodations Program.



- Eric Levey, MD, from American Academy of Pediatrics



With that, I present you our first speaker, the Honorable Steven J. Tingus.



Panel Discussion

Role of Research and Disability



Steven J. Tingus

Director, National Institute on Disability and Rehabilitation Research (NIDRR), Department of Education (DOE)

Good morning, everybody. I'm so honored to be here to speak before you all on the critical issue of how disability research impacts the New Freedom Initiative (NFI).

I want to first thank the White House Office of Science and Technology Policy and the Department of Veteran Affairs (VA) for spearheading this wonderful conference that brings together Federal leaders and stakeholders to talk about myriad issues related to the goals of the NFI.

My speech addresses some of the accomplishments that the U.S. Department of Education (Department), through the National Institute on Disability and Rehabilitation Research (NIDRR), has made in regard to the NFI.

The President unveiled his New Freedom Initiative in February 2001. President Bush, who is both personally and professionally committed to all people with disabilities, whether young or old, developed the NFI to set the blueprint for his disability agenda.

Basically, the goals that we have in the administration—shared by Dr. Margaret Giannini, Dr. Michael

Weinrich, Dr. Mindy Aisen, and others—is to promote improved functionality and independence for all people with disabilities.

Roughly 54 million Americans are disabled. We at the Department of Education are just part of the team helping to further the goals of the President's NFI.

Four tenets comprise the NFI. First, we seek to increase access through technology. In this room, we have leaders from the Department of Commerce—David Brantley, Ben Wu, and others—all of whom are working with the Department of Education to further our opportunities for technology transfer.

Second, we want to improve educational opportunities for students and adults with disabilities.

Third, we need to expand employment opportunities for people with disabilities. We must increase the percentage of people with disabilities integrated into the workforce, whether it is through telework or through the traditional workplace.

Fourth, we seek to boost community participation and promote independent living options for all people with disabilities.

I am very interested in the NFI both as a consumer and as a former researcher on the development and promotion of assistive technologies for all people. I'm particularly interested in children and seniors. As a person who is vent-dependent at night and wheelchair-enabled during the day, I have a firm understanding of and devotion to helping improve the lives of my peers with

disabilities. I would like to give you some highlights of what we at the Department have achieved regarding these tenets.

Under the first tenet, increasing access through technology, we'll stick to some of our recent accomplishments.

In fiscal year 2002, the Department, through the President's budget, dedicated \$37 million to the alternative financing program, which is part of both Title III of the Assistive Technology (AT) Act of 1998 and the AT Act of 2004. This enables individuals to acquire low-interest loans to purchase AT for their daily needs.

The Department allotted \$20 million in 2002, \$19 million in 2003, and \$20 million, I'm proud to say, in 2004 to fund NIDRR's Rehabilitation Engineering Research Centers (RERCs) to promote research on assistive and universally designed technologies.

In fiscal years 2002, 2003, and 2004, we received \$5 million for the assistive technology development fund, otherwise known as the Small Business Innovation Research (SBIR) program, to assist small businesses in the development and transfer of new technologies.

Three million dollars was allocated in 2002, 2003, and 2004, as part of the President's NFI, for the Interagency Committee on Disability Research (ICDR) to improve coordination and collaboration

among other Federal research agencies and departments, such as the National Center on Medical Rehabilitation Research (NCMRR) and the VA's Rehabilitation Research Development Office (RRDO) and also to advance coordination of initiatives on assistive technology. We also work with the Office on Disability at the U.S. Department of Health and Human Services (HHS) under Peg Giannini's leadership.

In addition, this year we have developed a new Subcommittee on the New Freedom Initiative and a Subcommittee on Employment.

The ICDR, as I said, collaborates with members, such as the U.S. Department of Commerce (DOC), on research for improving technology transfer opportunities. NIDRR is one of the leading Federal agencies to support research and development (R&D) and increase access to information technologies and services for people with disabilities.

Examples of new 2004 awards to RERCs include Telecommunications Access at the Trace Center at the University of Wisconsin, one of NIDRR's premier centers, which advances the accessibility and usability of emerging telecommunications products.

Second, I'd like to mention the RERC award for telerehabilitation at the University of Pittsburgh, which develops systems and technologies that support remote delivery of rehab and home

health services. Telerehabilitation is especially important for service men and women who have been injured in the line of duty.

Other examples of NIDRR projects include the first center on cognitive technologies for people with Intellectual Disabilities (ID) and Developmental Disabilities (DD) at the University of Colorado System's Coleman Institute. The center will focus on developing technologies and approaches that will have a positive impact on the function of people with ID and DD in community living and the workplace.

Another project we have is Cyber Coach, an automated system to help integrate individuals with memory disabilities into the working world or independent living settings, which is funded under an SBIR grant at the Applied Human Factors Center in Helotes, Texas.

The next step for improving access to technology is in the President's FY 2005 budget, where \$20 million is proposed for RERCs, \$15 million for the AT alternative financing program, \$5 million for the AT development fund or SBIR program, and \$3 million to continue our efforts through the ICDR.

We at NIDRR place a particular emphasis on Tenet 3, which centers on integrating Americans with disabilities into the workforce. The NFI strives to bring more people with disabilities

into the workplace, expand telework—which is spearheaded by the Rehabilitation Services Administration (RSA)—implement the Ticket to Work and Work Incentives Improvement Act (TWWIA), and enforce the Americans with Disabilities Act (ADA). The NFI also seeks to promote the use of tax incentives, which I put into action since being at NIDRR, to enhance the workforce investment system, remove disincentives to work, and promote best practices in Federal Government as a model employer.

One NIDRR-funded project is Cyber Coach, an automated system to help integrate individuals with memory disabilities into the working world or an independent living setting.

Already, many accomplishments have been made. First, under the President's Access to Telework Fund and the Department of Education's RSA, we have funded 20 projects to allow individuals with disabilities to work from home or other remote sites away from the office. This is particularly important for those of us who have recurring conditions.

Second, the Department of Labor (DOL), HHS, and the VA are conducting a two-year study to evaluate how various home-based telecommuting arrangements boost employment for people with disabilities. A final report will be due to Congress in 2004.

In 2001, the Social Security Administration (SSA) and DOL established the Ticket to Hire, a free national employer referral services to help those in the Ticket to Work program find work.

Other NIDRR accomplishments support research by expanding employment opportunities for youths and adults with disabilities. Some recent awards that the Department has made include the Rehabilitation Research and Training Center (RRTC) for workplace supports and job retention

at Virginia Commonwealth University, the RRTC for improving employment services and outcomes at Hunter College of CUNY, the RRTC for employment policy and economic self-sufficiency at Cornell, and finally, the RRTC for substance abuse and disability employment at Wright State University.

Currently, a memorandum of understanding has been formalized between DOL's Office of Disability Employment Policy and the Department of Education's Office of Special Education and Rehabilitative Services (OSERS) to develop an interagency research partnership across the spectrum of disability employment research, with the goal of increasing employment opportunities for adults and youth with disabilities.

We're going to be looking specifically at current barriers, the demand side of employment, and how to make the case for businesses to hire people with disabilities. I believe that's an area where we need to focus our attention.

Tenet 4, promoting full access to community life, will realize the Olmstead Decision (the 1999 Supreme Court decision that interpreted Title II of the ADA and its implementing regulation, requiring States to administer their services, programs, and activities "in the most integrated setting appropriate to the needs to qualified individuals with disabilities.") and the President's Executive order in 2001 to improve community integration for people with disabilities, not only by changing existing practices but also by providing affordable housing, transportation, and access to programs and services throughout the country so that people with all types of disabilities are able to participate in life to the fullest extent.

NIDRR'S accomplishments in regard to children and adults with disabilities include an RRTC awarded in 2004 for integrated systems of care for child and adolescent mental healthcare at the University of South Florida. Another RRTC was granted for strengthening family and youth participation

in child and adolescent mental health services at Portland State University. An RRTC was granted to Boston University for recovery and recovery-oriented psychiatric rehab for people with long-term mental illness.

I am firmly committed to working with SAMHSA (the Substance Abuse and Mental Health Services Administration) in incorporating the recommendations of the President's Commission Report on Mental Health into NIDRR's new long-range plan.

I intend to do more in this area. With the support of the Department, we'll look at new areas for improving self-determination and recovery options for people with mental health care needs. Other examples of R&D centers include the RERC for wheelchair transportation safety at University of Pittsburgh, the RERC for ac-

cessible public transportation at Oregon State, the RERC for recreation technologies and exercise at the University of Illinois Chicago, and the RRTC for personal assistant services for individuals with disabilities at the University of California San Francisco.

The direction of NIDRR in regard to community integration is clear. I believe that it's important not only to focus on employment, but how to get to the job, and also to promote optimum health for people with disabilities.

Unfortunately, so many of us in the disabled community—like the late Christopher Reeve—can be quickly overcome by just a minor infection that turns systemic. We at NIDRR, and other agencies, must do more and will do more to improve health awareness, nutrition, exercise, and well-being for people with disabilities.

With that, I just want to say thank you again for the opportunity to address you. At the end of the forum, I welcome your questions. Thank you.

Bio:

Steven J. Tingus, MS, CPhil, has led the National Institute on Disability and Rehabilitation Research (NIDRR) since 2001. Tingus also chairs the Interagency Committee on Disability Research, the Federal committee that coordinates disability and rehabilitative research across Government agencies. Prior to joining the Education Department, Tingus was Director of Resource Development and Public Policy at the California Foundation for Independent Living Centers and the Foundation's nonprofit project, the Assistive Technology Network. He earned his MS degree and PhD candidate degree in physiology from the University of California, Davis, where he studied muscular dystrophy and the effect of anabolic steroids on skeletal muscle regeneration.



Panel Discussion

Technology Enabling Independent Living



Eric Dishman

Intel Proactive Health Research

Thank you. It's an honor to be here on behalf of both Intel and the Center for Aging Services Technologies, or "CAST" as we call it. I particularly want to thank Dr. Marburger's office. He and his staff have been very helpful with our launch of CAST, a new organization to help accelerate the commercialization of aging-in-place technologies.

My topic today is about using everyday technologies for inventing independence, for giving seniors and their families more choice about where they prefer to age in place, whether at home or across the continuum of care. I am going to focus decidedly on aging here today, with an argument that if we look at aging and what's coming demographically and if we design with the aging challenge in mind, we're going to end up developing home and personal healthcare systems that are good for all disabilities and all citizens.

I'm going to wear several hats today. The first is as a family caregiver. When I was a teenager, my grandmother was in the full throes of Alzheimer's, and I can tell you that not having the time to get your driver's license at the age of 16 because of the impact that Alzheimer's has on you and your family leaves quite an impression. For 20 years now I've been wondering what could be done to help people with Alzheimer's and what could

have assisted the four or five of us who were trying to care for my grandmother. My second hat is as a social scientist who has worked in technology companies for the past 16 years. My very first job out of grad school was for Paul Allen, the cofounder of Microsoft, developing technologies to help build better nursing homes. We led an anthropological study of a nursing home to try to understand the needs of seniors. After we had built all these wearable heart monitors and wireless safety sensors—and that was kind of hard to do back in 1992—we realized we had asked the wrong question. Not "How do we make better nursing homes?" but "How do we move technology into the homes of people so that they can live wherever they choose?" That's a theme I'm going to carry through today as I show you some prototypes from my lab of technologies we're using to help people with Alzheimer's to maintain their independence.

This theme has carried over to my current work at Intel in our Proactive Health Lab, where we're trying to figure out what technologies can help today's and tomorrow's seniors to live better with, or even to prevent, cardiovascular disease, cancer, and cognitive decline. Many people ask, why Intel? We're not a healthcare company in any way. But we see home healthcare as an important market and ecosystem that Intel's chip technologies—in your PCs, PDAs, and cell phones—will increasingly be used for, especially with the aging.

My third hat, as Chair of CAST, is as an evangelist and advocate for aging-in-place and home health-friendly policies. Back in 2002 at Intel, when we'd just started my lab, we instantly received an avalanche of press and attention about

the prototypes we were building for Alzheimer's households. Then I started getting calls from engineers and scientists from big companies like IBM and GE and Honeywell and small research labs, many of the research labs Steve Tingus (director, National Institute on Disability and Rehabilitation Research, Department of Education) and his organization fund, asking, "How did you get Intel to focus on aging? How do we get some of these great technologies that are sitting in our labs out into the hands of seniors and their families?"

Over the last 18 months, what started out as an informal conversation housed at the American Association of Homes and Services for the Aging (AAHSA) has now turned into CAST, a 300 organization-strong advocacy force to try to accelerate R&D to help people age in place. Our debut event last March—thanks to Senator Larry Craig (R-Idaho) and his staff on the Senate Subcommittee on Aging—brought together some of the leading universities and companies working on aging-in-place and assistive technologies. This was followed by Senate testimony and a major presentation to the National Governors Association. The exciting news is, momentum for aging-in-place technologies is growing. Three hundred companies, long-term care providers, and university labs joining forces in 18 months show a real "there" there. Now we need to move this ball forward with a

true nationwide effort to prepare for the age wave. Thus, my presence here with you today.

I'd like to turn for a moment to the logic and motives behind Intel's research and our support of CAST. Realizing full well that even a company our size cannot promote this kind of paradigm shift alone, Intel's goal is to catalyze an ecosystem of evidence-based technology research around home health and wellness solutions. We don't want to just throw these home health systems out there and hope that they work. Unfortunately, the commercial market is more forgiving than the scientific community, so we may end up with a lot of technologies out there that haven't been proven and don't work. That would be a critical mistake.

We want to show outcomes. We want to show that these technologies are feasible and efficacious, that they save money and can lead to a better quality of life. Our own focus is decidedly on the consumer, the home, and the person in their everyday life, not on the clinical and IT enterprise. Our research is much more about "daughters" than "doctors," although getting the two to work together in harmony is the only real solution to our age-wave crisis.

The current U.S. healthcare system, already pushing the economic limits at \$1.6 trillion annually, is not prepared to deal with what I call a disruptive demog-

raphy. This worldwide age wave is coming soon to a reality near you. Today, we have 600 million people who are over the age of 60 in the world—35 million in the United States, 90 million in India, and 140 million in China, where the one-child policy is wreaking havoc because there are not enough caregivers to help take care of their aging population.

We're not alone in this in the United States when we talk about baby boomers. It's a worldwide phenomenon, even though they don't use that term across the oceans. We are all going to witness a disability epidemic that comes strictly from aging. In 2050, many countries in the world will have 25 to 30 percent of its population over the age of 60, including the U.S., with household disability becoming an everyday experience for most citizens.

This is an important Department of Commerce issue. American-based companies are woefully behind in the development of assistive and everyday technologies for home healthcare and aging-in-place. The aging population is already larger in some parts of the world. Western Europe and Japan's over-60 populations are already at 20 to 25 percent, while the rest of the world averages between 9 and 19 percent.

Also, the liability climate has been greatly reduced in Western Europe and Japan, so that they

don't have to fear, as many of the American-based companies do, investing in technology R&D in the aging arena. Many foreign countries also have a wireless build-out to the home—thus, a national, government-subsidized commitment to give every citizen broadband access, not driven by getting your Hollywood movies to your set-top box, but being driven by the practical economic realities that these governments are going to have to deliver new healthcare services and technologies to the home.

We need to move the locus of innovation, IT, and healthcare technology from the mainframe to the home—from mainframe healthcare to personal healthcare. Just think about the mainframe personal computer decades ago, and now we all have personal computing on our desktop or even in our pocket or purse.

Well, that's what we have today for healthcare, a mainframe system that is far away from our everyday experience except when we get sick. Today we have to make a pilgrimage to the hospital or to the doctor to use enormous, expensive machines.

Fifty-four million adults are caregivers today. Over the next decade, one in two adults in the United States workforce will be caring for an aging parent.

We need to put personal technologies into the hands of seniors themselves, making them more proactive on a daily basis about their health and wellness before they ever have a problem. We need to give technologies to the boomers who are going to be doing all that caregiving. Fifty-four million adults are caregivers today. Over the next decade, one in two adults in the United States workforce will be caring for an aging parent.

Caregiving is going to be our next full-time jobs. We've got to leverage this family and friend workforce because we're not going to have enough

professional caregivers. Even if we increase the output of nursing programs and physician programs by a factor of 10, we would not have enough formal staff to take care of this age wave that's coming. We need to address the issue of telemedicine. How do we connect this data back to the healthcare mainframe and invent new paradigms of remote care, without having to force those with disabilities to travel? David Brailer (Coordinator, National Health Information Technology Project) made a subtle point earlier that I think is very important: The electronic health records we're putting in place—and I'm thrilled that the Government is standing up to push standards and to help make this happen—are a twenty-first century pipeline that's only going to be effective if we develop twenty-first century healthcare.

Today, we have 600 million people who are over the age of 60 in the world—35 million in the United States, 90 million in India, 140 million in China.

If we somehow managed 100 percent adoption of electronic health records and wrung all of the efficiencies out of them that are possible, most estimates say that we would get about an 8 to 10 percent cost savings. That's not going to take care of the doubling of the most expensive population to care for in the world. So, the electronic health record is a crucial piece of infrastructure to build, but it is not enough to stop there. We have to think about how technologies—many of them in our homes, in our cars, even on our body—are going to enable earlier detection of problems and diseases before they become expensive and emotionally draining on people.

We need to figure out how to promote healthy, daily, preventive behaviors. We've known for decades that smoking cessation, a bit of exercise, and eating better are going to save potentially hundreds of billions of dollars. The hard problem is: How do we change peoples' behaviors? That's

a huge challenge—the kind of going-to-the-moon challenge in which our nation must engage.

How do we support both family and friend caregivers? That's going to be the only way of getting out of this demographic mess. Telemedicine is a great starting place. However, most telemedicine that's being designed today keeps the doctor and the nurse in the loop on every single encounter. Again, this doesn't solve the scaling problem with the age wave that's coming through.

We've got to leverage the technologies that are already appearing into peoples' everyday lives, the HDTVs, the DVD players, the cameras, the cell phones, the PDAs. Those technologies form the infrastructure by which we need to do next generation healthcare. We don't have to build this whole home health infrastructure from scratch. We need to put new capabilities into these devices that many people are already carrying around with them—and will be increasingly buying and using. That is going to help change the game in healthcare—being able to rely on everyday consumer electronics to help with safety monitoring, disease detection, medication reminding, and wellness coaching.

A recent vision video we put together at Intel details how technologies that are in people's everyday lives can lead to freedom and independence for seniors

and people of all ages with disabilities. All the pieces in the video are actually things we are researching in our lab today.

In fact, we just finished a small study of the devices seen in the vision video. The sensors in the cane ended up being hugely beneficial, because a lot of the people who we're studying with cognitive decline forget to pick up their cane or use their walker when they get out of bed. They wake up thinking they're still 40 years old and forget they even need a cane. We can do some fairly elegant, simple things technologically that just say, "Hey, don't forget to use your cane" and try to prevent falls before they ever happen.

A lot of this is low-hanging fruit. Much of this technology has been around for 15 or 20 years. My industry and the consumer electronics industry don't pay attention to this, for whatever reasons. Part of what we have to do is educate researchers about existing opportunities to move products into the aging arena. We have to show that there is more to life than the youth market and digital entertainment.

I want to just close by giving you a quick overview of some of the evidence-based technology research we're doing on cognitive decline.

We spent a year studying 100 households in four states across the United States with a wide range of cognitive decline, from full-blown Alzheimer's to vascu-

lar-based dementias, Lewy body dementia, and stroke recovery, so that our engineers who are, by and large, not yet facing disabilities in their life, can realize there's a lot of people out there who need help getting dressed by themselves. Many people out there can't remember the meds that they need to take, or even how to go about making a cup of coffee.

I'm going to just give you one extended example from our study. Barbara is 59. She is diagnosed with unspecified dementia. We'll come back to that because the differentiation of dementias and different kinds of cognitive decline is enormously difficult today. I was thrilled, by the way, to hear that Steven Tingus had funded some of the work on cognitive technologies at UC Boulder. I think that's going to be an important step to help differentiate some of these forms of cognitive decline that plagues millions of U.S. families.

Barbara was diagnosed after years of "weirdness," as her family put it, which was similar with my grandmother. We used to say about my own grandmother's "confusion" that her blood pressure medication was just acting up. But it was probably 10 years—way too late—before we ever sort of admitted to ourselves or noticed that she was having signs of dementia.

Barbara's husband, Jim, had to retire early from engineering to

be a full-time caregiver. This upper middle-class family is quickly facing poverty because of the disease. Jim and Barbara are “spending down” their life savings frighteningly fast. The family is trying to keep her at home, but the daily challenges are stacking up.

Jim is so afraid of Barbara falling that he doesn’t even let her go out and walk, which means now she’s not getting enough exercise, which in itself is complicating for the disease. Intel is putting wireless sensors into the ends of canes to try to figure out not only whether the person is about to fall but whether there are patterns in the changes of motion that you can collect. Can wireless sensors, over time, help us detect when this person is moving into a time period where they’re more likely to fall? Can we intercede, in the case of someone like Barbara so that she is still free to take neighborhood walks?

I should point out that these systems need to deliver just the right amount of assistance. Everyone that we studied was highly variable in their cognitive decline. On Tuesday, for example, one female participant was so far gone she didn’t know me from her husband. One Wednesday, she seemed totally fine, but by Thursday, she was having trouble dressing herself. The fact that we’re sending people once every 12 months for doctor visits that last only 15 minutes—15 minutes to diagnose the progress of their disease!—is pretty scary when you realize just how variable the health of these seniors can be.

Intel is funding research at the Oregon Health and Science University to analyze the keystrokes of folks with cognitive decline who are still using a PC to see if we can look at changes in how they’re interacting with their PC keyboard on an everyday, natural basis as a potential indicator of the onset or the continuation of the disease.

Similar studies are being conducted with remote controls and even video games. A lot of the seniors in our studies actually do use a PC and they

play Freecell or Solitaire. We’re actually looking at how they play the video game and the number of lost moves over time to see if that’s a better cognitive test than a once-a-year, 15-minute encounter at the doctor’s office.

Another thing we’re doing is really trying to figure out is how to remind people like Barbara how to do ordinary tasks. We didn’t know Barbara had any problems at all until she went to make coffee for us. An hour and a half later, she had not come out of the kitchen and was still standing there transfixed because she couldn’t determine the steps and sequences to making coffee.

We’re using simple sensors, cheap Radio Frequency Identification Device (RFID) tags that are on the shelves at Wal-Mart and elsewhere, to try to develop a system that can say, “First of all, you’re becoming dehydrated. It’s 3:00 in the afternoon and you haven’t had anything to drink.” With many of the patients who we studied, their physicians thought that their Alzheimer’s was progressing, but it was often dehydration causing their memory loss.



Radio Frequency Identification Device

Longer term, can technology help us intervene at the point at which someone is having trouble with an everyday task? In the case of someone like Barbara, it’s a TV system that says, “I think you’re having trouble making coffee. Would you like some help?” And it tries to guide the person through that task step by step. Assistive

technologies like these require much hard computer science and artificial intelligence (AI) research. Why haven't those AI researchers being funded by the National Science Foundation (NSF) applied their intelligence to a domain like this? Their discoveries may lead to better science for their own field and may lead to real products that could help all of us.

For Barbara and so many of the people with early stage cognitive decline, name recognition was the first thing to go. They were terrified to answer the front door or the phone, not because they can't function any longer, but because it's embarrassing not to know who is on the other end.

At my lab at Intel, we're collecting sensor data about how much time they're spending with other people and how much time they're using the phone. We've developed basically a "caller ID on steroids" system that shows on the screen who is calling, as well as a social network map of other people they know in common, because a lot of times they still don't remember the name or face when they see a photo. Most importantly, the system prompts them to let them know the last time that they spoke to these people and what topic they talked about.

Some of our study participants would call their adult child at work 8:00, 9:00, 10:00, 11:00, 12:00, 1:00, not remembering they'd already called. This system, when you dial out, says, "Do you realize you've called your adult child at work today five times? Here's what you talked about."

By the same token, many of the families that we observed each thought the other brothers and sisters were calling in to check on Mom, when actually the phone hadn't rung in a week. In this case, we're just using simple technologies to say to boomers, "Here's a way to visualize your Mom's social network. You can see who's been interacting with Mom and Dad. You can know whether or not the phone's been off the hook." The goal is to increase the social health between the households.

These ideas—the early research prototypes I've shown you today—may not be the right answers to our age-wave crisis or for Alzheimer's. They are simply possibilities. Intel's goal with CAST is to assert that even if we don't have the right answers here, at least we should be asking the right questions and exploring possibilities. We should be asking "How can we promote freedom and improve the quality of life for seniors and their caregivers while

somehow reducing healthcare costs?" How can home health and aging-in-place technologies deliver upon the promises of preventive care, early detection, improved compliance, and remote caregiving? How will our nation prepare for the epidemic of disability that will accompany the coming age wave?

I hope the rest of you will work with us to get the right answers to these challenging questions. Thanks.

Bio:

Eric Dishman, received three BA degrees from the University of North Carolina at Chapel Hill in speech communication, english (with Honors), and drama. He went on to earn an MS in speech communication from Southern Illinois University and is a PhD candidate in communication from the University of Utah. Dishman joined Intel in 1999 as a senior social scientist with the People and Practices Research group in Oregon. He is currently the Director of Intel's Proactive Health lab and National Chair of the Center for Aging Services Technologies (CAST). Before joining Intel and CAST, Dishman was one of the founding members of the social science research team at Paul Allen's lab, Interval Research.



Alfred Mann (left) & Eric Dishman (right)

AMF* Panel Discussion

Technology Transfer: Industry's Role in Getting Life Changing Inventions to the People Who Need Them



Alfred E. Mann

President, Alfred E. Mann Foundation

I'm honored to have this opportunity to speak to you, because some of the subjects that we were asked to cover are critical to our country's future and pertain to the issue of bringing assistive technologies to the marketplace where they can help people.

The subject I've been asked to talk about is technology transfer, particularly how we can facilitate the translation of these technologies to industry. We also need to figure out the role of industry in getting life-changing inventions to the people who need them. I am going to talk about this very important subject in a way that, hopefully, won't disappoint some of you, because some of my ideas may be rather controversial.

First, let's consider the processes that exist today. Substantial government support is provided to academia for research, and the quality of science created at our elite research universities is extraordinary.

However, not many of these discoveries end up in products. Why this failure? Scientific discoveries create knowledge, not products. Often, the researchers try to speculate how their science can lead to products. They and the technology transfer offices of the universities then try to find partners.

All too often, the professors themselves try to get involved and maybe for the wrong reasons. In my opinion, the process prostitutes the role of the university, degrades the potential of the technology, and rarely leads to success.

I believe the process is all wrong, and the results essentially attest to this stance. Although occasional exceptions exist, the professors usually fail to gain their objective and the university often gets very little from the investment.

Indeed, even in the few successes, most of the value goes to others. What's wrong with this scenario? Most importantly, rarely does the academic have any idea what it takes to get a product to market.

I've been asked on numerous occasions to speak on the subject of entrepreneurship. In those talks, I generally list what I consider the 10 most important factors leading to a product's business success. In my list, capital is at the top, at number one, and the product is at the bottom, at number 10.

On occasion, I further consider the factors needed to create a promising product. Here again, the basic idea, the intellectual property itself, is number 10, at the bottom of the list. The entire concept of technology transfer today, in my view, is misguided.

How can we fix this? A number of approaches might improve the odds. Essentially, all of these approaches incubate the idea using an industrial team—not an academic team, but an industrial team—to advance the development to a later stage when far greater value can be realized.

My own approach is derived from what I have observed. The financial markets today have such a short focus that thriving public companies can't really support basic development that won't yield marketable products in a short time, at least in most industries.

Of course, infrequent exceptions do exist, like our colleague over here from Intel, because sometimes you might find a company like Intel developing a new microchip that might take a significant amount of time.

With Wall Street's demands for increasing profits every quarter, what is a public company to do? This is especially a challenge for the larger companies. How does a company with annual revenues of \$20 billion increase its revenues and profits by 10 percent or so a year, enough to satisfy the financial world?

The answer, of course, is through acquisitions. Yet these companies are reluctant to acquire early stage ventures with only basic intellectual property. They view the risks as too great, and they worry that the opportunity will get lost in their bureaucracy.

They prefer acquiring new products by buying the companies later in the process, usually after most of the technical risks are resolved. They understand and are willing to accept market risks, but they shy away from the risk in the product itself. They would

rather pay a higher price when there is greater certainty of success.

The approach so often employed today is for some new technology to get developed into a product within a startup company. Once the development risk is largely eliminated, the venture is acquired. When this scenario works, everyone usually wins. Often, it fails in an early stage because the initial principals don't adequately understand the opportunity and its limitations.

Too often, the inventors are principals in the venture, and they are imbued with the not-invented-here syndrome. Too often, they fail to see the limitations of their inventions.

The angels, or venture capitalists that fund the efforts, probably don't really understand the market or the technology. The outside management team that is hired simply wants success at any cost, no matter what. As a result, most of these ventures fail, and so the process becomes very expensive.

A number of approaches are being explored that intend to yield a better likelihood of success. One especially pertinent to companies based on technology is to create incubators to carry on the initial development efforts, at least until technical feasibility is established.

By sharing community resources, such as laboratories, expensive

equipment, and support infrastructure, the costs are reduced. Yet the basic challenge of prudent product selection is often still not answered, so even these incubator projects often fail.

I've seen one incubator spin off 30 companies over a few years, 25 of which have already failed. If appropriate diligence is utilized in selecting the projects and if adequate resources are applied to both people and capital, a promising plan should evolve.

Years ago, I myself adopted a somewhat different approach. I've been very fortunate. I've started a number of companies, and the first seven companies that I've founded and led have all been successful. I have amassed a significant fortune, and I am trying to give back to society and to my country.

I aim to do this by creating industrial product development organizations on the campuses of elite research universities. I plan to endow a total of at least 12 of these Alfred Mann Institutes over the next few years, devoted entirely to life sciences. Each will be initially endowed with \$100 million, but this amount may increase significantly if the institute is well received and is promising.

The institute director and its board of directors will establish the specific areas of interest for each institute. The institute will employ a staff of product development engineers and scientists

recruited from industry with relevant experience, and will establish adequate support infrastructure to move the appropriate intellectual property from the university to a late stage of development.

One AMF project is Second Sight, which has developed a visual prosthesis already implanted in six human patients. The prosthesis provides usable sight to people with retinitis pigmentosa and macular degeneration.

Medical devices developed within the institutes are to be pursued at least through product qualification and often through clinical trials. Pharmaceuticals are generally to be carried at least through Phase II clinical trials. Only then will these later-stage development projects be licensed out to existing or startup ventures. By this time, substantial value will already have been created.

The financial returns to the institute are divided among the parties. The inventor receives a moderate portion of the income and/or the equity, and the institute and the university are rewarded with much larger shares. To be sure, these institutes will probably also pursue projects that are doomed to failure. So, the selection process is critical. Before adopting the institute model, I created the freestanding Alfred Mann Foundation (AMF). I've seen great success from this organization, which now employs 103 engineers and scientists.

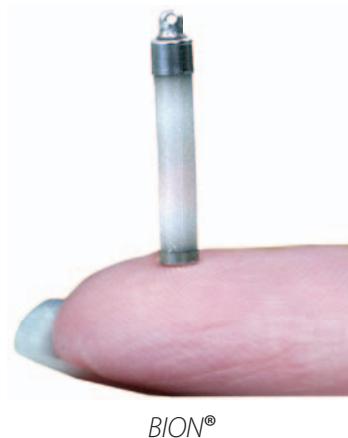
At AMF, the projects are usually initiated using self-invented intellectual property. I'm not going to go into too much detail, but I'd like to give you just a little flavor of the potential programs and the achievements at AMF.

One project was development of an advanced cochlear implant system that does not just provide cues to enable communication, but truly restores quality hearing to severely and profoundly deaf

people. Today, we are even seeing these people enjoy music, with the ability to recognize hundreds of percepts—in one patient, 1,200 percepts. This had never been done before. This product is now licensed to a subsidiary of Boston Scientific and enjoys sales of close to \$100 million, growing at more than 30 percent per year—almost 60 percent projected for next year. Another product is a long-lived implantable glucose sensor, which is being combined with an insulin pump at Medtronic to create an artificial pancreas.

AMF also developed this tiny, single-channel neurostimulator called the "Bion." This is a fully powered system, even with bidirectional telemetry. It's in clinical trials now and is designed to eliminate migraine headaches, urinary incontinence, sleep apnea, erectile dysfunction, and soon many more applications.

The Bion system is being further developed so that these tiny devices will be able to communicate with each other and with a sensor and a control unit. These versions will be used to restore function to arms and legs that are paralyzed by stroke, spinal cord injury or others diseases. These systems will operate without the wires that have limited the success of systems in the past. And AMF has done so much more. Some of its contributions are in technical support of other companies. For example, AMF has helped Second Sight in developing a visual prosthesis. You're going to hear a little bit more about it in one of these other programs this afternoon from Dr. Rizzo from the Retinal Implant Project at the Boston VA Medical Center, and you heard this morning from Secretary Principi about the interest of the Government in this kind of a program. Work in visual prostheses is also going on at the



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Naval Research Laboratory. This is a very exciting future program. Second Sight has been developing the visual prosthesis and has already implanted its first generation in six human patients. The results have truly exceeded our expectations, so much so that Second Sight will actually commercialize its second generation system, which is expected to begin clinical trials in mid-2005. So, in just a few months, we're going to be seeing patients with visual systems we think will restore a reasonable function of sight.

We've learned a great deal from these early implants, and we believe this system will provide quite usable sight, first to people blinded by retinitis pigmentosa, and perhaps later for those impaired by macular degeneration.

There's so much more. Indeed, AMF has already created a number of major products. As the result, AMF has already earned royalties and license agreements that will turn over \$200 million to its endowment.

The institute model is being fashioned to build on the success at AMF. The first of these institutes was established at the University of Southern California (USC). It's currently pursuing eight medical device projects that appear to be very promising. Because of the early success at AMI/USC, I've already increased its endowment to \$162 million, and I may increase it still more. The association has been

very successful also for USC in a number of ways because, for example, it has helped in recruiting prestigious faculty and promising students. It's also played a significant role in attracting three major Government-sponsored centers of excellence in the last couple of years.

My current challenge is to determine which additional universities ought to receive AMIs. I've already selected Johns Hopkins, and I have a list of 18 other prime prospects in the United States.

Because of limitations on my time, I'm forming a small search committee that will evaluate the potential partners and bring to me a selection of about 15 potentially suitable universities. With this search committee, I will make final selections and move to establish affiliation agreements, probably for a total of about 12 institutes.

I can't really say that all these AMIs will meet the challenge of getting life-changing inventions to people who need them. But it is one approach that I believe could be significant, one that could make a difference.

This may be one way that I believe we can help improve the transfer process. It's my hope and my way of repaying to my country and society for what they've given to me.

We need to be very constructive. We've got to start with a clean

sheet of paper because what's happened so far has had very limited success. We need to find ways of translating the intellectual property to the clinic and to the commercial markets.

I am trying to do it in one way, and I'm sure there are other people out there trying to find other solutions to the problem. If we all are lucky and work hard, we'll make a difference.

I'd like to take a couple of moments to talk about some other impediments to the goal of getting valuable products to market. First, our Government expends considerable money supporting research at our academic institutions. These investments are generally quite important, and they sponsor really vital research.

Yet there seems to be a reluctance within the Government to support such developments in young companies. There are a few programs that are available to companies, and they are important but with relatively small funding. With the added obstacle of financing that has been affected because of the business scandals of these last few years, it's very, very difficult for young companies to raise money. Venture capitalists today seem to prefer more advanced programs, and so the young companies really need help. We need to find ways of doing this. A few arrangements are available where the government can provide limited support, but it's only modest. We

need a lot more if we are to efficiently bring some of the life-saving or life-improving products to those people who can benefit from them.

Another problem we have is our regulatory process, which must be redefined to better identify the risk/benefit ratios. Some progress has been made in the past couple of years, but not nearly enough. I realize that it's difficult for a Government employee to assume even minimal risk. He or she does not think as an entrepreneur. Much more could be done to make the process quicker, more effective, and far less costly. As one example, how can we justify denying experimental therapies to hopelessly terminal patients? Yes, there's been an attempt to find a way, but it truly doesn't work.

We apparently need legislation to give complete freedom to a patient judged by maybe two or three physicians to be terminal. Such a patient should be entitled to choose any therapy he or she wants without any impact on a company that supplies experimental products. If the patient is terminal and sent home to die, why should he or she be restricted? Even if the therapy is potentially ineffective or even unsafe; after all, dying is not safe. Is the person really worse off trying alternative treatments? Even an unsafe therapy may be palliative.

Other improvements to the regulatory process need to be implemented to accelerate availability of promising new therapies. One possibility might be to carry out some of the efficacy trials as part of a limited marketing program, with postmarket surveillance. Another need, I might say, is to increase the salaries of FDA staff and all Government, for that matter, to competitive levels so that our Government will be able to hire adequate staff. Of course, this is difficult, especially in these days of huge budget deficits. Yet we've got to find a way of getting the right kind of people into Government because that's what we need if we're going to make this process effective. Thank you.

Bio:

Alfred E. Mann is the Chairman of the Board of Trustees of the Alfred Mann Foundation, founded in 1985, and the Alfred Mann Institute for Biomedical Engineering at the University of Southern California. The Foundation and the Institute are nonprofit research organizations devoted to development of advanced medical products in a variety of fields. Mr. Mann is Chairman of Advanced Bionics® Corporation; Second Sight, LLC; MannKind Corporation, Quallion, LLC; and Chairman Emeritus of Pacesetter® System, Inc., and MiniMed Inc., all companies founded by Mr. Mann. Mr. Mann formally retired as CEO of Pacesetter in 1992 but continued to serve as Chairman Emeritus. Pacesetter System, Inc., now a St. Jude Medical company, develops, manufactures, and distributes cardiac pacemakers and implantable defibrillators worldwide. Mr. Mann had also founded a business in microinfusion pumps and glucose sensors used for delivering controlled profiles of insulin to treat diabetes. Prior to his involvement in the medical device industry, Mr. Mann had also been founder and was President of Spectrolab of Sylmar, California. Before founding Spectrolab, Mr. Mann was a group supervisor at Technicolor Corporation, where he directed research and development in the fields of instrumentation, radiation damage, optical physics, multilayer thin-film vacuum deposition, and digital and analog computer analysis. In addition to his business activities, Mr. Mann has contributed significantly to numerous technical advances in medical devices, photovoltaic power conversion, illumination, radiometry, vacuum physics, thin-film optics, and advanced methods of mathematical analysis. He holds numerous patents, with a number pending, and has authored a number of scientific papers. He is a graduate of the University of California at Los Angeles with extensive graduate work in nuclear and mathematical physics. Under Textron's sponsorship, Mr. Mann also attended an Advanced Management Program at the Harvard Business School.



Panel Discussion

Technology Enabling Employment



Dinah F. B. Cohen

Director, Computer/Electronic Accommodations Program, Department of Defense (DoD)

It's a real pleasure to be here with all of you today and talking specifically on assistive technology and its impact on employment.

As I walked here this morning, I was listening to everyone talk to each other and greet each other. The first thing people usually say to each other is, "What do you do?"

Most of the time when we talk about what we do, we're talking about our careers. How are you employed? What is your job? My field is the impact of assistive technology on employment.

Let me give you a quick background about the Department of Defense's (DoD's) Computer/Electronic Accommodations Program (CAP), of which I am the director. We were established in 1990 as a centrally funded program for the DoD to ensure that its employees have the assistive technology

they need to do their jobs. Based on the findings of a Presidential task force, implemented in the National Defense Authorization Act of 2001, CAP became the Government's centrally funded program to provide assistive technology for Federal employees.

We currently have all of DoD taken care of, and we have partnerships with 61 Federal agencies. I'm happy to say that some of our partners include the Department of Veterans Affairs (VA), the Department of Commerce, the Department of Health and Human Services (HHS), and the Executive Office of the President.

Within all of those agencies, if they have an employee with a disability, all they need to do is let me know. I buy and pay for the assistive technology, and then get it to the user.

We have a very simple mission. We provide the assistive technology and accommodations to ensure that people with disabilities have equal access to the information environment and to employment opportunities in DoD and throughout the Federal Government. We want to level the playing field for people with disabilities. I don't want to hear

that we can't hire people because of the cost of accommodation. The cost of accommodation really is relatively small, but is used often as an excuse not to bring people with disabilities into the workforce.

So, by getting rid of that excuse, getting to the point where managers don't have to worry about the cost of accommodation, where to get the accommodation, or who provides it, we can really have an impact on the employment of people with disabilities.

Since our inception, we have filled more than 40,000 requests for accommodations. Further, being part of the centrally funded program, we have found other ways we can contribute to this discussion. We can see the trends and changes in assistive technology. First, we've noticed that prices have gone down. Second, the quality of assistive technology has gone up.

The challenges we have now relate to aging workforce. I don't particularly care for the concept of the aging workforce, since I just turned 50 years old. I like to think of myself as getting chronologically gifted. Now, as we get "gifted"—right?—some of us

won't hear as well. Some of us won't see as well. We'll start to walk a little slower. We'll have problems with our dexterity.

I am noticing that a lot of the accommodations we're being asked for are not so much for employees' primary disabilities but for their secondary disabilities.

People who came to us for assistance, who may have been blind or had low vision, are now developing dexterity disabilities. People who walked in the door who may have had a hearing loss now may also have a visual impairment.

Our challenge with assistive technology is to see how well these things are working together. If we say we're providing technology for the blind, are we also providing the technology to help those who are losing their hearing? That's where I see the changes when it comes to the population we have served and the population we're going to serve.

Let's talk about what we really are doing today. I like to think of how we can deal with employees throughout their work lives, from the time they walk in the door to the time they retire.

Many different initiatives are out there that I don't think we're taking advantage of. First, we have the President's management agenda, which has required all Federal agencies to have a plan, a human capital scorecard that talks about diversity, reducing the cost of workers' compensation, disabilities, and accountability. We need to put a little more into that as far as what we want to see happen in the Federal Government with that human capital scorecard.

We talked a lot about the New Freedom Initiative this morning and how President Bush came out with the initiative early in his administration, in February 2001. I'm pleased to say that he gave his New Freedom Initiative speech with CAP at the Pentagon on June 19, 2001. What an honor to host the President as he delivered his passionate

speech about his initiatives for Government employees with disabilities. He talked passionately to people in the industry and asked that they make sure that when they design something, they design it for the masses and include people with disabilities.

He talked passionately about Section 508 that was going to go in effect a few days later and said with our incredible electronic information environment, we should make sure everyone can tap into that information well and easily.

We have the Department of Labor and its Office of Disability Employment Policy that's developing employment strategies, making sure that as we start to think about the next challenges—where we're going to hire, where our employment opportunities are—that we include people with disabilities. Are we making sure those buildings are accessible? Are we making sure the information is accessible? Are we talking about opportunities that can really attract all Americans?

The Equal Employment Opportunity Commission (EEOC) is looking at how we're doing when it comes to Federal employment levels for people with disabilities. It's a little sad to report that the numbers are going down.

Why is that? I have a feeling that maybe we're no longer the employer of choice, maybe because we haven't spread the word how important it is to bring that talented disabled person into our workforce.

We need to go back and say, "OK. What are we doing? Are we walking the walk and talking the talk? Are we not including people with disabilities in our own workforce? Let's make sure that's not happening."

We're talking about hiring and recruitment, that entire life cycle. EEOC says you need to have a strong affirmative action program and make sure that it's addressing all those issues.

The Workforce Recruitment Program, which brings college students with disabilities into the workforce, is a good example. This program has so much support. A letter went out from Secretary of Labor Elaine Chao and Secretary of Defense Donald Rumsfeld to all the Federal agencies, that said, "Hey, folks. How are you doing when it comes to recruiting college students with disabilities, since we are the co-sponsors of this program?"

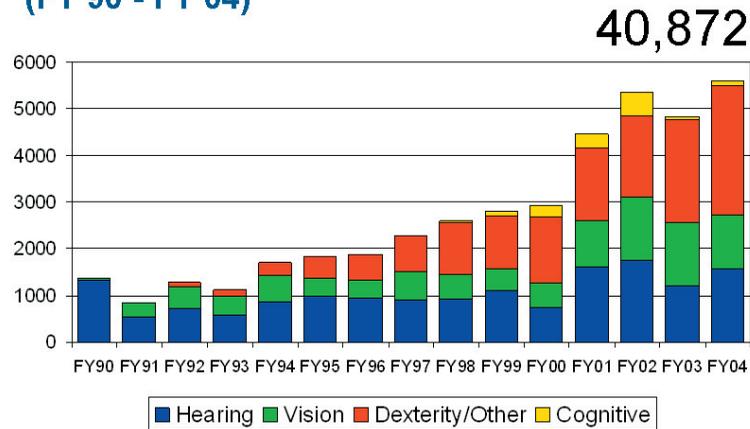
Embarrassingly enough, very few agencies are really participating in this wonderful program, where we go and recruit college students from the best colleges and universities all over the country and determine they are ready to be employed. Why aren't the agencies hiring them?

At DoD, we centrally fund that, so it's not an issue for our DoD agencies to say, not only will they hire people with disabilities, they will make it a priority for their summer employment programs.

I'm a real advocate for this program. I'm one of the original recruiters. A couple of years ago, I had this wonderful summer student working for me. In fact, she worked for me the summer that President Bush came to the CAP office.

I gave her the assignment of getting the briefing ready for the President. Now, some people say, you don't give that kind of assignment to a summer student. But I knew she could do it

CAP Accommodations Profile by Disability (FY 90 - FY 04)



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because she was working on her second master's degree. At the end of the summer we always have a little going-away party. I said to her, "I'm sure the highlight of your summer was meeting President Bush, because you got to shake his hand as he walked off the stage. You had your companion dog with you, and he even petted your dog."

And she turned to me and said, "Well, Dinah, it was a highlight, but the real highlight of my summer wasn't meeting the President. It was meeting you." Now, that is what you call a smart summer student, that kind of talent.

We talk about retention and promotion. I'm not impressed with Federal agencies that hire a lot of people with disabilities, but they stay the same grade for 10 or 15 years. So, what are we doing to make sure our training centers are acces-

sible? How are we providing the assistive technology so that when someone goes to a training center, he can be a true participant in training?

Telework: We already heard from Steve about how important telework is. After all, work is what you do, not where you do it. We need to make sure we have an environment that recognizes that telework is smart.

In the CAP office, we have already filled more than 200 requests in 2004 to accommodate employees who asked to work at home. We're not talking studies. We're not talking theories. We're talking reality. We are providing Federal employees a reasonable accommodation to work at home.

Developing the technology so they can do it is our challenge. We're helping reduce workers'

compensation costs by making sure they have the technology to resume their jobs quickly. We have more than 7,600 injured service members. They address assistive technology a little differently. Their mentality is that of warriors.

I met recently with one of our folks at Walter Reed who's a double upper-extremity amputee. As he was waiting to get fitted for his new prosthetics, his first question was, "Will they be strong enough so I can do my 50 pushups? Because I'm a Marine."

That's the kind of assistive technology we are addressing. It's not the typical soft stuff. We want to know what's really needed. Talk to our service members. Talk about what it's like to be warriors with disabilities because they still see themselves as warriors.

We need to talk about the new technology, that new environment. What is the office environment of the future? How are we going to remain the employers of choice?

We need to partner with the Department of Veteran Affairs Technology Transfer Program. I'm so glad I get the opportunity to work with Steve (Tingus, Director of Disability and Rehabilitation Research at the Department of Education) and with Ben Wu (Assistant Secretary of Commerce for Technology Policy and Administration) and with the VA and all the people who are talking about how we're going to develop the next wave of technology.

Since its inception in 1990, the Computer/Electronic Accommodations Program has filled more than 40,000 requests for assistive technology.

After all, voice recognition was developed by the DoD. We developed it for our pilots. Now it's one of the most commonly used technologies for people with severe dexterity disabilities.

Are we doing well with information sharing? Do we know the requirements of our power users? Are we aware of what's really needed, and are we talking to each other?

When we look at the new office environment where assistive technology should be available for Federal employees, are we developing an enterprise architecture that includes open architecture and the ability to use assistive technology?

I look at the Department of Navy. They have this new concept called seat management, where everyone can go and work anywhere. As long as they have their computer access card and swipe it in, their profile will go straight to that computer.

For people with disabilities, that can be extremely powerful and flexible. The challenge is, as we develop the seat management, do we remember to include the assistive technology that would be involved in a seat management plan?

My concern about the future office is security. Obviously, post-9/11, security is our number one issue. Do we use security as an impediment for assistive technology? We are all so secure and concerned that if we open portals to allow people with disabilities to have some new technology, are we creating a vulnerability?

As we talk about the new wave of assistive technology, let's make sure that we're addressing how it's going to work in today's secure environment.

Integration and interoperability: Do we provide technology for one population and forget that another population could benefit from it? We need to make sure that we cross those different issues, that we're not pigeon-holed, not thinking of technology for just one population, not forgetting that another population may need to benefit from it. One of the humorous ways we've seen technology transfer is when they started to use voice output for people who are blind and low vision. And they were thinking, "This is great

because it reads what's on the computer. You can hear what's on the computer screen."

All of a sudden it got a little modified. It wasn't a male voice. It became a woman's voice. And it ended up in our navigation systems in the fancy cars to help all of you men who refuse to stop and get directions.

You see how technology can be used in many different places in many different ways. We need to think that if we develop something, how can we make sure it's used by all sorts of different people in all sorts of environments?

Individual accommodations: We cannot lose sight of that. Survey your power users. So often we go back to the most unemployed folks because we have such a passion, and we should, to bring the people who are not working into the workforce.

If you need to know what is going to be required from your employees of the future, survey your power user. Survey the folks who are already part of the structure, part of the CAP family, and find out what they need to make sure that as they get more and more "chronologically gifted," they have the technology to continue to work because their employers have already invested so much in them. They are already part of the workforce. We have a couple of valuable resources, and we brought some of our information with us. The first one I want

to share with you is our CAP Technology Evaluation Center (CAPTEC).

I was honored that President Bush chose the CAP program to talk about and present his New Freedom Initiative. He came to our technology center and saw the technology for people who are blind and people with low vision, people who have dexterity disabilities and cognitive disabilities, and people with hearing disabilities.

He saw the technology and he knew that we were on the right track. I invite all of you to come visit our technology center. We have a wonderful Web site, and we have a CD-ROM that won multiple awards, not only because it's accessible, which means it's captioned, but it's also audio-descriptive. For some of our folks who don't like all of that extra stuff, just turn it off.

In conclusion, what do we have in front of us as our tremendous challenges? Making sure that assistive technology is readily available for our employees with disabilities. Making sure that we have the tools so we can do our jobs. I may not need a lot of assistive technology because of my disabling condition, but it doesn't mean I won't need it in the future. This is the one and only population anyone can join at any time. Ask the late Christopher Reeve. Ask Superman. I don't need to preach to the choir. You already know. You need to sell it to the employers out there

because it's not about them. It's about disabled Americans. If you want to have a real organization that has the power to lead, then you need to have the talent of each and every one of us no matter if and when we become disabled.

This month is National Disability Employment Awareness Month. And the theme for this month is, "You're Hired: Success Knows No Limitations." I'd like to change the title to, "You're Hired: The New Apprentice." I think it's because I have that Donald Trump hair thing going here. But I like to think of people with disabilities as the new apprentices that you want to hire.

I want you to think of us as being new hires who are really going to contribute because you know one thing we bring to the boardroom that no one else does as well as we do, is that we're problem-solvers. We have to be. We don't have potentially the ability to maybe do those fast, last-minute changes. We're always thinking, plan A, plan B, plan C. We are problem-solvers, and we've always been problem-solvers.

As you start to think of that new apprentice, maybe some of us will be a little bit younger. Maybe some of us will be a little older. Maybe we're coming out of college. Maybe we're your coworkers who look a little different now because we've become disabled because of an accident, an illness, a diagnosis.



Firefighter (right) with the aid of a C-Leg®

Maybe that new apprentice is that wounded service member, that soldier, that sailor, that airman, that marine. And when you see one of them and you have the assistive technology, then you can yell out loud and strong, “You’re hired.” Thank you very much.

DR. AISEN: Thank you, Dinah. We have time for a few questions. And I ask that you address the panel. Yes?

A PARTICIPANT: A question for Dinah. Do you ever see the CAP program evolving into physical accommodation for the workforce as opposed to information/electronic accommodation?

MS. COHEN: I see CAP always being a source of information and a resource for helping managers recognize what is needed. But it’s very hard to go to a Secretary of Defense and say, “Sir, can you centrally fund the building structure requirements that have been in place and in law for over 40 years that people have ignored?” We need to always make sure that as we build things, we’re building them for people of all generations with all physical abilities and disabilities. But I don’t see

us going to the physical requirements of building structure, since that has been well established in laws for over 40 years and is a design concept that practically every single State has a design requirement for State codes and everything else.

But I can easily see us providing a lot of information and valuable input on some of the design dos and don’ts that can really benefit Federal employees, or any employees. Because I think the CAP model can be used in both the private sector and public sector.

MR. BRIGGS WYATT: Ms. Cohen, I was interested to hear that the number of people with disabilities is going down in the DoD workforce. And what DoD has not done well is hiring disabled veterans. And I’m curious, both in your shop as well as DoD, why? What is the use of the 30 percent hire, 30 percent or more servicemen and your disabled veterans? You’re going to be hired immediately. You don’t have to go through any rigamarole, for one.

Two, DoD is doing a terrible job of buying from service disabled veteran business owners. And I’m curious as to whether CAP is doing something to set leadership by example in the rest of DoD, and if not, why not? And if you need help, of course, we can provide it. My name is Briggs Wyatt, Vietnam veteran.

MS. COHEN: Okay. First and foremost, I think you’re absolutely right. I don’t think of—first of all, the numbers are not going down in DoD. They’re going down throughout the Federal Government. DoD is still on the increase compared to other Federal agencies.

So, we’re still the leaders when it comes to the employment of people with disabilities over other Federal agencies. EEOC came out with a report, as a whole, that the number of people with disabilities is going down in the Federal sector. But DoD has been actually increasing and holding itself in many of the areas. What we’ve lost are the people with disabilities in the lower pay positions, in

cafeteria work, mail rooms, which we have outsourced. As we look at the numbers, we're always looking at whether we're losing people in management positions, and I'm happy to say we're not, at least not in DoD. But we're losing people in the unskilled professions because they have all been outsourced.

When it comes to your disabled veteran question, I totally agree with you. I think DoD and the Federal Government—I don't think it's a DoD problem. I think it's worse in other Federal agencies than DoD, that we don't use Schedule A to bring people with disabilities in noncompetitively, and we don't use the disabled veteran authority very well. I think because we have such a growing number of returning wounded service members, there's a reenergized feeling and expectations and energy put into all types of hiring authorities, especially disabled veterans hiring authorities, because I think we all realize that this is a time to really make sure that we make every opportunity we can for both the disabled veterans from past wars and those from current conflicts and operations.

They should be considered first and foremost, as a thank you for what they have done for our protection. I think you're going to see changes in that. I think people have totally forgotten about that. And I think the Office of Personnel Management (OPM) and the EEOC have kind of let it drop, they haven't pushed affirmative action programs, they haven't pushed reporting, they haven't pushed accountability. And it's only right now that those things are being pushed so we can now see where we have fallen short in all of those hiring initiatives. So, I agree with you, but I do think it's going to change because we now must go back every year and report to EEOC and to OPM what we are doing, and we haven't been doing that for years. People got lazy.



Dinah F. B. Cohen

Bio:

Dinah F. B. Cohen is the Director for the Department of Defense (DoD) Computer/Electronic Accommodations Program (CAP). CAP is the centrally funded program to provide assistive technology and accommodation services to employees with disabilities in DoD and throughout the Federal Government. Ms. Cohen received the "1995 Federal 100" Award, sponsored by Federal Computer Week, for her impact on the development, acquisition, and management of information technology in the Federal Government and the DoD Exceptional Civilian Service Award for her leadership and management of CAP. Prior to joining DoD, Ms. Cohen was the Disability and Federal Women's Program Manager at the Agency for International Development. Other Federal experience includes the Equal Employment Opportunity Commission and the Naval Research Laboratory. She became a Certified Rehabilitation Counselor (CRC) in October 1980. She received an MS degree in counseling psychology with a concentration in rehabilitation counseling from the State University of New York at Buffalo. She holds a BS in social science/elementary education from Russell Sage College in Troy, New York.



Panel Discussion

Technology Access for Children



Dr. Eric Levey

American Academy of Pediatrics

Hello, my name is Eric Levey. I'm a pediatrician and I serve on the Committee on Children with Disabilities at the American Academy of Pediatrics.

I thought all of you made wonderful presentations this morning. You clearly understand the needs of people with disabilities and the aging population. I didn't hear any of you speak specifically about children with disabilities and the unique challenges they face, especially as they move into the workforce.

I want to just make a few comments and then let you answer my question and challenge to you. One is that there are a lot of technologies out there already, but the reason they're not being used is lack of financing.

People don't have the cash to get the technology into their homes, to get the adaptive equipment that already exists and is on the market. The Medicaid program is not the solution right now. Though it is helpful, only about a third of all children with disabilities are on Medicaid.

Most commercial insurance doesn't cover adaptive equipment very well at all. And as children move into the workforce, they lose their Medicaid and therefore their ability to pay for technologies.

We need to couple the development of new technologies with financing to purchase those technologies. If we have a lot of new technology, it's going to increase the cost to the system, at least initially, as we move it into the marketplace.



Disabled child

DR. AISEN: Thank you for that comment. I know that Al Mann has some very strong feelings about cochlear implants, for example, and their potential to help young children, and the great challenges in reaching them.

MR. MANN: Yes. Thank you. We heard today all about the New Freedom Initiative and No Child Left Behind. But frankly, we are failing in one particular area because we're needlessly leaving children behind where it makes zero sense.

If you look at cochlear implants, Medicare pays for an inpatient implant—and by the way, the equipment plus the out-of-pocket cost to a hospital today is about \$29,000. That's for the equipment, the operating room, and all of the supplies

and so forth that go with it. In addition, you have the surgeon's cost, the anesthesiologist, the audiologist, and so forth. The total cost is something in excess of \$40,000. There's also an ongoing cost over the years, so that if you took all of the children who are born deaf or are deafened in the first few years, and if you gave all of them a cochlear implant, the total cost could be about \$200 million, which is very modest in terms of the Federal budget.

Yet we mandate by law that deaf children must have access to a school for the deaf, where the annual costs can be quite high. In that sense, it may not take long to pay for that \$40,000 implant by saving the costs of a school for the deaf. And improving hearing at such an early age may improve the child's chances of a higher-income career as an adult, where he or she would be paying taxes back to the Government over a lifetime.

So, we are really failing in that area, and one of the reasons is because we have this "bucket" phenomenon in funding. The Department of Education and State and local authorities across the nation don't pay for cochlear implants, but they do pay the extra education costs for the deaf.

It makes no sense. The savings to society could be enormous over time. If we would only do this, it could pay for itself in a couple of years. I challenge the Government to solve that problem.

DR. AISEN: Of course, the Department of Education does not fund healthcare. That would be the Department of Health and Human Services (HHS). Steve (Tingus), do you have anything you'd like to talk about in terms of pediatric programs?

MR. TINGUS: Yes. The National Institute on Disability and Rehabilitation Research (NIDRR) is probably one of the few lead agencies, besides HHS and the Centers for Disease Control (CDC), obviously, that are devoted particularly to children and seniors with disabilities. NIDRR, as you may know, has a Rehabilitation Engineering Research Center for children with special healthcare needs at Georgetown University. In addition, under my leadership, we're working very diligently with the Substance Abuse and Mental Health Services Administration (SAMHSA) to look at pediatric and adolescent mental health services.



Nurse with disabled child

As far as employment goes, we are looking at secondary and postsecondary outcomes for students with disabilities and hopefully will, in the future, continue to do even more in that area.

It is essential that we do early outreach to children in elementary and junior high to prepare them for the workforce. We need to partner the administrators of schools with the business community and our one-stops to prepare these students for entering to the workforce. As Dinah (Cohen) has said, telework is an option. Is it an option for everybody? No. It's an option for those who need to work from home because of one factor or another. We are doing a tremendous amount of work at the department and will even do more with the involvement of many people here in the room as our stakeholders.

One thing I didn't point out in my talk is the importance of balancing consumer relevance with the need for scientific rigor. It's very important that we always, all Federal agencies, keep that at the forefront. Thank you.

DR. AISEN: Dr. (Eric) Dishman, can you tell us about Intel and what you're doing for children?

DR. DISHMAN: I've gotten about 50,000 emails in the last year—so please don't send me email, please—from consumers who have seen things about the technology that we're working on. About a quarter of them have been from parents of children with autism saying, "Hey, these things that you're trying to do for people with Alzheimer's or other typically age-related diseases would be very helpful for

us, too.” We’re trying to figure out what are these horizontal technology building blocks that could be used in lots of markets, lots of spaces? In fact, we’re going to need to get a company like Intel, or a GE, or a Honeywell interested in this to define the market, not as a disability market, and not even as an assistive technology market. That term is great for developing legislative energy, and it’s what the law actually reimburses for.

About one-third of all children with disabilities are on Medicaid.

But “assistive technology” is a terrible phrase for marketing these technologies. We’ve tried it and tested it in almost every country that we sell to, and it just doesn’t work. We need a new phrase. What do we name it? How do we give it power in some new and interesting ways by naming it something different? And then, how do we construe it broadly enough to include the needs that children have, that people of all ages have, so that really big players can help come to the table and commercialize some of this?

DR. AISEN: Excellent. That will be the end of this morning’s panel.

Bio:

Dr. Eric Levey is a researcher and pediatrician specializing in children with severe developmental disabilities and is an Assistant Professor of Pediatrics at the Johns Hopkins University School of Medicine. He provides clinical services at Baltimore’s Kennedy Krieger Children’s Hospital in the Phelps Center for Cerebral Palsy and Neurodevelopmental Medicine and the Center for Spina Bifida and Related Conditions. Dr. Levey graduated from the University of Pennsylvania School of Medicine in 1993 and then completed residency and a fellowship at Johns Hopkins. Since 1999, he has been working at the Kennedy Krieger Institute, where his current positions include Medical Director of the Spina Bifida and Related Conditions Center and Associate Medical Director of the Carter Center for Brain Research in Holoprosencephaly and Related Malformations. Dr. Levey is cochair of the Committee on Disabilities/CSHCN of the Maryland Chapter of the American Academy of Pediatrics (AAP). He is also a member of the national AAP Committee on Children with Disabilities.



Keynote Address



Patrick E. Ryan

Former Chief Counsel and Staff Director of the House Committee on Veterans Affairs

I am very pleased and honored to be here to address you today, to talk about my role in Congress, and to learn more about your involvement with the New Freedom Initiative. I want to express the full appreciation of all of the members of the House Committee on Veterans Affairs for your efforts this week and beyond. 2004 marks my twenty-first year on the veterans committee. I've had the honor and privilege of working with three chairmen—first, G.V. “Sunny” Montgomery (D-MS) for 13 years; then the late Bob Stump (R-AZ) for 4 years; and the current chairman, the Honorable Chris Smith (R-NJ) for the last 4 years. I am proud to have played a small role in the accomplishments that have been achieved on behalf of all of our nation's veterans and especially the accomplishments on behalf of the nation's 2.4 million disabled veterans.

Today, I would like to share with you some of what I have learned about the VA's role in assisting people with disabilities, about the need for better cooperation between Federal agencies, and about an agency designed to serve veterans has proven essential in aiding all persons with disabilities. Disabled veterans, like all persons with disabilities, want to reclaim their ability to lead independent lives. Serving on the veterans committee, I've learned that when injured soldiers and marines are being treated, one of their first questions is “When can I return to my unit?” As I see it, that is what the New Freedom Initiative is all about. Not just to provide assistance to disabled persons, but also to remove barriers and provide the right tools so that continuing aid is no longer necessary. Not just a hand-out, but also a helping hand to get disabled persons back into battlefields, ball fields, academic, or any other fields that enriches and gives meaning to their lives.

For many Americans, the image of the VA remains that of a Federal bureaucracy primarily responsible for taking care of old soldiers. The VA does indeed do that. Our nation owes nothing less to those men and women in-

jured when defending our freedom. It is what President Lincoln had in mind during his 1865 second Inaugural Address, when he said that our Government has an obligation “to care for him who shall have borne the battle and for his widow and his orphan.”

Over the years, the VA's role has grown and its orientation has changed. Today's VA is dramatically different from the old soldiers' homes built to house disabled soldiers after the Civil War, from the VA that was put together from disparate agencies in 1930, or even from the VA that existed when I started there in 1974.

My first job in the VA was at the regional office here in Washington, where I helped veterans, many of them disabled, with their benefits claims. In my first year, I met a guy by the name of Jesse Brown, who was working with the Disabled American Veterans and who later became the Secretary of Veterans Affairs. During those days, I developed an appreciation for the challenges facing disabled veterans.

Today, the VA's role is not just caring for or compensating those who are injured but, whenever possible, helping to rehabilitate

disabled veterans so they can live independent lives. The VA's role is to help veterans become self-reliant. Our injured service men and women desire this above all else, and it is also what I believe all disabled Americans want. Congress has encouraged the VA to provide a holistic, multidisciplinary approach toward disabled veterans that provides recovery, rehabilitation, compensation, housing, transportation, education, employment, and entrepreneurship. This is true not just of the VA but of other agencies as well.

The goal of this panoply of programs is to supply disabled veterans with the tools to maximize their ability to live independently and to care for themselves. Of course, not all disabled veterans can achieve independent living, which is why the VA must maintain its capacity to fulfill our national obligation to these men and women. However, as technology advances, opportunities must be seized to wholly reintegrate persons with disabilities into the mainstream—which is essentially what this conference is all about.

In a sense, the VA does for disabled veterans what the New Freedom Initiative proposes to do for all disabled Americans: remove barriers, develop new technologies, adapt environments, and do everything possible to allow disabled Americans the full opportunity to seek their dreams.

The VA has been working on disability issues for a long time. I can remember when I worked in the VA's General Counsel's Office during the Carter Administration. I became aware of the dedicated efforts of VA attorneys and others to assure that the Government buildings achieved barrier-free design through the Architectural and Transportation Barriers Compliance Board. This experience made me realize what complex challenges lay ahead in making it viable for persons with disabilities to move, live, and work wherever they wanted.

I also learned that these goals could be achieved through true intergovernmental cooperation. A

recurring theme on the Veterans Committee and, I believe, one of the most important keys to the success of the New Freedom Initiative, will be interagency cooperation.



Ray-Paul Nielsen at the Creative Arts Festival

For more than two decades, I have been involved in efforts by the Veterans Committee to improve the sharing and cooperation between the healthcare programs at the VA and the Department of Defense (DoD). These two massive agencies have tremendous opportunities to share resources, facilities, equipment, and personnel across the country. The VA and the DoD share similar and overlapping population, often concentrated in the same geographic locations.

Before I even came to work for Congress 24 years ago, the Congress enacted Sunny Montgomery's legislation, which was intended to bring down barriers that would inhibit sharing between the VA and DoD. Chairman Chris Smith, whom I work for now, voted for that bill in his very first term in Congress.

Twenty-four years later, the promise of that legislation remains largely unfulfilled. I am reminded of a story about three brothers. These three brothers left home, went out on their own, and prospered. Getting back together, they started boasting about the gifts that they had given to their elderly mother. The first said, "I've built a big house for our mother." The second said, "I sent her

a Mercedes with a driver." The third smiled and said, "I've got you both beat. You know how Mom enjoys the Bible and you know she can't see very well. I sent her a brown parrot that can recite the entire Bible. It took 20 monks in a monastery 12 years to teach him. I had to pledge to contribute \$100,000 a year for 10 years, but it was worth it. Mom just has to name the chapter and verse and the parrot will recite it."

Soon thereafter, the Mom sent out her letters of thanks. She wrote the first son, "Milton, the house you built is so huge. I live in only one room, but I have to clean the whole house." She wrote the second son, "Marvin, I am too old to travel, I stay home all the time. So I never use the Mercedes, and the driver is so rude." She wrote the third son, "Terence, you were the only son to have the good sense to know what your mother likes. The chicken was delicious."



Veteran participating in the Golden Age Games

Regrettably, whether caused by competition between the VA and DoD or by someone who just misses the whole point of Government, far more opportunities are ignored than achieved between the VA and DoD. Sometimes, the opportunities to cooperate are so obvious that it defies explanation. A couple of years ago, we were looking into possibly strengthening this cooperative legislation and we sent staff to various parts of the country, including the naval hospital in Charleston, SC, and the VA facility down there as well.

The staff visited with the director of the naval hospital—himself a pharmacist—who lamented that the hospital was really dropping the ball on filling prescriptions. They just could not meet the demand of 500 prescriptions a day. What he didn't know was that directly across the street—literally, he could look out his window—was one of the VA's eight consolidated mail-out pharmacies. This pharmacy mails out 60,000 prescriptions a day. So, the staff member pointed out the building and said, "Do you know what's over there?" They took him to the VA facility and met with the director. Obviously, 500 prescriptions was a drop in the bucket. A cooperative venture between the two facilities was something that could have been easily accomplished. The latest report I have is that while progress has been made, the idea of seamless sharing has not yet been achieved between

these two neighboring institutions. I've also learned that where there is strong motivation and urgency, cooperation can be attained. I'm going to take, for example, the matter of providing prosthetics for our service members who have lost the use of limbs. Earlier this year, the Veterans Affairs Committee held a remarkable hearing on the efforts of Walter Reed Army Medical Center to meet the prosthetic needs of soldiers and marines who have suffered traumatic amputation during Operation Iraqi Freedom and Operation Enduring Freedom (OIF/OEF).

I see Lieutenant Colonel Paul Pasquina sitting here right in front of me and I acknowledge his presence. He was one of the witnesses at that hearing. Frankly, the witnesses were very honest and said that the Army and the VA had not seen amputee patients like this since the end of the Vietnam War. New knowledge had to be acquired and disseminated in a real-time environment. What was so obvious to those at the hearing was that all of the VA and Army personnel were able to make policy choices based on the needs of recovering service members. They made those choices without quibblers or naysayers, or even general counsel attorneys, blocking them from realizing their goals.

I think the lesson we learned is that when the will, the motivation,

and the sense of urgency are present, barriers can be overcome and progress achieved—but it is not easy.

I believe a robust VA is essential to the development of new medications to help disabled persons. Far too many people believe that VA only helps veterans. As I trust most of you in this room know, the VA does so much more. The Department of Veterans Affairs operates our nation's largest integrated healthcare network, with more than 200,000 employees, 163 medical centers, 850 outpatient clinics, and more than 10,000 research projects underway at 115 research programs. More than a billion dollars has been earmarked for its research programs.

The VA currently operates dozens of specialty care centers, often referred to as Centers of Excellence. I will name a few of them, but this list is by no means exhaustive. The VA operates the Center for Limb Loss and Prosthetic Engineering, the Center for Innovative Visual Rehabilitation, the Center for Wheelchair and Related Technology, and the National Center for Rehabilitative Auditory Research. Several of these institutions are represented here today.



Veterans competing in the Wheelchair Games

The VA has a proven track record of world-renowned medical research. VA physicians and scientists have a rich history of developing practices that have provided scientific breakthroughs and revolutionized the practice of medicine. VA

scientists pioneered tuberculosis treatment, developed the cardiac pacemaker, and contributed to the development of the high-tech diagnostic procedures of computerized axial tomography, magnetic resonance imaging, and magnetic source imaging. The first successful drug treatments for high blood pressure and schizophrenia were pioneered by VA researchers, as were kidney and home dialysis techniques. The Seattle Foot was created by the VA, which was the first prosthesis with a moveable ankle that allowed amputees to walk more naturally, even to run and jump.

VA researchers have been honored by awards from the most prestigious organizations, including the Nobel Institute. When it comes to biomedical and clinical research, the VA is the Federal Government leader. Supporting a strong and well-funded VA helps all Americans, particularly those with disabilities. And I think VA's research offers great hope and potential knowledge for all persons with disabilities.

When I was growing up, I was taught that there were three great virtues: Faith, hope, and love. Throughout my life, I would often hear or see examples of tremendous faith or love. But the memorable lessons about hope were less frequent. Hope was often something more commonplace, such as I hoped my car wouldn't be in the garage for too long, or that I would pass the bar exam, or that my then-girlfriend would say yes to my marriage proposal. What makes hope such an important virtue? Where is the supply of hope needed for this time and these days? One author has written, "Hope is not a matter of optimism, but a source for strength and action in demanding times."

Nobel prize recipient Elie Wiesel said this about hope: "Just as despair can come to one only from other human beings, hope too can be given to one only by other human beings." All of you who have a hand in devising innovative methods of treatment and adaptations for persons with

disabilities must realize that you are giving hope to these persons and their families. Indeed, you give hope to people you do not know and will never know.

Let me share with you an experience I had one cold December night in Sarajevo in 1998. We had landed in the airport the night before. To this day, I cannot block from my mind the vision of that war-torn city where citizens had killed each other senselessly for several years. It was both eerie and a stark reminder of all the evil that had erupted in Bosnia over several years of ethnic war. I was with a couple of World Bank officials and we went to the apartment of a young man who was wounded during the war and became a paraplegic. He was trying to organize a disability rights organization and had some success. The things he was looking for were pretty basic: Somebody to teach a course in wheelchair repair and some way of assuring that repair parts could be obtained. Following our conversation, he gave me a poster. I can't read all the words

on this poster, but I want to share the vision that this young man had about what it means to be free. The poster shows Miss Liberty radiating her message of independence and hope from a wheelchair.

Collectively, each step you take in achieving greater freedom for individuals through innovative technology means that generations of scientists and researchers to come can build on your work and grow closer to making these devices and technologies available to those in need. This, in turn, fosters greater independence for all disabled people. Each of these steps is part of the fabric of hope that makes life worth living.

Hope encourages us to inquire about the reason for our being and to struggle for better lives for ourselves and those we love. Through our innovation and dedication, which is the subject of this conference, you keep hope alive for millions of people throughout the world. Thank you for all that you do.

Bio:

A lawyer by training, Patrick E. Ryan has played a critical role in the drafting of many major veterans' laws adopted during the past two decades, including all 17 laws signed by President Bush since 2001. Before serving as the Veterans Affairs Committee's former chief counsel and staff director, Ryan was appointed deputy chief counsel and has held other critical posts since 1983. Prior to his tenure on Capitol Hill, Ryan served as a staff attorney in the VA's Office of General Counsel and as budget analyst in the VA Office of the Comptroller.



Veteran competing in the Winter Games



Panel Introduction

Emerging Assistive and Transformational Technologies



Dr. Kathie L. Olsen

Associate Director for Science, Office of Science and Technology Policy

I would like to start this session on emerging assistive and transformational technologies. And I'd like to welcome you to this afternoon's panel. This morning you heard about the state of assistive technologies and some of the challenges. The goal of this afternoon's panel is to highlight a few innovative technologies that are still in the developmental and testing stage, but have very, very exciting potential.

I'm a neuroscientist, and I've had a lifelong fascination with the ability of the brain to adapt and to change. We see striking evidence of the tremendous adaptability of the human brain, indeed, of the whole human organism, and the amazing ways that people with disabilities are able to adapt to assistive technologies to overcome physical impairments. Today's advanced assistive technologies employ the full range of medical science and technological capability in complex integrated systems that actually begin to merge mind, body, and machine, and completely transform the concept of rehabilitation.

Our first speaker is Dr. Margaret Giannini, the Director on the Office of Disability in the Office of the Secretary of Health and Human Services, who will give an overview of the emerging assistive

and transformational technologies and discuss the importance of technology for people with disabilities to fully participate in employment and educational opportunities.

Dr. Giannini has had a very distinguished career in disability and research and awareness, including serving as the first director of the National Institute on Disability and Rehabilitation Research. She's a member of the American Academy of Pediatrics and of the Institute of Medicine at the National Academy of Sciences.

On our panel today are:

Margaret Giannini, MD, Director, Office on Disability, Department of Health and Human Services (HHS).



John P. Donoghue, PhD, Professor of Neuroscience, Brown University.



Joseph F. Rizzo III, MD, Codirector, Retinal Implant Project, Boston VA Medical Center (VAMC) Associate Professor of Ophthalmology at Harvard Medical School.



Hunter Peckham, PhD, Director, (FES) Department of Veterans Affairs (VA) Center of Excellence in Functional Electrical Stimulation FES, Cleveland VA Medical Center (VAMC).



Hugh Herr, PhD, Director of the Biomechatronics Group, MIT Media Lab.



Bio:

Kathie L. Olsen, PhD, is the Associate Director for Science for the Office of Science and Technology Policy (OSTP) in the Executive Office of the President. Her appointment was confirmed by the Senate. OSTP's responsibilities include advising the President on science and technology and providing leadership and coordination for the Government's role in the national science and technology enterprise. Olsen is responsible for overseeing science and education policy including physical sciences, life sciences, environmental science, and behavioral and social sciences. Prior to joining the OSTP, she was chief scientist at the National Aeronautics and Space Administration (NASA) and acting associate administrator for NASA's Office of Biological and Physical Research. Before joining NASA, Olsen was the senior staff associate for the Science and Technology Centers in the National Science Foundation (NSF) Office of Integrative Activities, an NSF aide to Sen. Conrad Burns of Montana, and a Brookings Institute Legislative Fellow. She received her BS with honors from Chatham College in Pittsburgh, Pennsylvania, with a major in both biology and psychology, and was elected to Phi Beta Kappa. She earned her PhD in neuroscience at the University of California, Irvine. She was a Postdoctoral Fellow in the Department of Neuroscience at Children's Hospital of Harvard Medical School. Subsequently, at the State University of New York–Stony Brook, she was both a research scientist at Long Island Research Institute and assistant professor in the Department of Psychiatry and Behavioral Science at the medical school. Her research on neural and genetic mechanisms underlying development and expression of behavior was supported by the National Institutes of Health.



Panel Discussion

Overview: Technology and Physical Impairments



Dr. Margaret Giannini

Director, Office on Disability, Department of Health and Human Services (HHS)

It's really a pleasure for me to speak to you this afternoon, especially so because so many of my old colleagues are here and also because of some new colleagues whom I have met at this forum.

I also bring you very warm greetings from Secretary Tommy Thompson. As healthcare professionals and bioengineers and others in the twenty-first century, we are witnessing advances in medicine, rehabilitation, research, development, and technology that would have seemed miraculous to our forebears in healthcare.

We live in an age in which telehealth is no longer a dream of the future, but a reality of the present; in which smart houses enable aging people and those with disabilities to live in the comfort of their own homes surrounded by friends and family; an age in which it is not only possible for disabled people to enter the workforce, but in which the Federal Government, by law, must make the accommodations necessary to facilitate disabled employees to achieve their full potential.

We live in an age in which the Federal Government, State and local governments, the medical community, academia, and private industry are working very hard together to tear down

barriers for people with disabilities. You heard a lot about that today in the panel discussion on the President's New Freedom Initiative, for which I'm responsible within Health and Human Services (HHS) to be sure those goals are met.

Moreover, we live in an age in which we are reaching out as far as we can, spanning the globe, to form common bonds with other governments to safeguard public health, to prevent disease, and to improve the health and well-being of people with disabilities.

In this new age, we have joined hands across agencies and across the globe to support the World Health Organization (WHO) and such accomplishments as the International Classification of Functioning Disability and Health, recognizing that health is about human functioning.

We live in an age in which the emphasis has changed from focusing on a person's illness to focusing instead on the person's ability to function. We live in an age, ladies and gentlemen, in which we are not only charged with enhancing the capacity of people with disabilities to live full lives as individuals and members of society, but with ensuring this civil right is a priority for President Bush and his administration.

We live in an age of promise. This panel will focus on many aspects of emerging technologies to promote opportunities for people with disabilities. I am here to tell you, as a physician who has devoted my entire professional life to disabilities, that the emerging technologies we will speak about today are trailblazing, reflecting human genius at its best. What we talk about today

will determine how people with disabilities live long after we are gone. In my three years of concentrating on the New Freedom Initiative at HHS, from listening to people with disabilities, their families, and their caregivers to working across all Federal agencies and where there are many constituents, we've learned that not just nationwide but worldwide healthcare professionals need to look at disabilities across the lifespan. This means children, adolescents, middle-aged people, seniors and aging people. We recognize that each has special needs that must be addressed.

Additionally, we need to concentrate on the health of people with disabilities. Recognizing that in order to ensure full community integration throughout someone's lifespan, his health must be addressed. Therefore, we are working to optimize the health and well-being of people with disabilities to prevent or reduce the occurrence of a secondary comorbid condition.

We are also seeing that today's consumer is very demanding, and rightly so. Powered wheelchairs are certainly not a luxury item, but something disabled people need. When these individuals find themselves in need of some of the most remarkable technologies of our time, as healthcare professionals, we must ensure that they have access to these devices and that they are affordable. Otherwise,

all the research and technology that we talk about today, and all of our combined work, will be for naught. Mobility limitations make up the largest area of disability in the American population. Ambulation, as you well know, is presently being restored through the use of orthoses, leg prostheses—which are improving every day—internal joint replacements, new surgical procedures, special shoe configurations, special canes, crutches, you know them all. One of my favorites is functional electrical stimulation (FES), which you will hear more about later. In the last decade, the engineering advancements made by human joint replacements, especially hip and knee replacements, have improved ambulation and reduced unbearable pain for many with arthritic joint conditions.



*Powered wheelchair
from Otto Bock®*

Prosthetics and orthotics have benefited from biomechanics, biomaterials, engineering, and bioelectronics. Users have told us that they need more attention to the fit of a socket with the

residual limb. As you know, if the socket doesn't fit properly, the prosthesis really doesn't work well. Some Government-funded research projects in this area include computer-aided design and computer-aided manufacture of sockets for prosthetic limbs. I am very pleased to tell you that the first center of this kind was created in Seattle when I was in the Department of Veteran Affairs (VA), under the leadership of Dr. Ernie Burgess. With this type of technology, we have intelligent knees with computer chips programmed to respond to changes in walking speed, rotary hydraulic prosthetic knee mechanisms to provide stance stability while walking, and ultrasound 3-D imaging of residual limbs for better fitting of the socket.

“Last year, manufacturers integrated a motorized elbow, wrist, and hand for the first time and announced a new type of motorized hand sophisticated enough to pick up a single piece of paper.”—Margaret Giannini, MD

The revolutionary computer-aided C-Leg® is a new prosthetic with onboard sensors and microprocessors that allow it to adapt to each individual's movements. The sensors and microprocessors measure the speed and change of the knee angles and direct the hydraulics to adjust

the amount of resistance. And because the knee stiffens or loosens automatically, walking feels natural and takes less concentration. Sensors in the shin measure how much weight force is on the foot, and the carbon fiber dynamic response foot provides for energy return and comfort. Technological responses to motion limitations range from surgical interventions to prosthetic and orthotic devices to robotic devices. Tendon transfer surgery is proving successful every day in boosting manipulation ability and has also been successful in conjunction with implantable electrical stimulation systems for hand grasp and release in adolescents with tetraplegia secondary to spinal cord injuries. Emerging technologies are addressing this need and focusing on lightweight orthoses, FES applications, and myoelectric arms that can receive instructions from the brain by way of electrodes that detect electronic impulses shooting through the undamaged muscles. Last year, manufacturers integrated a motorized elbow, wrist, and hand for the first time and announced a new type of motorized hand sophisticated enough to pick up a single piece of paper.



Pilot with C-Leg®

Technologies under further development include, for example, electromechanical arm interfaces, compact and flexible arms, and robots customized for individual needs.

New technologies are emerging every day. Still, we need to address the physical disabilities and the specific populations across the lifespan to

ensure we fill gaps that might exist as a person transitions from one life stage to another. I would like for a moment to focus on emerging technologies with respect to children, youth, young adults, and seniors. Children present their own set of needs, and the emerging technologies are those that can improve the lives of children with orthopedic disabilities. Research is focusing on three of the most important life activities of children: manipulation, mobility, and play/recreation. Rehabilitation Engineering Research Centers (RECs), funded by the National Institute on Disability and Rehabilitation Research (NIDRR) and the VA, address the manipulation needs of children with upper-limb deficiencies, current fitting practices for children's prosthetics, and developing improved elbows and presensors for young children. In addition, emerging technologies are attending to the unique needs of children with cerebral palsy, spina bifida, spinal cord injury, muscle disease, and other chronic conditions that affect the child's ability to ambulate. RECs are developing lightweight orthopedic components and evaluating the effectiveness of FES to correct gait abnormalities in children with cerebral palsy.

Special attention to bilateral high-level arm amputees and growing children is important as their needs and assistive technology requirements are unique. A prosthetic hand for children that uses a new mechanical geometry and can add cable-actuation function and a power module as the child matures shows great promise. In addition, we know that the vast majority of Americans, but especially youth with disabilities, are not engaging in the recommended amount of physical activity that is so important for health benefits and increased quality of life through social interaction in fitness activities. Much research is going on to address those issues with the secondary conditions to prevent diabetes, obesity, cardiovascular disease, and musculoskeletal limitations. In my office we created an initiative, "I Can Do It, You Can Do It," which addresses physical fitness for young children with disabilities. The program features

adults who will mentor children, and it's the first of its kind nationwide where every disabled child who wishes to be in the physical fitness program will be able to participate. Programs like this are of paramount importance for integrating children with disabilities into society. The President delivered on his promise to increase and sustain funding for individuals with disabilities in education, including the Individual Development Accounts (which were expanded to allow disabled students to purchase assistive technology through the accounts).

We know that mobility impairments can affect children in several ways. Some students may take longer to get from one class to another, to enter buildings, or to maneuver in small places. A mobility impairment may affect, to varying degrees, a student's ability to manipulate objects, turn pages, write with a pen or pencil, type at a keyboard, or retrieve materials. A student's physical abilities may also vary from day to day. All of these are areas in which accommodations are now being made for students with mobility impairments. Other examples include accessible locations for classrooms, labs, and field trips, wide aisles and uncluttered work areas, adjustable heights and tilt tables, all equipment located within reach of the individual, and note-takers, scribes, and lab assistants.

I can go on and on about all the things that are happening, such

as the addition of computers with speech input, Morse Code, alternative keyboards, course materials available in electronic format, and access to research resources on the Internet and, of course, remaining vigilant to ensure environmental modifications are in place such as wheelchair ramps, curbs cuts, restrooms, and elevators. Transportation is key to community integration of children with disabilities. There are loan programs for assistive technologies across the country that are being encouraged and promoted by the Administration of Children and Families in HHS. This is an excellent example of Federal, State, and local collaboration to use creative means to meet the assistive technology and transportation needs of children with disabilities.

We have programs for youth and also young adults with disabilities, a direct outcome of the New Freedom Initiative based upon constituent input in this new and very important target population. Governmentwide, we are focusing much attention upon this. The population is young adults between the ages of 16 and 30. The trend is that thousands of young people with disabilities are enrolling in Social Security insurance and Social Security disability insurance. These young adults are not successfully moving from high school to postsecondary education to employment and to independence. Why? They're unable to secure appropriate housing and suffer from a lack of edu-

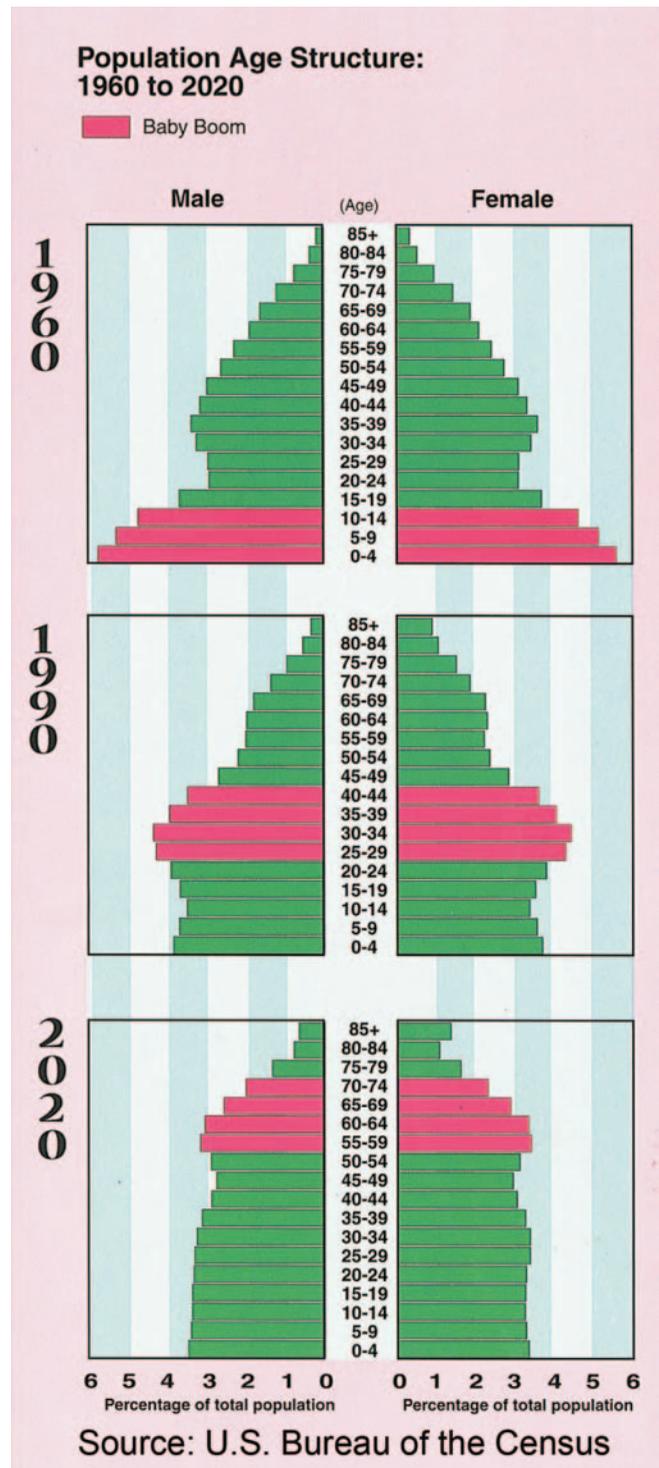
cation, continued dependence on parents, social isolation, lack of involvement in community activities, and lack of affordable healthcare. Assistive technology can take care of all that. We are trying to coordinate and integrate Federal, State, tribal, and local government services to address these issues.

Regarding seniors with physical disabilities, I want to comment on some things that are emerging in a project at NIDRR, which has been looking at improved recovery and regaining of function following a hemiplegic stroke. One study focused on the development of a rehabilitator for arm therapy after brain surgery. This is a self-therapy rehabilitator for the arm after hemiplegic stroke and other types of brain injury to correct the current lack of appropriate technology. The fastest growing segment of our population today is seniors, specifically 85 years of age and older, who are most likely to develop many types of disability. I may add, for the women in the audience, that this growing population in the 85 and up category is women who are not married, who never had a significant other, or have not had children, so take your choice.

By the year 2011, the baby boomers will be 65 and will probably have disabilities. Emerging technologies for seniors focus closely on related areas of communications, home-monitoring, and smart technologies. Rapidly developing technologies include

wireless technology, computers, sensors, user interfaces, control devices, and networking. Home-monitoring products are leading to enhanced independence and quality of life. We've already mentioned that one of the most sensational technology transfers was for the hearing impaired, the Cochlear implants, probably the most technologically impressive advancement in assistive technology to date. Other emerging technologies include closed captioning eyeglasses, multi-band technologies where two or more frequency bands can be separately amplified, multimemory hearing aid programs for a number of different patterns of amplification, and multimicrophone directional hearing aids. We have automatic signaling processes, automatic speech recognition technology, and implantable hearing aids and alerting devices.

With all the emerging technologies we have, we are also focusing on accommodating people with multiple disabilities, for example, physical disabilities in addition to blindness. Here, technology is looking at solutions for wheelchair travel and technology for way-finding. A whole area is being developed with respect to robotics and manipulation. We developed a robot at Palo Alto, when I was in the VA, that could actually take food out of the freezer, put it in the microwave, take it out of the microwave, slice the food, feed the tetraplegic, clear the table, wash his face, comb his hair, and brush his teeth. That is available, but it's not accessible and affordable. It costs hundreds of thousands of dollars to have that robot that we created in the laboratory. The technology is there. We've got to figure out how we can make this affordable and accessible. I would like to tell you more about all the things we are doing in transportation, but I'll just say a word or two on people with disabilities who want to drive. There's much being done in fitting adaptations for cars to ensure that people with physical disabilities can drive. Additionally, automakers and university researchers are testing and refining sensors, monitors, and other devices to compensate for the coming decline in reaction time and awareness among the growing number of baby boomers.



The progressive growth of the elderly (age 65 and over) population and the future influence of the Baby-Boom generation (persons born between 1946 and 1964) can be seen by examining age-sex population pyramids for 1960 to 2020. The 1960 pyramid shows a marked "pinch" for ages 20–29 years, a result of exceptionally low birth rates during the Depression years. The Baby-Boom bulge appears in the 1960 pyramid in the ages 0 to 14. During periods of fluctuating births and improving survivorship, the elderly grew from 5 percent of the U.S. population in 1930 to nearly 13 percent by 1990.

Some manufacturers already sell options to make driving easier for aging people with disabilities. Some offer night vision options that project an infrared image of the road on the windshield, and there are many other things also emerging that use such technology. Finally, we need to take advantage of emerging technologies in regard to environmental controls as well as the building environment. We have this. It's available. We don't promote it enough. Things for the blind such as talking lights that say, "you are now in the hallway," "you are now in the men's room," "you are now in your office." We need to have voice command technology that is accessible and affordable to a person so they can say, "lights go out," "thermostat go up," or "windows lock." We are not there yet.

We need to move quickly on robots to assist tetraplegics. Finally, the built environment includes public and private buildings, tools and objects of daily use, and roads and vehicles being modified. Also, we must concentrate on universal design, which we are actively trying to promote with all the Federal agencies.

I've attempted to give you an overview of emerging technologies. I certainly haven't touched on near enough, I must say, very little to enhance the lives of people with disabilities. We've reached a point where new science and technology is emerging every day. The challenge that we need to collectively look at,

and I believe together we can accomplish this through the New Freedom Initiative, is to build partnerships across all Federal agencies, at the State and local levels, with private industry, manufacturers, and advocacy organizations. That is the key to the success of everything we've done and will do.

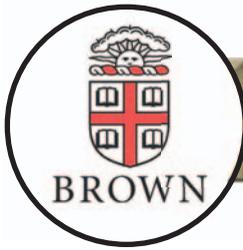
Now we need to ensure that all these remarkable technologies are available and accessible to those who need them through Medicare, Medicaid, temporary assistance for needy families, waivers and block grants, private insurance companies and private industry, and through every creative means possible. This is a very complex issue, but we all know it is of paramount importance. If we want to accomplish this, and indeed we do, it is something that no single one of us can do alone, but we must do it together to ensure that this assistive technology reaches the people that need it quickly, cost-effectively, and without going through a maze of paperwork. The age of promise ends rather in despair if we don't do that. Yes, we live in a new age with the most remarkable technology ever known to man, but we must get it into the hands of those who need it. I always like to say that all people with disabilities, rich or poor; white, black, or Native American; young or old, all smile in the same language. If we continue to be vigilant, committed, persistent, and compassionate, we can ensure that they continue to smile.

Bio:

Margaret Giannini, MD, was appointed Director of the Health and Human Services (HHS) Office on Disability by Secretary Tommy Thompson on October 1, 2002. She serves as advisor to the Secretary on HHS activities relating to disabilities. Prior to that, she was appointed by President George W. Bush as the Principal Deputy Assistant Secretary for Aging at HHS. From 1981–1992, Dr. Giannini was Deputy Assistant Chief Medical Director for Rehabilitation and Prosthetics at the Department of Veteran Affairs. There, her work focused on technology transfer and assistive technology involving all disabilities. In 1979, President Jimmy Carter appointed her as the first Director of the National Institute of Handicapped Research. In 1950, Dr. Giannini created the largest facility for the mentally disabled and the developmentally disabled of all ages and etiologies in the world. This facility became the first University Center of Excellence on Developmental Disabilities.



Dr. Margaret Giannini



Panel Discussion

State-of-the-Art and Promise of Neuroprosthetics



Dr. John P. Donoghue

Professor of Neuroscience, Brown University

It's a real privilege and honor to be here speaking to this audience. I'd like to thank the organizers for inviting me.

The conference has been extraordinarily informative for me, coming from the basic sciences and working to translate some of the ideas and findings in our laboratory into the world where they can be used and distributed effectively to people who can take advantage of this technology.

I want to mention that I do come here as both an academic at Brown University and a cofounder of Cyberkinetics, the company that is trying to translate our laboratory findings.

I want to start with something from a clinical trial we've just begun. What I am talking about is a device that is basically a TV controller. It's something you can buy at Radio Shack for, I think, \$20.

It allows anyone to control a TV set from a computer by pointing and clicking on virtual buttons displayed on the monitor. This controller has four buttons: channel up, channel down, power, and volume.

One participant in our clinical trial is using such an interface to control his TV set. However, he is

not guiding a mouse with his hand to run this computer-controlled TV interface, because he is tetraplegic. He has a transection around the level of his fourth cervical vertebra (C-4) and consequently is unable to move either his arms or legs.

What's extraordinary is that he can use neural signals directly from his brain to control that cursor in place of his hands. That is, he is using his thoughts directly and is bypassing his paralyzed arm. Our clinical trial participant is the first person implanted with what we call a BrainGate neuromotor prosthesis, a pilot clinical system designed to provide signals about the intention to move from the brain to assistive technologies.

The BrainGate system has a small sensor about the size of a baby aspirin that is surgically implanted onto the surface of the brain in the area controlling arm movement. The sensor supplies neural signals designed to provide a neurally-controlled cursor that replaces the hand-controlled mouse. This is basically the essence of the neuromotor prosthesis, something that can couple the brain to the outside world for paralyzed individuals.

"We're now investigating how well a person's thoughts can replace movement."—John P. Donoghue

Why a neuromotor prosthesis? We know that there are, of course, many disorders in many people who are limited in their ability to move. Importantly, their cognition is often intact. These individuals have a perfectly functioning, productive, able brain, but they can't get the signals from

the brain out to the muscles to produce movement. Science has been pursuing a number of ways of restoring lost motor function—the biological and the physical. The biological approach attempts to induce repair by regrowth and reconnection of the damaged nervous system. This highly desired, but very challenging avenue, is being actively investigated.

Another approach entails physical means to restore the connection from the brain to the outside world. Ideally, such a system would couple the brain back to the muscles, but another approach would be to link the brain to assistive technologies that are able to accomplish what the hand, arm, or leg might ordinarily do, such as control a mouse to operate a computer.

The BrainGate system is a pilot system being tested for its ability to serve as a physical repair. Next, I am going to discuss how this concept is being evaluated in a clinical trial of BrainGate. Let me outline the fundamental concepts behind this device.

This first issue is to obtain movement-intent signals from the functioning brain. The problems we faced were to identify the region of the brain that generates movement commands, for example, the place that issues those commands to move the arm. Neuroscience research has found that motor commands for the body come from the motor

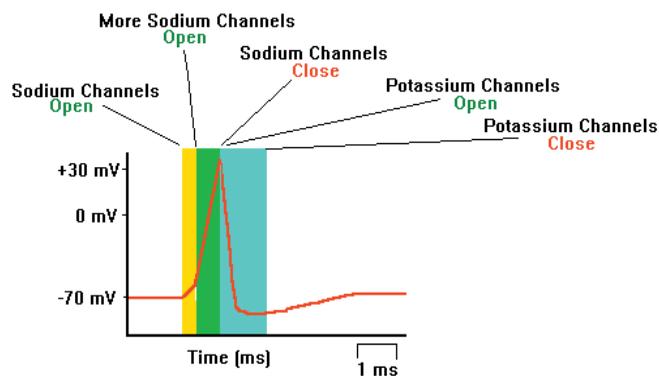
strip, or the primary motor cortex located on a distinct gyrus on the outside of the brain. The motor cortex contains functional subdivisions—arm-related movement commands are generated in the middle sector, the legs are represented medially, and the face laterally. Within the motor cortex, in fact, throughout the nervous system, information is carried in neural action potentials, also known as spikes. Spikes are brief, a thousandth-of-a-second-long impulses issued by neurons. The code of the brain is appeared to be based on how many of those spikes occur in time—an impulse rate. The motor cortex issues a spike pattern from millions of neurons that, for example, provide the commands on how you would like to move your arm. This complex spike pattern for the arm area of motor cortex, effectively carries a signal, such as “where do I want to move my hand through space?”

Once a primitive hand motion signal is obtained, it is possible to couple command signals to

a number of assistive technologies or assistive software packages that will restore the ability to manipulate and control your own environment. One significant issue in obtaining the hand motion signal is the problem of sensing, or picking up the signal—these tiny electrical spikes from the brain—from sufficiently large numbers of cells so that at a meaningful control signal can be derived. It is generally agreed that a compact array of many microelectrodes is the appropriate signal.

Over the past 8 years or so, we’ve worked in collaboration with a number of people, including Richard Norman at the University of Utah, to develop this electrode array system. The array consists of a 4 × 4 mm platform, about the size of a baby aspirin, which has hairlike protuberances that can pick up the neural signals.

The detector system we’ve developed now is passive. Each signal comes out to a multiple connector plug roughly the size of



Neuron action potential figure

Used with the permission of Eric H. Chudler, PhD, Department of Anesthesiology, University of Washington, Seattle, WA.

a penny that is mounted on the skull and goes through the skin, bringing the signals to the outside where they can get processed. On the outside, we have placed signal processing computers and equipment. We have all this on the outside, because right now, we're not exactly sure what type of configuration it should take. We could miniaturize it, but we're trying to understand the optimal design features of the amplifiers and computers necessary to process this information and then, by thought alone, allow cursor control.

In our clinical trial, we're trying to determine how well a person can use their own neural activity to control something like a mouse cursor—or more precisely, a neural cursor. In 2004, through the company we founded, Cyberkinetics, we submitted a request to the Food and Drug Administration (FDA) to carry out a small pilot trial of this system in five severely paralyzed individuals. The trial received institutional research board (IRB) and FDA approval, and patients are now being recruited for the trial.

In June, we implanted the first patient, who became paralyzed as a result of a knife wound at C-4. We implanted the array in the arm area of his motor cortex. We have early preliminary data on how his brain could control use of the neural prosthesis.

One important finding is that there are actually neural spikes, the electrical impulses coming out of the arm area of his brain's motor cortex. Remember, this area has been cut off from the body, in this case, for several years as a result of the spinal cord injury. Function of a neural prosthesis would require that thinking (not acting) was sufficient to create activity in motor cortex—that is, "If he thinks and tries to activate motor cortex, could he activate it?"

In a very exciting but simple initial demonstration, we found that, in fact, he could modulate neurons voluntarily by thought. This not only has profound implications for control devices but also says that a piece of the brain that has been cut off is active

and can be controlled voluntarily, which has many implications for where we go with therapies. Because these neurons appear to remain viable, perhaps we could coax them someday to grow back to their ordinary targets in the spinal cord. Let me tell you how the spike activity of these neurons is affected when the patient is thinking about moving. When we said, "left," there was a big burst of activity on one of the channels we were monitoring. Then he relaxed and activity diminished. When we said "left" again, you could see that merely by thinking about moving his hand to the left, he's activated activity again. This was the first big step in realizing we could possibly build something that could drive devices.

We're now investigating how well your thoughts can replace movement. We came up with a type of video game for the participant so we could measure his abilities. This video game has two kinds of targets—the square targets you avoid and the little bell targets you hit. The cursor is under the participant's neural control, and he's not perfect, and sometimes he hits a square target that he didn't want to hit. But this is without any training; it is completely with direct decoding. We saw that he can use that cursor.

As the game progressed, we noticed that although he's not perfect, he is able to move the cursor to get to the target he wants to hit and appears to be able to avoid some targets. The performance seen in this early data is not as good as that from an able-bodied person, but the trial is designed to learn the extent of control.

Just think, if you could have a signal like that, something that could provide an X and Y signal, what could you do with it? What kinds of technologies could you couple it to? I want to tell you about some extremely early demonstrations of possibilities. For one, we have set up a very primitive computer desktop, in other words, an interface, on the computer monitor. This simplified desktop consists of large icons for his controller, a simple email program, and a paint program.

During the evaluation, the patient is able to talk about what he's going to do, selecting a task and actually doing it. He can actually select a task and do it. He can open his email program and read the mock email messages we created. He did this entirely on his own, and it was extremely difficult. We also had the patient use the paint program to try to draw a circle on the monitor. On the third attempt he was able to complete a closed loop.

Is this a change in behavior learning? It is too early to make a judgment. But I think it's extraordinarily promising what the participant might achieve with this technology. In addition, a lot of discussion has revolved around what might you be able to do with these kinds of signals other than interact through a computer—although I maintain you can do almost anything through a computer.



This typical electric hand, shown with its cosmetic cover, was supplied by Liberating Technologies, Inc., of Holliston, MA. It is manufactured by RSLSteeper in the UK.

With the use of a prosthetic hand that was generously lent to us by Liberating Technologies, Inc., we asked the patient to imagine

squeezing and relaxing the hand, which was coupled to transducers that would drive motors of the artificial hand. We observed a trace of spiking input from the participant's brain as he thought about opening and closing the hand. We recorded the spikes and played them back into this artificial hand. The hand has a motor-driven grasp, which we adjusted to open and close with neural activity—demonstrating that, in fact, you can use neural activity to drive prosthetic devices. Most importantly, we can use these activities not only to drive computers but also to drive a variety of prosthetic devices. As you'll hear from Dr. Hunter Peckham in a few minutes, a potential exists to take this technology and couple it up to the muscles through a functional electrical system (FES). Someday, someone will stand up here and say, "By the way, I'm a tetraplegic, but I have a BrainGate in my head, I have an FES in my arm, and I'm moving in a natural way."

"In a very exciting but simple initial demonstration, we found that the study participant could modulate neurons voluntarily by thought. This not only has profound implications for control devices but also says that a piece of the brain that has been cut off is active and can be controlled voluntarily."—John P. Donoghue

Not only could we take signals from the arm area, but—we haven't done this yet—it would be valuable to take signals from the leg area for paraplegics or even tetraplegics to increase access to mobility. They could possibly move their legs and support their own weight, which could have effects on bone and muscle health as well as cardiovascular benefits.

Next generation systems will really have a bunch of challenges. Right now, we have a technician who helps manage the machines, and there are a lot of computers on the outside. All of that stuff needs to run itself. It needs to be on the inside, fully implantable and wireless, so we can realize this dream of people walking around, or at least being mobile with their arms when they're a tetraplegic.

We have made some progress, although a tremendous amount of work remains. I want to point out a couple of advances that were done in the lab of Dr. Arto Nurmikko, a collaborator of mine at Brown University.

We have a 3-volt power supply that can be driven by light. It is about the size of a strand of spaghetti. If someone put a fiber-optic thread next to it, you could use it to power chips that are inside the head. The other thing going on in Dr. Nurmikko's lab is to take a computer or an amplifier system and shrink it all down to be integrated into the chip. That's

also a formidable challenge. We're working on a prototype of a 16-channel version that doesn't have a computer on board but has 16 amplifiers integrated onto the back of it. Not a trivial thing to do. We're making progress, so I think a fully implantable miniaturized system is realizable. We also have a dream scenario, where we've actually replaced parts of the nervous system that are not functioning correctly with sensors in the brain—perhaps wirelessly, or with fiber optics, or wires—coupling to controllers inside the body that communicate to assistive technology on the outside or to the muscles on the inside.

Neuromotor prostheses can reconnect the brain to the muscles but can also link up the brain to assistive technologies, either for individuals who are paralyzed or for those individuals whose muscles are unable to function.

I'd just like to close by pointing out the needs that I see in getting assistive technologies into the marketplace, having gone this route from the laboratory into early clinical trials. We really do need more fundamental research in neuroscience, engineering, computer science, and applied mathematics. All of those fields are contributing to this endeavor.

In addition, we need interdisciplinary groups of scientists, engineers, and healthcare professionals. Some barriers are present. We need to do everything possible to make sure that graduate students in neuroscience and in engineering understand the healthcare needs of disabled individ-

uals. Of course, we need enhanced support for the development and translation of neurotechnology to the public. And by enhanced support, I don't only mean money, because we always want more money for research and to develop the science. By support, I mean we need Federal agencies and private agencies to help academics and inventors to move this technology into the commercial sector.

This is a very difficult road, and I think if we can break down those barriers, it will really help us move these things into the marketplace where they can be available to everyone. Thank you very much.

Bio:

John Donoghue, PhD, is the Henry Merritt Wriston Professor and Chair of the Department of Neuroscience at Brown University. Professor Donoghue also serves as Director of the University's Brain Science Program. In 1998, he and Nobel Laureate Leon Cooper and Field Medal Winner David Mumford were the driving force behind the creation of the Brain Science Program, an interdisciplinary research collaborative that aims to advance our understanding of brain function, human behavior, and nervous system disease. Professor Donoghue cofounded Cyberkinetics, now a public company headquartered in Foxborough, Massachusetts. He is the author of more than 100 research articles, book chapters and abstracts, which have appeared in publications such as Nature, Science, and the Proceedings of the National Academy of Sciences. Professor Donoghue earned a BS degree in biology from Boston University, an MS degree in anatomy from the University of Vermont, and a PhD degree in neuroscience from Brown University. He joined the faculty in 1984 and became the founding chair of the Department of Neuroscience in 1992.



Panel Discussion



Dr. Joseph F. Rizzo III

*Codirector, Retinal Implant Project,
Boston VA Medical Center (VAMC)
Associate Professor of Ophthalmology
at Harvard Medical School*

Thank you very much for the opportunity to speak here today. This meeting is devoted to the discussion of disabilities, and we should be mindful of the fact that we rarely see those individuals with the most severe disabilities. A giant spectrum of disability exists in the general population.

The field that means the most to me in my professional work is vision. I'll tell you a little about myself and how I got into my research and how it might be relevant to our long-term goal.

Originally, I was a neurologist, and within neurology, I found the visual system to be the most interesting. Then I became an ophthalmologist and, subsequently, a neuro-ophthalmologist, and I still see patients two days a week.

Retinal Prostheses: How Close Are We and Who Will It Help?

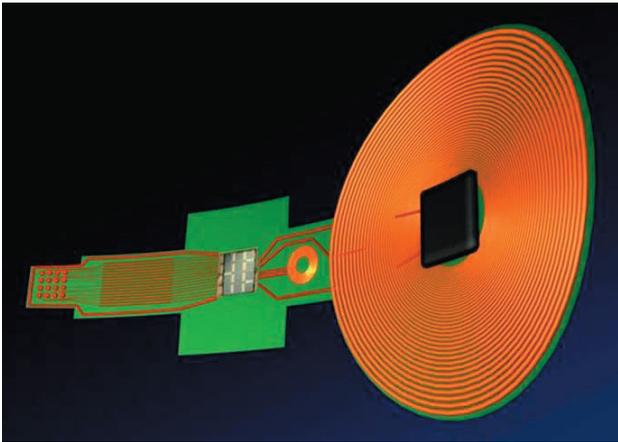
It has been that opportunity to work with patients individually as their doctor—to come to know them and understand their problems—that has motivated me to try to help people more by doing research. If I'm lucky, my research will make it possible for me to help a large number of people, people whom I would never meet in my capacity as a physician. The balance between helping individuals in the role as a physician and hoping to help a large number of people in my research led me to begin our program at Harvard Medical School/Massachusetts Eye and Ear Infirmary.

I want to tell a personal story, if you can indulge me for just a moment. The Department of Veterans Affairs (VA) has played a large role in my work. There are two reasons I wound up joining the VA team. One of those was my father, who served in World War II in both Europe and the Pacific and received a Purple Heart and a Bronze Star and who just passed away very recently. Today, in fact, would have been his 82nd birthday. Now, to return to my research, let's think for a moment about the kinds of patients we're trying to help, for example, veterans at our VA hospital in

Boston. The patients we're most likely to help early on are those who are severely blind, primarily from retinitis pigmentosa. They can get around reasonably well with a cane, but just think what it would be like if I were that person right now and I wanted to leave this room without asking someone for assistance. It would be essentially impossible.

You can understand what a hazard it would be and how likely it would be that I would run into someone or something and possibly hurt myself. I consider our primary goal to be improving quality of life for severely disabled patients so they can ambulate independently and safely in an unfamiliar environment.

If we are ever fortunate enough to achieve our primary goal, we can move onto advanced objectives, such as getting severely visually disabled patients to perform more sophisticated tasks. We should also remember that patients do reasonably well with a cane, so whatever we build has to be substantially better than a cane. Of course, anything we develop would also have to take into account whatever risks and costs are associated with the new therapies.



Overview of the retinal prosthesis being built by researchers at the Boston VA hospital, Harvard Medical School, and Massachusetts Institute of Technology. Only the small square end on the left will enter the eye. The remainder of the device will be positioned outside of the eye. For a sense of scale, the round coil structure on the right is roughly the diameter of a dime. The part of the device that enters the eye is much thinner than a human hair.

This goal to improve vision is a very special VA initiative, first and foremost because of the veterans. Age-related macular degeneration is the leading cause of blindness among veterans and in the general population. Here's a beautiful win-win opportunity not just for veterans but for our population at large.

No available therapy can restore lost function in neural forms of blindness. To be able to do this requires advanced technology, and we've established a VA/academic partnership that has been, for me at least, a remarkable opportunity.

Our project will be successful only if a long-term and comprehensive approach is maintained. These technologies are hard, and they will only be developed if the institutions that work together understand it will take a long time.

Let's think for a moment about the various forms of blindness. The retina lines the back wall of the eye. The retina is nerve tissue, actually a part of the brain that grows forward out of the skull so

it can capture light. It is connected to the visual part of the brain, which is in the back of the skull, by way of the optic nerve. Light enters the front of the eye and strikes the retina. Light goes through the retina tissue. By the way, each retina holds about 150 million nerve cells. It's quite a complicated neural structure.

The rods and cones receive light and create a nerve signal, sending that nerve signal to other cells that sit on the inside part of the retina. Those cells connect to the optic nerve. Light comes in and creates a complicated nerve signal that is eventually transported to the brain.

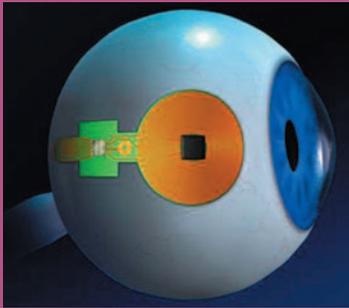
In macular degeneration and retinitis pigmentosa, these rods and cones are lost, but a substantial number of other nerve cells survive. The patients are blind because they no longer have the rods and cones that can convert light to a nerve signal. However, these cells had been formed properly at one point and are sitting there essentially unused. This creates the perfect situation for a prosthetic device to restore vision.

One can build that prosthetic device to put underneath the retina, as we're doing, or one can build a prosthetic to put on the inner surface of the retina, as one of the Al Mann companies, Second Sight, is developing.

The VA has provided a home for our research group for the last three years. I told you there were two reasons I came to the VA. The second was, in fact, Dr. Mindy Aisen [Director, Rehabilitation Research and Development Service, Office of Research and Development, VA], whom I met about four years ago. I heard her give a talk, and she had a clear message of her desire for the VA to be at the forefront of rehabilitative technologies, and also her belief that multidisciplinary programs were important to the long-term success of VA rehabilitation research programs.

That attitude was exactly what we needed. Ultimately, it worked out very well, and we've now

formed this collaboration between Harvard Medical School, the Massachusetts Eye Infirmary—where I see patients—MIT, and the Boston VA.



The device is thin enough to be flexible so that it can conform to the natural curvature of the eye. The eye will be able to move freely after implantation.

We have many other partners, and I have purposefully left one area blank in my presentation. That's because what we really need, ultimately, is a partner to take our device into the commercial realm. We don't have that now, and there are a lot of reasons why. I'll talk more about that at the end.

In other words, developing the technological base is the beginning of the story, not the end of the story.

Our device includes an ultrasmall camera mounted on a pair of glasses that takes pictures—in essence, replacing the lost photoreceptors. The visual information would be sent wirelessly from a transmission coil on the pair of glasses to a receiving coil around the back of the eye. The wireless transmission system resembles an old television set

receiving an airwave. The details of the visual scene are sent into electronics that sit on the outside of the eye, and then from those electronics, the information is translated to the retina to stimulate the nerve tissue.

Very briefly, the substrate, the material onto which we embed the electronics, is an ultrathin material. It's only 10 microns thick, several times thinner than a human hair. Yet it's flexible and contains embedded electronics, which we do with standard microfabrication technologies. The receiving coil is roughly about the size of a dime.

One of the aspects of our design that we think is particularly favorable is the fact that 99 percent of this device—and remember, it's about the width of a dime—sits outside of the eye.

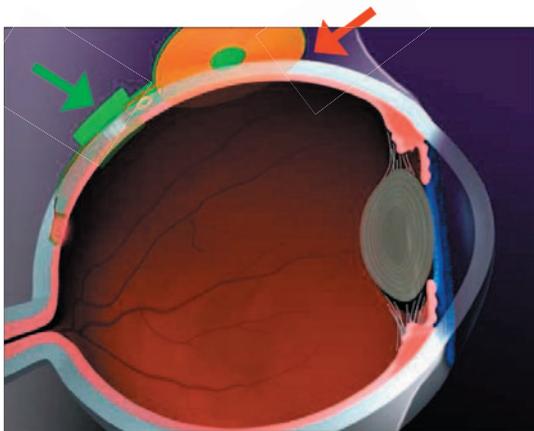
We're trying to develop a minimally invasive approach so that the only thing that goes into the eye is a very, very thin membrane that contains the stimulating electrodes. Our electrodes—and we can readily make hundreds of these on an array as easily as 10 with microfabrication technology—are only 50 microns in diameter, roughly about the size of a human hair. Each one of these electrodes has a wire, so you can communicate to it individually. Only that part, the very end of the structure, is put into the back of the eye. We can do this by raising a very small incision in the back of the eye and then insert-

ing it all underneath the retina. Our hope is that we will be able to implant this type of device without going into the eye, just going through into the back of the eye to reach the retina.

How plausible is it that this kind of a strategy might work? The basic concept is that if you think about light falling on the retina where there are these thousands and thousands of nerve cells, and if you put an electrode array on those nerve cells and stimulate the cells in some particular pattern—let's say a pattern that looks like the letter "E"—it is very reasonable to assume that, because of the anatomy that connects the eye to the brain, a person would in fact see a letter "E." That's a quite reasonable hope. What about being able to read a scoreboard? That's a loftier hope.

To demonstrate how plausible our design is, I want to discuss our best results from the testing of six human patients. In these patients, who are completely blind or nearly completely blind with retinitis pigmentosa, we put one of these ultrathin arrays in the back of the eye. The electrode array includes eight large electrodes and a large number of smaller electrodes. In one instance, we drove those electrodes, and immediately a 72-year-old woman, who had been legally blind for 40 years, reported seeing four clouds. Under the surgical drape, we have them draw, and she drew an image that is a very close

correlate to the pattern of stimulation. Is it possible to restore some vision to patients who have been blind? The answer is yes. If you can accomplish what we did in a relatively brief experiment, there is a hope that we will be able to produce better vision, perhaps creating a letter with a device like the one we are developing. Although this is highly debatable within our field, I would just like to say we haven't been able to get patients to integrate images more complex than very simple geometric shapes.



Cross-sectional view of the eye. Retinal prosthesis rests on the tissue at the uppermost surface of the eye (red arrow), hence invisible externally. Currently developing a minimally invasive surgical technique around the back portion of the eye for implantation of the stimulating electrode array (green arrow).

I've been fond of saying that even if the scientists at MIT provided me with the perfectly engineered device, blind patients aren't going to see any better because I don't know how to use it, nor will they know how to interpret these artificial stimuli. That will take a while to learn. We have to learn how to stimulate. They have to learn how to interpret. The point is, when you think about making a device like this, or any prosthetic device, you have to remember that for a complex behavior you have to learn how to interface with the nervous system. Our field of retinal prosthetics is moving into what I think of as a Phase II. Many very interesting devices have been built. Now our

job is to learn how to use them. This goes back to my neurology background, because ultimately we're moving from an engineered device to working with the nervous system. This is the part of the domain I really love.

I was asked to make a comment how close we are. Well, numerous things are standing in the way. I have to say, as much success as I think we've had, and although I hope we have a lot more in the future, we have faced some significant impediments. I was happy in some ways to hear Al Mann's talk earlier, because I agreed with almost every word he said. No path had been forged for a project like ours at the time we had begun our work. No precedent existed for this type of endeavor.

No Governmental funding program was available for a long-term, high-risk project. In addition, no commercial opportunities were accessible, given that a prosthetic device had to be built. We also did not fit into the drug or pharmacy markets. The device companies, some of which are very successful, typically become interested once the developmental work has been completed.

As a country, we need funding programs for biomedicine to support long-term development projects akin to those at NASA. The individuals who are here today have the opportunity to solve this problem. New ideas emerge typically from academic centers, but academic centers do not have the infrastructure, nor do they have the culture, to know how to transfer these technologies into the marketplace. From our standpoint, institutional and administrative issues have impeded our effort. I will offer my services and time to anyone interested to hear our side of the story. I am eager to help work to try to solve our problem, which I suggest is a collective problem faced by many researchers.

Venture capitalists are often suggested as a solution to our problem to help sustain a large developmental program. But venture capitalists come in quickly and want to get out quickly. Our goals

are completely different. It's already taken nearly two decades to get where we are. It's going to take longer to create higher quality vision. There's a very, very long-term horizon. The question is, how does one sustain high levels of funding for a period of decades without having a return? It's a real problem.

From a technical standpoint, I see three potential problems with the retinal prosthesis. One is their biocompatibility.

As we've learned just recently here in this country, we often find that biocompatibility problems develop long after devices have been implanted. The FDA has a difficult job, but an important one. Biocompatibility has gone well with these retinal prosthetics, but it's still not a completely solved problem.

Power safety is another potentially significant problem. If we want to give higher quality vision, we have to use more electrodes. The more electrodes we use, the more power we need. The more power we use, the more potential damage there could be from the radiation exposure. These are mutually antagonistic forces, and we don't know yet how to resolve the issue. The last potential problem is hermetic encapsulation. Just within the last month, in fact, a significant recall of cochlear prostheses occurred because of problems of this type. Some very experienced companies have trouble solving this problem, and it's because it's

a really tough technical problem. Assuming all of these issues are successfully resolved, I believe that once retinal prosthetics are properly built, we will still need to learn how best to use them. Learning how to use these sophisticated devices will be the core of our research effort for the foreseeable future.

I'd like to thank the VA, the National Science Foundation, and NIH for their support. My program represents just one within the VA's system. You'll hear today

from Hunter Peckham [Director, Cleveland Functional Electrical Stimulation Center]. You heard from John Donoghue [Professor of Neuroscience, Boston University] earlier. The VA has a number of programs with technologies that bear a lot of similarity. A culture flourishes within the VA for developing advanced engineering developmental work for the purpose of rehabilitation. Lastly, I'd like to thank our patients. They almost get overlooked in the partnership with researchers. Of course, they're



The device that is attached to the eye will receive the power that it needs to operate and the details of the visual scene from an external coil that is attached to the sidebar of a pair of glasses. Wireless, radiofrequency transmission will be used to send in the power and information signal to the prosthesis that is attached to the eye. An ultrasmall camera (not shown here) will be positioned on the front of the glasses to capture the details of the visual scene that the blind patient can no longer appreciate. The output of the camera will drive the external (i.e., primary) coil, which in turn will drive the implanted secondary coil. The implanted device will not be visible to anyone looking at the patient because the device will be positioned beneath natural tissues on the front surface of the eye.

the people who are heroic and who make themselves available for the experimentation that gives us the information to be successful. Thank you very, very much.

Bio:

Joseph F. Rizzo III, MD, is an Associate Professor of Ophthalmology at Harvard Medical School and the Massachusetts Eye and Ear Infirmary. He is also the Codirector of the Boston Retinal Implant Project at the Boston VA Medical Center (VAMC) and the Director of the Center for Innovative Visual Rehabilitation at the Boston VA. He earned his medical degree from Louisiana State University in 1978, and completed his residency at Tufts New England Medical Center (1982) and Boston University Hospital (1985). Dr. Rizzo then completed a fellowship at the Massachusetts Eye and Ear Infirmary in neuro-ophthalmology in 1986. Dr. Rizzo initiated the Boston Retinal Implant Project in the late 1980s.



*Drs. Joseph Rizzo (left) and Stacieann Yuhasz,
Editor of JRRD (right)*



Panel Discussion



Dr. P. Hunter Peckham

Director, Department of Veterans Affairs (VA) Center of Excellence in Functional Electrical Stimulation, Cleveland VA Medical Center (VAMC)

I am honored to be asked to speak to you today.

Dr. Mindy Aisen [Director, Rehabilitation Research and Development Service, Office of Research and Development, VA] gave me the title for my talk, "Paralysis: Natural recovery versus assistive technology?" However, as I will try to demonstrate to you natural recovery and assistive technology are not competitive. They are complementary approaches to functional recovery.

Natural recovery can be enhanced or hastened by employing technology. Assistive technologies, such as neuroprostheses that interface directly with the nervous system, can improve function, even in the absence of natural recovery. Our center, one of the national VA Rehabilitation

Paralysis: Natural Recovery Versus Assistive Technology?

Research and Development Centers, is focused on developing ways of using functional electrical stimulation (FES) in the peripheral nervous system. What can this do? Of course, many of you know that electrical stimulation can make muscles contract. It can also do numerous other things—stop spasms and activate or suppress networks of cells. Many of us also know about deep brain stimulation and the incredible impact it's having on movement disorders. Deep brain stimulation activates groups of neurons and modulates the activity of groups of neurons.

In the case of peripheral activation, we're working in the domain of cases where the nerves are intact from the spinal cord out to the muscles. This technology can potentially impact groups of people, such as people with spinal cord injury, hemiplegia, head injury, and cerebral palsy.

Much of our focus has been focused on spinal cord injury and how FES could impact the functions of the body. How do we do that? How do we interface and do this in a safe, effective, reliable, robust way that meets the needs of the individual with a disability? To demonstrate this

impact, I would like to present some specific examples of how FES might be used or is being currently used. Those areas are exercise and muscle conditioning, retraining, and neural prosthetics.

Neural prostheses can have many different applications—bowel and bladder control, upper extremity, lower extremity, standing.

The use of FES for exercise and muscle conditioning has been highly publicized by the extensive exercise regime the late Christopher Reeve endured throughout the time of his post-spinal cord injury.

A second way FES can be beneficial is for retraining, perhaps taking advantage of the neural plasticity of the nervous system, perhaps in conjunction with body weight-supported walking and robotic therapies. The third scenario is a neural prosthetic, a substitutional approach.

In the area of exercise and muscle conditioning, pressure ulcers are a huge problem.

What can we do to manage these? Neuromuscular electrical stimulation can alter intrinsic and extrinsic pressure ulcer risk factors. Some of the intrinsic properties that can cause pressure ulcers are muscle atrophy and decreased blood supply. Electrically induced exercise can build muscle mass, increasing blood supply and decreasing atrophy.

We've built muscle mass for neuroprosthetic applications with percutaneous electrodes implanted in the buttock region to stimulate some of the muscles. This simple application increases the size of the muscle, providing cushioning and vascularity to the muscle. Pressure distribution is also modified, which is very important in terms of maintaining tissue health.

The second example is more complex and is evolving as we speak. The idea of retraining involves the activity-dependent plasticity of the nervous system. Once again, we have employed a percutaneous approach for stimulating muscles in the shoulders of people who have subluxed shoulders. Their shoulders have "fallen out of joint," which causes severe pain. With implanted percutaneous electrodes, the shoulder comes back into joint, the subluxation is reduced, and pain is diminished. In some cases, when the pain eases, the patients begin to use their shoulder and function improves.

Another example is using residual voluntary function to trigger activation of paralyzed muscles. We trigger the stimulation of hand muscles with the activity that remains in the wrist extensor muscles, causing the hand to open. Here, a muscle that has voluntary control is activated, and the stimulation can be applied to that muscle or a synergistic muscle (one working in accompaniment with that muscle) to regain use of the hand. We call that an electromyographic (EMG)-triggered stimulation.

Looking at the control group versus the treatment group, EMG-triggered stimulation does not work in all cases. Patients have to have some level of

function, but they do experience a greater return to function after applying this technique. Again, we don't understand why, but our research is working to understand the basis.

Functional electrical stimulation (FES) can be used for exercise, muscle conditioning, retraining, and neural prosthetics.

In addition, we are exploring a combination of body weight-supported walking and FES to enhance movement. We're beginning to learn how this technique can be used in rehabilitation to restore function, but we need to know the mechanisms. In this area, Dr. Igo Krebs' robotic system is being developed in conjunction with Dr. Janis Daley's work at our Louis Stokes Cleveland Veterans Affairs Medical Center (LSCVAMC).



Physical therapist from the Cleveland FES Center, VA Center of Excellence, Stroke Relearning Program, led by Dr. Janis Daley working with stroke survivor to regain upper-limb function

What happens if recovery patterns cannot be facilitated? Then we might consider a neural prosthetic approach. Neural prostheses can

have different applications—bowel and bladder control, upper extremity, lower extremity, standing.

Technology is absolutely, critically important. The question is how will the technology specifically address the needs of people with disabilities?

We're developing a neural prosthesis for bowel and bladder control. It utilizes, in this case, an implanted receiver, which is an external telemetry device that sends impulses across the skin with a radio frequency technique to an interface with the nerves in the spinal groups pertaining to the bowel and bladder. This device provides voluntary bladder emptying and bowel evacuation.

The cost of the device implanted early on is about the same as a cochlear device. The cost of traditional care—disposable supplies—for people with bowel and bladder control issues is roughly a dollar a day and these are mostly eliminated by the neural prosthesis. After five or six years, the cost of the neural prosthesis is made up and after that, there is a cost saving. If you count in the societal costs, the cost of drugs, and the cost of treatment for bladder infections and other conditions, a neural prosthesis is a less expensive treatment in the long run. Another example of an implanted neural prosthesis is one that we're developing for the upper extremity. Same

fundamental concept: An interface with the peripheral nerves is controlled by myoelectric information from the limb. One of our patients, Annette, was a service dog trainer prior to her injury and has an implanted neural prosthesis in her left hand. She uses the electrical activity, the myoelectric information, from her wrist extensor to control the opening and closing of her hand.

This device is fully implanted, with the exception of an external control and a radio control placed over the device. With this device, she's able to control the opening and closing of her hand, as well as pinch and hold onto objects. Annette can now perform the activities of daily living: eating, drinking, and grooming. The last thing I want to discuss is a standing transfer system that our colleagues Drs. Ron Triolo and Chip Davis is testing. Same basic configuration: The implantable device and external controller, in this case, are controlled by switches on the hand.

One of our patients, Marcus, has a thoracic-level spinal cord injury. With the standing transfer system, he is able to stand up and move into a booth that is inaccessible to him from his wheelchair. The standing transfer system complements the wheelchair as a mobility device and also gives Marcus the ability to perform other functions in an upright position. Another example is someone who has a high level, C5 spinal cord injury,

so transferring people like him from one surface to another is important. It relieves the attendant care needs if the person can lift himself. Standing is provided by the electrical activation. With feet placed on a rotating platform, the person can move from one surface to another, the bed to the wheelchair, for example. In summary, I've tried to explain some of the ways FES might be effective in the peripheral motor system to restore function to the individual. FES complements other assistive technologies. It works in conjunction with the other approaches. FES enables recovery to be more complete, faster, and to substitute for the absence of recovery.

Many new opportunities are coming into place. Brain recording is one of them. John Donoghue [Professor of Neuroscience, Brown University] has told you in the preceding talk about brain recording and activation within dwelling electrodes. New platforms for implantable technology are going to be needed to deliver these tools, as well as new combined therapies and regenerative and neural prosthetic modulation techniques.

We face many challenges. We need to educate and train clinicians and scientists throughout their careers. I cannot speak enough about the importance of making people familiar with these tools during their training. We must prepare the healthcare system for these technologies

as well as demonstrate the cost-effectiveness of these tools. Interdisciplinary teams have been talked about extensively today, and I can't say enough about how essential they are. In addition to interdisciplinary teams, we must facilitate clinical trials. We need to move things into testing and deployment as early as reasonably possible.

With implanted percutaneous electrodes, the shoulder comes back into joint, the subluxation is reduced, and pain is diminished.

We need to manage this regulatory process. It is extremely complex with these new technologies. Many of these new technologies are going to be combinational therapies and the regulatory process is burdensome. Advanced technology has given us great opportunities to enhance the independence and functioning of people with disabilities. The rest is up to us. Thank you very much.



Dr. Stephen Fausti (top left), Dr. Rory Cooper (bottom left), Dr. P. Hunter Peckham (top right), and Laura Schles (bottom right).

Bio:

P. Hunter Peckham, PhD, received a BS degree in mechanical engineering from Clarkson College of Technology, Potsdam, New York, and MS and PhD degrees in biomedical engineering from Case Western Reserve University (CWRU), Cleveland, Ohio. He is currently a Professor of Biomedical Engineering and Orthopaedics at CWRU and also directs the Rehabilitation Engineering Center in the Department of Orthopaedics based at MetroHealth Medical Center (MHMC), Cleveland. He is Director of the Veterans Affairs (VA) Center of Excellence in Functional Electrical Stimulation (FES), a consortium involving the Cleveland VA Medical Center, CWRU, and MHMC. The FES Center focuses on the clinical development and implementation of systems employing FES to restore control of movement in patients with paralysis. The major area of Dr. Peckham's research is in rehabilitation engineering and neuroprostheses. His research focuses on functional restoration of the paralyzed upper extremity in individuals with spinal cord injury. He and collaborators have developed implantable neural prostheses that utilize electrical stimulation to control neuromuscular activation. They have implemented procedures to provide control of grasp-release in individuals with tetraplegia. This function enables individuals with central nervous system disability to regain the ability to perform essential activities of daily living. His present efforts concern the integration of technological rehabilitation and surgical approaches to restore functional capabilities. He is an awardee of the VA Magnusson Award and a member of the National Academy of Engineering.



Panel Discussion



Dr. Hugh M. Herr

Director of the Biomechanics Group, MIT Media Lab

It's an honor to be here.

In my research program, we think about the biomechanics and control of the whole organism—the whole body—down to the individual muscle cell, and we apply these sciences to the development of various technologies: prosthetics, orthotics, and also exoskeletons for human augmentation.

Today, I'm going to speak primarily about leg prosthetics, but a lot of what I have to say is also appropriate for upper-limb amputees as well.

I'll begin with a project that has been underway in my laboratory for many years, and it has been completed. It's now a product. And then I'm going to spend the rest of the time making fun of that device and telling you what's wrong with it and what we need to do as a community.

Multidisciplinary Approaches to Limb Loss: A Chain of Events Leading to a Single Step

The device is a transfemoral external knee prosthesis. We call it the Rheo Knee™ System (Össur, Reykjavik, Iceland), because it uses magnetorheological fluid.

How does it work? The device contains carrier oil and small iron particles suspended in that carrier fluid. We modulate the magnetic field inside the knee, and by doing so, we can vary knee resistance, or damping, quickly and quietly. So, this is a variable damping technology.

We recently compared the Rheo to two systems that have been on the market for quite some time: the Mauch S&S® (Mauch, Dayton, Ohio), a passive hydraulic system, and the C-Leg® (Otto Bock, Minneapolis, Minnesota), which we all are familiar with. The C-Leg® is also a hydraulic unit, like the Mauch, but it's controlled by a microprocessor. In the study, we found that the amount of food energy the above-knee amputee requires to move from point A to point B is affected by these distinct knee designs. We got a small but significant effect with the Rheo, a reduction in metabolic cost or an increase in walking economy. We've looked into the biomechanical mechanisms that might

explain this difference, and what we've found is that the Rheo, because of its different strategy for developing knee resistance or damping, is able to reduce the muscular effort at the hip on the affected side.

In terms of control, the Rheo knee is fairly adaptive. It often does not require a human to program the knee to the patient. The knee adapts its damping parameters to the patient, allowing the patient to walk at different speeds and across different terrains. The Rheo essentially does experiments and optimizes itself to the patient.

Patients with a dumb knee, with no computational intelligence whatsoever, no sensors or whatnot, will have a highly pathological gait for ascending or descending stairs. This is true even for patients who have adapted quite well, whose unaffected, biological limb is quite strong.

With the Rheo, patients are able to walk up steps foot-over-foot. The knee recognizes that patients are going up steps and outputs the appropriate algorithm. Patients are also, of course, able to go down steps. Recently, Össur, the second-largest prosthetic

manufacturer in the world—they're in Iceland—launched the Rheo as a product. It's now available to amputees throughout Europe and the United States.



Rheo Knee™ being used on uneven ground

Moving on, now I'm going to make fun of what I just told you about. What's the opportunity for making advances in this area? What are the issues?

Commercially available above-knee prostheses are variable damping mechanisms. What do I mean by this? I call them fancy car brakes. All they're able to do is dissipate mechanical energy.

The human knee is capable of dissipating mechanical energy, but additionally it's capable of actually supplying a motive force or torque and also acting like a spring and varying its stiffness. We need to do better in the prosthetic knee department.

In the foot/ankle department, current commercially available systems are completely passive, typically spring, devices. In a Flex-Foot design, you don't see an actuator or sensors. Therefore, the system has no ability to adapt to the amputee.

Biologists tell us there's a lot going on in the healthy human ankle. During the early stance phase in level-ground walking, even at a constant walking speed, the stiffness of the ankle is constantly being updated by the central nervous system. In late stance, the ankle supplies a tremendous amount of positive power, a motive moment, which is believed to be very important to human ambulation.

Given the passive nature of today's commercially available prostheses, how does that affect the patient? It causes a pathological gait, a limp, which typically causes excessive impact forces to the musculoskeletal system, which can trigger difficulties later in life, i.e., back problems and what-not. Normally, amputees also require a greater amount of food energy to go from point A to point B, substantially greater. The Rheo knee improved that somewhat, but we have a great deal to go from here.

To really push this area of medicine, we need to merge body with machine, to create an intimacy between the human body and the prosthetic device.

In the interest of time, I'd like to describe two key areas, although other critical issues exist. First, we need better motor systems, better actuators that are muscle-like. Second, we need distributed sensing and intelligence.

Beginning with muscle-like actuation, why are muscles so fabulous? Why do we desire to have muscle-like actuators? Muscle tissue has excellent functional characteristics. It's very mechanically powerful given its size. You can typically get 50 watts per kilogram of muscle tissue for continuous operation.

And muscle is functionally adaptive. We all know this. If we're couch potatoes and we do not exercise, then our muscles become weak. But if we work out, they scale to the task. Muscles are very scalable. They're in small critters all the way up

to blue whales. Muscles are quiet, too. If we were all humanoid robots in this room, powered by a synthetic motor system, gasoline-powered engine, electric motor, whatever, we'd raise a tremendous racket and barely would be able to communicate.

Noise is a really important concern and it's a difficult problem to solve. Could we use muscle tissue in our robots and prostheses? Sounds crazy, but in my group we're actually thinking about this idea of hybrid devices, where part of the device is living tissue and the remaining component is synthetic.

We've built this swimming robot. It's swimming through its own media, which comprises antibiotics, antimycotics, and also glucose to feed the muscle tissues.

So, we might want to think that someday, the prosthetic hand, for example, would be this hybrid device in which we'd use synthetic components only where synthetic components are better than biological components.

That's a hard problem, obviously, and it's going to take a few years to solve. In the short term, what do we do? Now, I want to talk about actuator systems that are muscle-like to some degree.

Several years ago, in the field of robotics, my friend and colleague Gill Pratt developed what's called the series-elastic actuator. It's muscle-like in an

abstract sense because what you have is an electric motor in series or next to a compliant spring, kind of like a muscle belly in series with a tendon.

"To really push this area of medicine, we need to merge body with machine, to create an intimacy between the human body and the prosthetic device. ... In my group we're actually designing hybrid devices, where part of the device is living tissue and the remaining component is synthetic."—Hugh Herr

To control the device, we sense the amount of energy that's stored in the series spring, similar to an artificial golgi tendon organ, and the control system basically controls how much energy is in the series spring or the spring deflection. By doing that, we can accurately control the forces that the system exerts on the world. It's very shock-tolerant, and very force-controllable.

This was originally developed for legged robots. We have a dinosaur robot we call Trudy that is autonomous, carries its own power supply, and walks in 3-D space. Trudy uses these series-elastic actuators. Recently, we've also used the actuators for rehab in my group. We had a gentleman who had suffered a stroke. He had

this classic drop-foot condition where the muscles of the anterior compartment of the leg were weak, so he'd hit the ground on his left side with his forefoot instead of his heel.

We developed a robot that wraps around his leg that pushes on him and restores his gait. With the device, there's a better symmetry between affected and unaffected sides and he's able to walk at a faster speed.

That's one possibility. But this system relies on electric motors. Electric motors are not silent. They're better than gasoline-powered engines, for sure, but you can still hear them.

Electric motors also require a power supply. We're often constrained to use battery technology, which has a rather poor energy density.

What about artificial muscle? This doesn't help us in the efficiency or the transduction efficiency arena, but it may help us in terms of the fact that artificial muscles are linear and they're also very quiet.

There is a series of muscles, electroactive polymers, that has been developed by SRI International in California, by Roy Kornbluh and his colleagues. In my view, their artificial muscles are extremely impressive.

They've done sort of a finger-type embodiment. It's activated by applying high voltages. They've already used the muscle

in biomimetic-type robots. They also have a giant fly, where the muscles are distorting the thorax of the machine, which flaps the wings. The fly can actually get off the ground, but they have no idea how to control it.

What are the remaining issues? One is a scaling issue. At SRI, they're very good at building muscles the size of your middle finger, but to build a gastrocnemius is more difficult. Also, there's a cycle life issue. If you keep the strains very modest, just a few percent, you can get a million cycles. However, at physiologic strains of 20 percent, the muscle breaks down quickly.

The muscle requires high voltage, as I mentioned, but if you keep the currents very low, a human can safely interact with the muscle. This is exciting, and I believe researchers in this area will solve these remaining problems.

So, we have muscle-like actuators, and that's indeed important. But how we use the muscle actuators, the muscle/skeletal architecture, is also critical.

It would indeed be a mistake to simply put one motor per degree of freedom. In our body, as we all know, some of our muscles span a single joint and some muscles span two joints and other muscles, polyarticular muscles, span more than two joints. Biologists tell us that this is important for having lightweight limbs, especially distally. Polyarticular actuation is important to have muscles that are proximal that do work and exert control distally.

I'm going to quickly take you through a walking step and give you a sense of how this works and why it's important. A typical walking step has seven stages, from heel-strike to toe-off. At stage three, the hip extends, which, since the foot is on the ground, straightens the knee. As the knee straightens, since we have the gastrocnemius that spans both the ankle and the knee, and that's linked to this massive tendon, the Achilles tendon, that action of actively extending the hip using hip extensors actually pumps energy into the Achilles spring.

Then that energy can, in turn, power the ankle. This is very intriguing because we can think of an above-knee prosthesis in which we actually harness the muscles of the amputee and we use those energies, we transfer those energies past the knee to power the ankle. That's very compelling because in principle one could do this with very small motors and variable damper and passive spring systems. This approach would lead to a low-mass, fairly quiet system. Again, it's not only the muscle-like actuators but also how we use them that is critical.

I'm going to finish with distributed sensing intelligence. Again, I'm going to make fun of my own design. The Rheo is adaptive and it adapts because it knows something about walking—biomechanical knowledge—and it knows something about how prosthetists can adjust alignment and knee resistance to get an amputee to walk better. But the knee doesn't have a direct measure of what the person wants, the user intent. With the Rheo or the C-Leg, or all these systems, the amputee has no way to tell his or her knee that there are stairs up ahead, or there's a pothole.



Rheo Knee™

We, too, are beginning to work with the Alfred Mann Foundation, and—as we all know—they've developed this wonderful technology called the BION. We just heard a talk about functional

electrical stimulation (FES), where the BION can be used to control skeletal muscle. We can also think about the BION as a sensor. We can implant the BION into muscle and measure the extent to which the spinal cord has depolarized a muscle cell.

We recently conducted an experimental session. I got wired up, and we measured my electromyographic signals from my residual limb. Another participant, Sam, wore a Vicon motion-capture system where we measured the state of Sam's leg as he moved his foot/ankle system. We're taking that data and trying to develop models to link the electromyographic signals to my desired movements or biomechanics.

Our plan is, about a year from now, we'll inject BIONs into my residual limb, and then we'll apply these algorithms. When I think about moving my ankle, plantar flexing and dorsiflexing, I'll look down at an active ankle we've developed already in my laboratory that will respond to my movement desires.

This will be very important to the amputee, who will have an active alignment control for going up and down hills and stairs. It will also dramatically increase the dynamic cosmesis of amputee gait. Just a note here: Another very exciting technology that is more preliminary and has not been fleshed out yet is the sieve electrode. One problem that we're

going to face is this issue of an afferent sensory signal. With the BION, I'll have my eyes, my visual system, to look down and to tell me what the position of my ankle is, roughly. And we'll perhaps embed tactile vibration into the socket to give me an additional afferent signal.

What would be fun is to think about the sieve electrode where we transect a peripheral nerve and we get it to grow through the electrode. With this, you have bidirectional controllability, in which you can actually close the loop.

Imagine a future with this type of technology that an amputee would not only be able to walk across a sandy beach but also could actually feel the sand against his prosthetic foot.

I'd like to thank my various sponsors. We are beginning to work with the Department of Veterans Affairs (VA). In the future, the Alfred Mann Foundation will supply us with BIONs and engineering support. The Defense Advanced Research Projects Agency (DARPA) is also a contributor to this work and other projects in my laboratory. And, as I mentioned earlier, Össur, a for-profit manufacturer of prosthetic components, helped us in the artificial knee development.

To summarize, advances in muscle-like actuators, neuroprostheses, and biomimetic control strategies are necessary to in-

crease the merging of body and machine to create an intimacy between the human body and prostheses. It's our thesis that such an intimacy will create a paradigm shift in this area of medicine. Thank you very much.

Bio:

The science and technology research accomplishments by Hugh M. Herr, PhD, have already had a significant effect on physically challenged people. The Variable-Damper Knee Prosthesis has recently been commercialized by Össur Inc. and is now benefiting transfemoral amputees throughout the world. In addition, the Active Ankle-Foot Orthosis is now being commercialized and has the potential for improving the quality of life of millions of stroke patients in the United States alone. Professor Herr has given numerous lectures at international conferences and colloquia, including the IV World Congress of Biomechanics, the International Conference on Advanced Prosthetics, the National Assembly of Physical Medicine and Rehabilitation, the Highlands Forum XXII (Life Sciences, Complexity, and National Security), and the TEDMED International Conference. He is Associate Editor of the Journal of NeuroEngineering and Rehabilitation and has served as a reviewer for the Journal of Experimental Biology, the International Journal of Robotics Research, IEEE Transactions on Biomedical Engineering, and the Proceedings of the Royal Society: Biological Sciences.

Breakout Session Reports

Opening Remarks

DR. AISEN: To open this morning, we have the Honorable Steven J. Tingus, Director of the National Institute on Disability and Rehabilitation Research (NIDRR) in the Department of Education, with a few stage remarks.

MR. TINGUS: Thank you, Mindy. Thank you all for coming today.

The technologies that were presented yesterday are quite exciting. I think they set the tone for the future in medical rehab-directed research, especially on emerging technologies, for all people with disabilities.

I want to applaud the Office of Science and Technology Policy, my colleagues at the Department of Veterans Affairs, the National Center for Medical Rehabilitation Research (NCMRR), and the Department of Health and Human Services for really being part of a great team and bringing you all together to talk about these emerging issues in assistive technology.

I think the findings we will discuss this morning, from yesterday's breakout groups, will be very informative not only for the White House but for all Federal agencies involved in this effort.

I want to thank you all for being here these two days, and I look forward to the dialogue this morning and your findings to really help us move our agenda.

We need to capture this opportunity in the history of our country with regard to people with disabilities and really move things forward, as many of you are doing not only in the research community but also at the grassroots level.

So I applaud you on behalf of the administration, and again, thank you all very much.

Breakout Session Reports

Introduction

Dr. Michael Weinrich

*National Center for Medical Rehabilitation Research,
National Institutes of Health (NIH)*

Good morning. I think the findings from yesterday's breakout groups will be very informative, not only for the White House but for all federal agencies involved in this effort.

I want to thank you all for being here these two days, and I look forward to the dialogue this morning. We need to capture this opportunity in the history of our country with regard to people with disabilities and move things forward, as many of you are doing not only in the research community but also at the grassroots level.

We're going to have the chairs of the breakout sessions present the findings of their deliberations. Each chair will have 15 minutes to submit what their group thought about and what recommendations they came up with. Please wait until the end of the presentation before asking for clarification, making comments, or requesting clarifications.

Then, I'd like everyone to pick their top three recommendations from each group. What are the three biggest opportunities? What are the three biggest impediments?

At the end, if anyone has any energy left, we'll see whether we can synthesize all of this into anything comprehensible. Thank you.

Breakout Session Reports

Transportation Progress, Issues, Challenges, and Innovations for Disabled Travelers

TRANSPORTATION SESSION TEAM		
Ronald Boenau, ronald.boenau@fta.dot.gov	Division Chief	Advanced Public Transportation Systems, Federal Transit Administration, DOT
Bryna Helfer, bryna.helfer@fta.dot.gov	Transportation Services Advisor	Federal Transit Administration, DOT
Hugh Herr, hherr@media.mit.edu	Director	Biomechanics Group, Massachusetts Institute of Technology (MIT) Media Lab
Julie Jacono, wactlar@cmu.edu	Operations Director	Functional Electrical Stimulation Center, Cleveland Veterans Affairs Medical Center (VAMC)
Eric Levey, Levey@KennedyKrieger.org	Assistant Professor of Pediatrics	Johns Hopkins School of Medicine
	Committee Member	American Academy of Pediatrics Committee on Children with Disabilities
Neil McAleer, Neil@vard.org	Managing Editor	VA Journal of Rehabilitation Research and Development
Ronald Schuchard, Ronald.Schuchard@med.va.gov	Director	VA Center of Excellence for Aging Veterans with Vision Loss, Atlanta
Phillip Selleh, pselleh@eadvantage.com	Founder, President, CEO	eadvantage Inc.
David Schneider, david.schneider@fta.dot.gov	Equal Opportunity Specialist	Office of Civil Rights, Federal Transit Administration, DOT
K. Thirumalai,* K.Thirumalai@rsps.dot.gov	Chief Engineer	Research and Special Programs Administration, Department of Transportation (DOT)
Ronald Triolo, ronald.triolo@case.edu	Associate Director of Education	Cleveland Functional Electrical Stimulation Center, Cleveland VAMC
Howard Wactlar, wactlar@cmu.edu	Vice Provost for Research Computing, Associate Dean, and Alumni Research Professor	School of Computer Science, Carnegie Mellon University
Celia Witten, cmw@cdrh.fda.gov	Division Director	Center for Devices and Radiological Health, Food and Drug Administration
Luke Zelly, lukez@disnetwork.org	Accessibility Specialist	The Disability Network

*Session chair



Dr. K. Thirumalai

Chief Engineer, Research and Special Programs Administration, Department of Transportation

The transportation group developed two proposals that we feel worthy of consideration and implementation.

We discussed the issues facing the disabled in transportation, highlighted technologies that can aid mobility, assessed ways to promote research and implementation, and arrived at two overall proposals:

- Coordinate research and implementation of assistive technologies nationally.
- Promote awareness on an ongoing basis of the technologies and accommodations available to the disabled around the country and how to use them.

Difficulties in mobility

• **Vehicle accessibility: Entering, exiting, seating space, facilities.** The disabled face a sequence of obstacles to enter, get about within, and exit mass transit vehicles, as well as to get to their ultimate destinations. Space is inadequate, especially on aircraft, but also on trains and buses. Seating is cramped and bathrooms are small and not easily accessible. Flight and transit de-

lays cause disproportionate inconvenience to the disabled. There is a lack of advance information on the boarding rules, seat layout, and types of accommodations available to disabled people, especially for different types of aircraft and different flights. While there have been several technological advances, they have not had a significant positive impact for the disabled in mass transit yet.



• **Automobiles: A preferred option.**

The most preferred mode of transportation for people with disabilities is the automobile, because it provides independence. Recent Department of Transportation statistics show that 65 percent of people with disabilities use or drive cars, and 12 percent of them have difficulty getting to public transportation. However, it is highly expensive to retrofit automobiles for use by the disabled. In addition, crash testing and safety standards for modified vehicles, and for disabled occupants in any type of vehicle, are inadequate.

• **Too few sidewalks in urban and rural areas, and crossing signals that are not optimized to benefit the disabled.**

The lack of sidewalks and advanced crossing signals is not only a barrier for the disabled to move about as pedestrians, but a safety hazard as well. Crossing signals

are standardized, but there is no system or mechanism to extend crossing times for the disabled, or notification to drivers that a disabled person is nearby.

Strategies to enhance mobility

- **Sidewalks/crossing signals.** More crosswalks with countdowns and audible signals will assist people who need more time to cross and need to know when to cross. Technology also exists to enable crossing signals to detect the presence of disabled pedestrians (e.g., with the use of smart cards carried by disabled pedestrians) and adjust crossing times accordingly. These features should be incorporated into new crossing systems that will be human-centered and provide universal benefit for people with all disabilities. These new systems should be distributed widely in both urban and rural areas.
- **Vehicle access.** Bathroom accessibility, in terms of space of design, should be mandated for all modes of transit: trains, buses, airplanes. An education module could be developed for both airlines and the disabled so that travelers would know important details for each flight, such as the types of accommodations, how to get in and out, etc. These guidelines should be available to travelers in advance of their flights.



- **Autos.**

Auto manufacturers should design more flexible, easily modified cars to make retrofitting less costly for the disabled. Automakers should also be given incentives to develop adequate safety standards and crash testing for auto occupants who are disabled. We should consider funding research to develop crashworthiness tests for disabled occupants.

- **Smart cards and Intelligent Transportation Systems.**

Electronic fare cards ease access for all, but especially the disabled, who may have difficulty handling money. More can be done with existing smart card technology, and the continued emergence of this technology will enable even more benefits. The needs of the disabled should be incorporated into smart card designs, toward the development of an affordable, practical universal card that the whole population can use anywhere, anytime. For demand-responsive paratransit systems—such as shuttle buses for the elderly and the disabled—enhanced scheduling and dispatching software can improve performance, saving time and money. Smart cards can be used to record each rider’s travel habits in a central database, enabling efficient scheduling. Smart transit card systems should be pilot-tested in ways to make implementation feasible locally, regionally, and nationally. Automated vehicle information systems (e.g., electronic displays showing arrival time and destination of the next bus, rail, or subway car) also help the disabled even more than the general population. Vehicle information systems should be expanded and made universal to benefit people with all disabilities (including hearing, vision, and cognitive impairments).



- **Personal digital assistants (PDAs).**

The rapid adoption of personal digital assistants (PDAs) can have profound benefits for the disabled. PDAs include features such as street maps and navigation aids, but could also



provide information on available mobility aids for the disabled. PDAs could be made more cost-effective and practical for the disabled, with systems incorporated to collect and synthesize data in ways to aid mobility.

Solutions to mobility issues

- **Establish a national committee.**

The United States should establish a national committee of experts to review this panel’s findings and coordinate assistive technologies in transportation nationally. Review the progress of emerging technologies to ease widespread adoption. Set guidelines and foster creation of pilot programs. Assess funding and resource needs.

“The rapid adoption of personal digital assistants (PDAs) can have profound benefits for the disabled. PDAs include features such as street maps and navigation aids, but could also provide information on available mobility aids for the disabled.”—K. Thirumalai

- **Develop a national information center.**

A national information center on assistive technologies in transportation should be created to provide a one-stop resource to provide information and guidance on assistive technologies to anyone, anywhere, at any time. We need to establish an institutionalized process to ensure everyone is aware of new and existing technologies and accommodations, as well as how to use them. Greater awareness of available technologies, systems, and accommodations should be fostered through outreach and user education.

For a full transcript of the breakout session on transportation, please visit our Web site at <http://www.vard.org>

Breakout Session Reports

Technology Delivery

TECHNOLOGY DELIVERY TEAM		
Mike Ambrogio, mambrogio@dekaresearch.com	General Manager	DEKA Research and Development Corporation
David A. Appler,* dappler@flcdc.cnchost.com	DC Representative	Federal Laboratory Consortium
Sally Atwater, satwater@acf.hhs.gov	Executive Director	President's Committee for People with Intellectual Disabilities
Dick Baker, Richard.baker@ch.doe.gov	Chicago Operation Office	U.S. Department of Energy
Russ Bodoff, rbodoff@agingtech.org	Executive Director	Center for Aging Services Technologies (CAST)
Conrad Clyman, Clyburn@tatrc.org	Director, Program Integration and Planning	Army Telemedicine and Advanced Technology Research Center
Eric Dishman, eric.dishman@intel.com	Director, Proactive Health Lab	Intel
Robert Greenberg, bobg@2-sight.com	CEO	Second Sight Medical Products
Mark Humayun, humayun@usc.edu	Associate Director of Research	Doheny Eye Institute
Charlotte Irby, charlotte@vard.org	Senior Technical Writer-Editor	Journal of Rehabilitative Research & Development
Brenda Leath, leathbrenda757@aol.com	President	National Consortium for African American Children
William Ledoux, wrlledoux@u.washington.edu	Health Research Scientist	VA Center for Limb Loss Prevention and Prosthetic Engineering
Alfred E. Mann, al.mann@advancedbionics.com	Chairman	Alfred Mann Foundation and Alfred Mann Institute
Duncan Moore, nancyg@seas.rochester.edu	Professor of Optical Engineering and Professor of Biomedical Engineering	University of Rochester
Jeffrey J. Moore, jeffrey.moore@hq.med.va.gov	Technology Transfer	Office of Research and Development, Department of Veterans Affairs (VA)

Paul F. Pasquina, Paul.Pasquina@na.amedd.army.mil	Chief of Physical Medicine and Rehabilitation	Walter Reed Army Medical Center
Dean Scribner, scribner@nrl.navy.mil	Research Physicist, Optical Sciences Division	U.S. Naval Research Laboratory
Janet Valluzzi, jvalluz@ahrq.gov	Service Fellow, Division of Statistical Research and Methods	Agency for Healthcare Research and Quality, U.S. Department of Health and Human Services
The Honorable Ben Wu, [†] ben.wu@technology.gov	Deputy Under Secretary for Technology	U.S. Department of Commerce
Yitzhak Zilberman, yitzhakz@aemf.org	President and CEO	Bioness, Inc.

*Session cochair

[†]Session chair



Ben Wu

Deputy Under Secretary for Technology, DOC

The technology delivery group met yesterday, a wide variety of people representing the three entities that perform research and development in our country: universities, industry, and Federal Government laboratories.

For us to realize the promise of technology in heightening quality of life and increasing independent living options for people with disabilities, we need to take the technology created in our laboratories and move it to the marketplace for commercialization.

When we are able to commercialize, put those innovations, processes, and inventions out into the marketplace, we can pass on the benefits to people with disabilities. We can also improve our nation's economy and strengthen our international competitiveness.

The technology delivery group looked at how we can effectively move technology from the laboratory to the marketplace. How can we make the process more efficient, with a goal of promoting assistive technology (AT) commercialization? Commercialization would encourage a robust United States AT industry. In doing

so, we could then speed up new technologies. We could cultivate a great focus on research and development. A healthy AT industry would also reap economic benefits through growth in exports.

One indisputable fact is that private industry and universities must concentrate on commercialization, because clearly the Federal Government has a poor track record in this area. We are also not equipped to handle the entrepreneurial aspects necessary to take an innovation from the laboratory to the marketplace.

The Federal Government, especially in our nation's Federal laboratories, has very specific missions required for our nation's security and well-being, and these do not include the ability to commercialize.

If we are to have a successful technology transfer structure and advocate commercialization, we need to be able to put it into the hands of industry. This should be done with the right incentives. We have statutory incentives in place already with the Bayh-Dole Act in 1980 and Stevenson-Wydler Act of 1980. Both pieces of legislation recognize that private industry is the proper entity to perform commercialization. Back in 1980, just 25 years ago, when those bills were enacted into law, the notion was actually quite revolutionary. It used to be that if the Federal Government paid for technology and

funded the research, the Federal Government owned it. Therefore, the Federal Government should determine how it gets utilized. In 1980, Senator Birch Bayh (D-Indiana) and Senator Bob Dole (R-Kansas) of the Senate Judiciary Committee pushed through legislation recognizing that not only could industry do a better job, but that industry should be given an opportunity to acquire the spinoffs. Often, those innovations and those new inventions were not necessarily part of the mission of the particular Federal laboratory. For example, at NASA, the Department of Defense (DoD), and the Department of Veterans Affairs (VA), you see new research and new innovations that have applications for people with disabilities. If industries take that technology and transfers it to the marketplace, they can best utilize the spinoff potentials.

It is critical we create the right incentives to get industry interested, willing, and able to put in the resources, energy, and funding necessary to get these technologies out into the world.

Difficulties in technology delivery

- **Research is duplicative.** Myriad laboratories and research institutions focus on individual objectives. Sometimes, their objectives overlap. How do we streamline duplication to create the greater good we seek through technology transfer?

- **Interdisciplinary teams between the Government, universities, and industry are hard to coordinate.**

But not impossible. The Naval Research Lab has teamed with two private companies to actually make technology work in a marketplace situation, and that's extraordinarily difficult. As we move into new fields of technology, such as marrying nanotechnology with information technology and biotechnology, without interdisciplinary teams we won't reap the benefits of innovation. With AT in the realm of spinal cord injury, interdisciplinary teams are going to be the downstream solution. However, our research institutions don't often work in an interdisciplinary environment, which is a major problem.

- **Lack of understanding.**

The Department of Commerce, in conjunction with the Federal Laboratory Consortium (FLC), the Department of Veterans Affairs (VA), and National Institutes of Health (NIH), undertook a study about 5 years ago to understand the AT industry. Today's industry has changed and grown dynamically. It was more cottage industry-oriented 5 years ago, although that aspect still exists somewhat. If you're going to take technology to the marketplace, the people who are going to risk their capital and risk their skills need a current understanding of the AT market, as well as where the industry will be 5 or 10 years from now.

- **Lack of communication.**

We often don't know what's available in the Federal labs. We need to spread that information out into the university community. A solution to an AT problem may come from a DoD laboratory focusing on a totally different aspect of applying the technology. An example of this is magnetic resonance imaging (MRI), which emerged from a Navy weapons system program 30 years ago. They certainly weren't looking for medical applications when developing that technology in the early 1970s.

- **The aging population does not see themselves as disabled.**

One of the things that came out in yesterday's presentation is aging people do not think of them-

selves as disabled. However, AT can be applied to a population that doesn't want to accept that terminology. Perhaps we need multiple vocabularies to broaden the market base, distinguishing between people who have accepted the fact they are physically or mentally disabled, and those who have not.



Nurse with elderly woman

- **A paradigm shift in research and development (R&D).**

Twenty years ago, 65 percent of R&D was performed by the Federal Government. Now, private industry and universities have overtaken the Federal Government. We must recognize this as we try to stimulate the innovation climate, because Government labs are not necessarily where a lot of the next generation of AT devices and products will be created.

Strategies for successful technology transfer

- **Evaluate feasibility of technology.**

If we are to successfully transfer the technology, we need to determine whether or not it will fit into the marketplace.

- **Study intellectual property.**

One member of our group, Alfred Mann [President, Alfred E. Mann Foundation] had a member of his staff look at the patent portfolio of a certain technology. He started out taking a good,

hard look at about 2,100 patents, whittled it down to 500, until he found about 50 patents that could move into a broader market. He also looked at whether or not the Mann Foundation would have to license some of those patents from the patent holders, or whether the patents were blocked. You can't ignore those factors; otherwise you might build this fantastic prototype that never goes anywhere. And that's a frustrating situation.

- **Evaluate realistic business opportunities.**

When examining the challenges of an AT, we must figure out if they can be managed or overcome, or if we need to team up with another agency or entity in order to find a successful solution.

- **Formulate a plausible business plan.**

We must know the size of the market and how it should be targeted. If we don't, we won't be able to raise the capital or survive with the existing capital long enough to bring the product to market. In this scenario, the consumer is the loser. Furthermore, if a product does not sustain itself in the marketplace, it disappears.

- **Prepare a global economic plan.**

If technology transfers are going to work in today's world, we have to think globally. If we don't, the new technology will not transfer successfully, or it won't survive long enough to make an impact.

- **Involve end users in the design process.**

This is a key issue. Consumer product companies always start

with the end user. There is no point in having technology that the end user cannot utilize or effectively embrace. Otherwise, we wind up with a nice idea we put on a shelf in a museum.

- **Look to wide distribution.**

We need to think creatively. The traditional distributors of technology to the marketplace today may not be around tomorrow. The best example of this is Toys R Us, which will be out of business next year. Why? Because Wal-Mart sells more toys than Toys R Us. It's a changing dynamic in the market segment. As we move technology to the marketplace, we've got to adjust the way in which we deliver technology to the marketplace, whether we like it or not, because retail market delivery does not stand still for anybody.

Solutions for successful technology transfer

- **Create a Government incubator.**

The Government traditionally has a big role in basic and applied research, the building blocks of science and technology. Industry tends to be on heavier on the development side, which is why you see few large research labs in the private sector. Places like Bell Labs are virtually things of the past.

Something is missing, an entity that could act as the middleman and coordinate the tech transfer process and the transition to the private sector. Who underwrites the costs and the skill set required to build a prototype? Who solves

the manufacturing problems in order to make the prototype cost-effective and replicable in a manufacturing operation? We thought about a Government incubator that would follow the Fannie Mae model. Would it be possible to create a public/private partnership that would provide a middleman solution?

*“Twenty years ago, 65 percent of R&D was performed by the Federal Government. Today, private industry and universities have overtaken the Federal Government.”—
The Honorable Ben Wu*

- **Formulate a Government simulation of the Alfred Mann Foundation model.**

The government cannot do much more other than to encourage the notion of commercialization. If philanthropists and other prominent figures were willing to dedicate a portion of their foundation or create a foundation, it would be very helpful in not just raising awareness about AT needs, but also in stimulating innovation and bridging the critical market capitalization gap.

- **Centralize information.**

With more than 700 Federal laboratories, several hundred major research universities, and dozens of individual research departments in the country, it is extraordinarily difficult to find out who is working in what areas. We

need to find ways to centrally access research information on new technologies. Additionally, we must streamline the information collection process for emerging technologies so that industry is aware of the technology transfer potential out there.

- **Hold the “lettuce.”**

Are you familiar with the term “lettuce conferences”? They are conferences in which people make recommendations and end up saying “Let us do this. Let us do that.” We don’t want everything to be said and nothing to be done. With a conference as important as this White House Forum, we need to utilize and implement some of the suggestions.

- **Develop a pilot project.**

Perhaps we can develop in conjunction with Congress a pilot project that will employ the Government incubator/Fannie Mae model in a public/private partnership.

- **Commission two studies.**

We need a comprehensive study of the ATs industry to help push the next generation of products to those who need them. An “age-wave” study is also essential, so we can fully appreciate the abilities or the need for ATs to a growing elderly population.

- **Develop incentives and accountability protocol.**

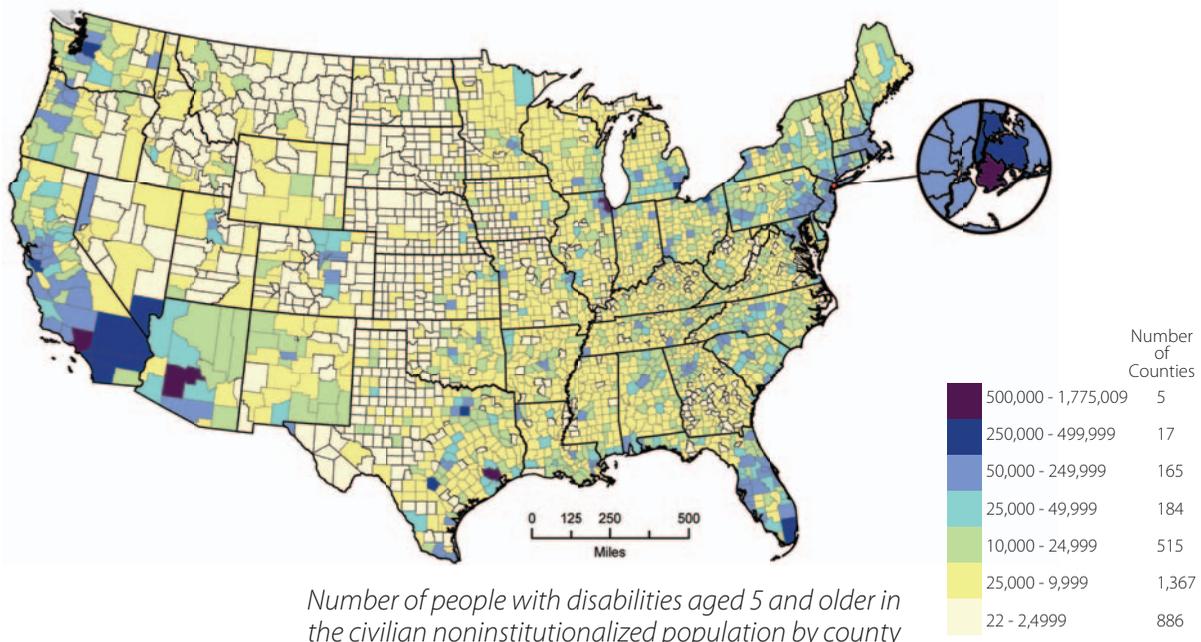
Federal agencies should also be held more accountable for ATs. At the Department of Commerce, we have statutory responsibility for Federal oversight over our Federal technology transfer enterprise. We’ve been working with the Office of Management & Budget (OMB) to make sure that we have accountability in the system that rests not just with the laboratory managers, but also with the secretaries and the people who are in the higher echelons of each department. We must also create incentives for Federal laboratory research teams for successful technology transfer.

- **Create more synergies.**

The three entities that perform research and development in this country—Government, universities, and industry—must work together more efficiently and effectively.

- **Eliminate barriers.**

In order to tap into key foreign markets, we need to eliminate trade barriers for international export. The United States AT industry must be able to export its products in a fair and free trade relationship.



Number of people with disabilities aged 5 and older in the civilian noninstitutionalized population by county

Data Source: Census Summary File 3; Table P42

- **Devise small business strategies.**

Small businesses comprise the heart of the AT industry. Can the Government create a different structure to assist small businesses other than the Small Business Innovation Research (SBIR) program or the Small Business Technology Transfer (STTR) program? Perhaps the Government can provide matching funds or seed capital.

- **Initiate tort reform.**

Legal and regulatory reform will allow new technologies to move most effectively to the marketplace. In particular, regulatory reforms in the area of reimbursement are urgently needed.



Ben Wu

Bio:

Ben Wu, JD (Juris Doctor), was sworn in as Deputy Under Secretary for Technology at the U.S. Department of Commerce on November 6, 2001. In this capacity, he supervises policy development, direction, and management at the Technology Administration (TA), a bureau of more than 4,000 employees that includes the Office of Technology Policy (OTP), the National Institute of Standards and Technology (NIST), and the National Technical Information Service (NTIS). He also participates in activities with the National Science and Technology Council (NSTC), a Cabinet-level council established by the President to coordinate science, space, and technology policy within the Federal research and development enterprise, and is the Executive Secretary for the NSTC Committee on Technology. Prior to joining Commerce, Ben held senior staff positions in the U.S. Congress, where he led on issues affecting U.S. technology and competitiveness policy. He worked in Congress from 1988, having served as Counsel to Congresswoman Constance A. Morella of Maryland and on the Science Committee, first serving on the Investigations and Oversight Subcommittee staff in 1993 and then on the Technology Subcommittee from 1995 until his current appointment. Ben has extensive experience focusing on information technology, biomedical technology, and technology transfer policy. Wu received a BA from New York University in 1985 and a JD from the University of Pittsburgh in 1988.

For a full transcript of the breakout session on Technology Delivery, please visit our Web site at <http://www.var.org>

Breakout Session Reports

Workforce Education

WORKFORCE EDUCATION TEAM		
Mindy Aisen, mindy.aisen@hq.med.va.gov	Director, Rehabilitation Research & Development Service, Office of Research & Development	Department of Veterans Affairs
Paul Aisen, psa@georgetown.edu	Professor of Neurology	Georgetown University Medical Center
Nell Bailey, nbailey@resna.org	Director, Technical Assistance Project	Rehabilitation Engineering and Assistive Technology of North America (RESNA)
Roxanna M. Bendixen, rbendixe@phhp.ufl.edu	Research Assistant, Rehabilitation Science Doctoral Program	University of Florida
Tricia Brooks, tbrooks@crpf.org	Director of Government Relations	The Christopher Reeve Paralysis Foundation
Margaret Campbell,* Margaret.Campbell@ed.gov	Program Specialist, National Institute on Disability and Rehabilitation Research	Department of Education
Dean Cole, dean.cole@science.doe.gov	Medical Services Division	Department of Energy
Rory A. Cooper, rcooper@pitt.edu	Pittsburgh VAMC	Department of Veterans Affairs
Gilbert Devey, gdevey@nsf.gov	Program Director, Biomedical Engineering/Research to Aid Persons with Disabilities	National Science Foundation
John P. Donoghue, john_donoghue@brown.edu	Professor of Neuroscience	Brown University
Patricia Dorn, patricia.dorn@mail.va.gov	Deputy Director, Rehabilitation Research Service	Department of Veterans Affairs
Alberto Esquenazi, aesquena@einstein.edu	Chairman, Physical Medicine and Rehabilitation	Albert Einstein Healthcare Network
Ephraim P. Glinert, eglinert@nsf.gov	Program Director, Human-Computer Interaction and Universal Access	National Science Foundation
Leslie Gonzalez-Rothi, gonzalj@neurology.ufl.edu	Research Health Scientist, Gainesville VAMC	Department of Veterans Affairs
Bert Harman, EPHarman@ottobock.com	President and CEO	Otto Bock Health Care

Frederick D. Isler, Frederickd.isler@fhwa.dot.gov	Federal Highway Administration	Department of Transportation
Christopher Jacobs, crjacobs@stanford.edu	Associate Director, Department of Mechanical Engineering, Palo Alto VAMC	Department of Veterans Affairs
Glenn Klute, gklute@u.washington.edu	Health Research Scientist, Seattle VAMC	Department of Veterans Affairs
Hermano Krebs, hikrebs@mit.edu	Principal Research Scientist & Lecturer, Mechanical Engineering Department	Massachusetts Institute of Technology
LTC Geoff Ling, gling@darpa.mil	Director	Defense Advanced Research Projects Agency (DARPA)
Albert Lo, albert.lo@yale.edu	Rehabilitation Researcher	Department of Veterans Affairs
Michael Manganiello, mmanganiello@crpf.org	Senior Vice President	The Christopher Reeve Paralysis Foundation
Mrs. Claude Mann, al.mann@advancedbionics.com	Co-CEO	Advanced Bionics
Celia Merzbacher, celia_merzbacher@ostp.eop.gov	Project Director, Technology Transfer Office	National Science & Technology Council
Stephen E. Nadeau, snadeau@ufl.edu	Research Health Scientist, Gainesville VAMC	Department of Veterans Affairs
Susan Parker, [†] parker.susan@dol.gov	Director of Policy and Research, Office of Disability Employment Policy	Department of Labor
Anne Plant, aplant@ostp.eop.gov	Agency Representative, National Science & Technology Council	Office of Science and Technology Policy, Executive Office of the President
Peter Rzeszotarski, bqq3@cdc.gov	Deputy, PPE Team	Centers for Disease Control
Joseph F. Rizzo III, jrizzo@meei.harvard.edu	Codirector, Retinal Implant Project, Boston VAMC, Associate Professor of Ophthalmology at Harvard Medical School	Department of Veterans Affairs
Ronald A. Schuchard, Ronald.Schuchard@med.va.gov	Research Health Scientist, Atlanta VA Rehab R&D Center	Department of Veterans Affairs
Dr. Joseph Schulman, carrie.hall@aemf.org	President and Chief Scientist	Alfred E. Mann Foundation
Steven J. Tingus, [‡] Steven.Tingus@ed.gov	Director, National Institute on Disability and Rehabilitation Research (NIDRR)	Department of Education

*Session facilitator

†Session cochair

‡ Session cochair



STEVEN J. TINGUS: I'd like to introduce my co-chair, Susan Parker, and the facilitator, Dr. Margaret Campbell, from the National Institute on Disability and Rehabilitation Research (NIDRR). For brevity of time and her expertise in the employment issues, I'm going to allow Susan to make the formal presentation of our findings from our breakout group. We have listed some key findings and comments that our group has developed. So with that, I turn it over to Susan Parker.



Susan Parker

*Director of Policy and Research,
Office of Disability Employment Policy, DOL*

Thank you very much, Steven. I'm very pleased to be here. I should tell you before I start out, and I won't do any campaigning or platform advancements here for my own program, but I do belong to the U.S. Department of Labor. My organization is the Office of Disability Employment Policy (ODEP). It is the newest of the eleven agencies within the U.S. Department of Labor. Take note: The name of our conference is, "Emerging Technologies in Support of the New Freedom Initiative: Promoting Opportunities for People with Disabilities." At the risk of being perhaps a bit too focused, I am going to confine my remarks to people with disabilities. But I know that I'm among friends, so it's fine.

Thank you very much to the Veterans Health Administration for biting the bullet, as we say in New England, to put on a conference of this mag-

nitude. We do conferences often in ODEP. I have no illusions what the time and what the sweat equity is in putting together an event. I also very much appreciate the diversity in this room. It is a rare opportunity for me, and I know for many others here, to hear the likes of the presenting panels and stars yesterday, all of whom are so very engaged in cutting edge research. Of course, this research all boils down to how it affects humankind. Wow. I can just say hats off to you.

Also thanks to my colleague, Steven Tingus, for doing a fine job in the National Institute of Disability Rehabilitation and Research (NIDRR) for holding the flag, and his colleague, Margaret Campbell. It's a lonely place sometimes in Government with disability, and while we talk the talk, let's remember Abraham Lincoln's words. Let's see if I can get it right in my haste. "The world will little note nor long remember what we say here, but they won't forget what they did here." We're stewards. We talk a lot. It's evident today. It was evident yesterday. We've all got good minds, and it's really a God-given pleasure to think about how it is we can take what it is, the equity is, in our world of research and science and, through the Government, and figure out how to execute the applications. So with that, let's move on.

We had a disparate group. The task was to look at the topic of education and the workforce. Now, that's a wee bit different than transportation, but we also in ODEP work on transportation as an employment support for people with disabilities. Everything we do, it's like a diamond, many facets. But everything rolls back to how it is we look at people with disabilities and what can we do. We had numerous topics. The facilitative staff created five different segments. I'm only going to raise a couple of them.

Difficulties in workforce/education

- **The labor and skills gap crisis.**
We looked at the situations in special education and workforce development curricula. We looked

at the disparity in the demographics in the next 6 to 12 years having to do with many more jobs, fewer people to fill them. People with disabilities need to be tuned up in a more pointed way in order to be able to fill the emerging jobs/skills gap. That's how we say it in Labor, jobs and skills gap. What are the minimal skills or requirements for tomorrow's workforce and how can people with disabilities acquire these skills?

"People with disabilities with Social Security disability status fear a reduction in benefits and loss of healthcare if they decide to join or rejoin the workforce."—Susan Parker

- **Engineering students aren't exposed enough to the needs of people with disabilities.**

A point we raised is that—and this came from one of the esteemed scientists in the group—few engineering students receive hands-on experience in making things work. It says it all, doesn't it? The engineering students don't have exposure to people with disabilities. But they have the desire. They have the sense of wanting to help other people. One of the people in the group raised the point that if there was research money that was sufficient or had the right earmarks or the right language attached

to it, students, when given the choice, would want to get into research applications and development, for example, in robotics, to actually help people with disabilities. I think that's illuminating, and I think it is a value that can form a strong strategy we can send to the White House. We need to catch students younger and introduce them to the myriad satisfactions that come from developing assistive technologies for the disabled.

- **Special education curriculum lacks hands-on experiences.**

The special education curriculum also needs to provide hands-on experience that contributes to mastery. Education is one thing, but providing very pointed experiences that contain learning opportunities from the point of view that people can partake of and can feel better about themselves and what it is they have to offer. We don't do enough of that. Some key points were raised concerning students and training. Educational environments need to be reshaped to concentrate on bringing full educational packages to all children.

- **Teacher training gets a C-minus.**

Focus for a moment on the teacher training. If we're going to address the employment workforce problem, we need to start young. We need to start with these kids when they're in elementary school. It's where the downward spiral into dependency has its start. We have to nip it in the bud, put the emphasis on teacher training that is positively reinforcing, but also at the

administrative level in the special education hierarchies within State departments of education, we need to figure out how to put in maximum investment, banking on the best applications that science gives us, and learn how to translate those findings into use in the everyday classroom.

- **Not enough bread-and-butter education strategies.**

As one person on the team said, "we need to figure out these applications in a bread-and-butter way, not the sexy stuff that gets the big press headlines." The applications for special education and workforce training must broadly disseminate the strategies in a focused way within our educational preparation systems, elementary school, secondary schools, and postsecondary institutions.

- **Too much focus on the elite.**

By the by, we can't focus on



Middle schoolers

people that are going to the top schools in the country. We've got to focus on the middle. The middle is where we're losing children with disabilities. They're dropping out. The dropout rates have never been higher for kids who reach the age of 16 and who are enrolled in special needs education. Didn't know that, did you? Outreach and early intervention

are paramount. Get them early. Get them focused. Use your best teachers. I don't think that's happening now. We must figure out how to get the best and the brightest teachers to work in special education. And we need to reach out to minority neighborhoods and to disadvantaged children, as well as develop programs that are culturally sensitive.

- **Fear of losing benefits.**

People with disabilities with Social Security disability status fear a reduction in benefits and loss of healthcare if they decide to join or rejoin the workforce. In fact, the way the system is set up now, it may be more advantageous—healthcare-wise—for a disabled person to stay on disability and not work.

- **Lack of educational training.**

Educational training for disabled youth and adults reentering the workplace is either virtually nonexistent or insufficient. Special education teaches also need to be trained in the use of assistive technologies in the classroom.



Twenty-first century classrooms

Strategies for successful workforce/education

- **Identify the skills for the twenty-first century workforce.**

Education and the Department of Labor, not strange bedfellows here, need to come together to identify skills for the twenty-first century work-

force. We need to turn this into a research project. We would do this by figuring out how to work with teachers, how to understand teaching in a more effective way these skills at earlier and earlier ages.

- **Consider the extremes.**

One way to get started in studying an issue is to look at the outlying areas, the people at either extreme of the standard deviation curve. Children with special needs who are doing well—why are they doing well? Children with special needs who are not doing well—why? What are those characteristics that we don't typically learn or describe? We need to draw from this information and apply it. It is not enough to have the thing sit on the shelf, but to actually apply it into curricula. Possibly we need to do social science retrospective studies of children that are doing well and not so well. We must make this a high priority—not in 2010, but in 2006.

- **Reexamine existing research.**

Where there is existing research, we need to do systematic reviews to see what is most feasible to implement as pilot interventions. I have a simpler way of saying that and that is that I know the wealth in NIDRR's research—I call it "the policy corpus that's resting." Disability in America has enjoyed a huge amount of research resources. Possibly, it's time to take a second, third, fourth look at what it is we already know and to make a pact among ourselves to not replicate, duplicate, or in any other way do what we've already done before. It's always easier to do something new. It's a little more rigorous, isn't it, to take a look at what we already know and to define—it takes patience—through systematic examination where the niches are in knowledge gaps.

- **Translation, translation.**

Translation was a topic that came up because we know many things about specialties. I listened to the scientists and medical people. We know a great deal about highly technical situations, findings, and applications. We are less adept at taking those findings, and translating them into how a special education teacher in the first grade might benefit from them. Now, if special education

teachers knew something like that and if they understood the value of positive reinforcement with regard to occupational therapy, they could integrate that finding into the classroom. We made the point that it's very costly to do research on translation technology. What language do we need to use to bring it into the curricula? It's on us to figure out how to talk to other people. We are the translators.

Solutions for workforce/education

- **Create incentives for research on affordable technology.**

We need to create incentives for the research on topics like affordable technology. That takes priority setting at the highest levels and an agreement that we need to do it. We must look at these applications for inclusion in the workplace and call it to the attention of the employers. And you don't dictate to employers. You find friendly employers. You find IBM, for example, which we use a lot. And they often talk with other employers. But we call that, very complicatedly, apples talking to apples.

- **Develop assistive technology techniques for workplace and school.**

Although it is very costly to do, we need to perform research that will show us how to translate assistive technologies into educational settings and into the workplace.

- **Reach out to high-growth industries and small businesses.**

We know about the high-growth industries. What we don't know much about is how people with disabilities can contribute to the workplace in these high-growth industries, each with their own sets of unique skills. Also, the majority of America is not made up of large corporations. The fastest growing segment in the world of employment is the small business, defined here as 250 employees and fewer. That's where we need to be going to see about training and retention of employees with disabilities.



High-growth industries

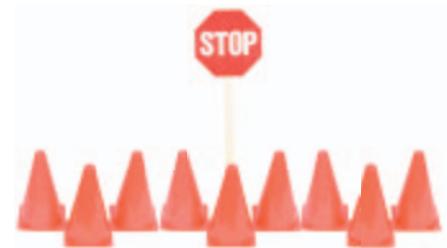
- **Promote distance learning.**

Technology has opened up huge areas for us in the area of distance learning. How effective is it? What do we need to do to bring together greater awareness of what's possible? And it really does come down to what's possible.

- **Establish preferences for end users.**

We must ask the end users of technologies what are their needs and preferences. What are the preferences—and that means choices—of children, youth, re-entry workers, and teachers. All of these people are both the users

and the implementers. Let's not forget to ask the employers what assistive devices and methods of workplace support make a person a better employee? This links the outcome directly back to workplace productivity. We also need to poll educators on how to train engineers from a universal design perspective. And to ask educators and providers what methods are most effective for training teachers.



- **Eliminate roadblocks.**

No discussion in Washington would be complete if we didn't discuss roadblocks because, after all, we're here from the Government and we're here to help, aren't we? Roadblocks in inter-agency collaborations need to be knocked down. Interagency collaboration, thanks to good people who are implementing the New Freedom Initiative, is not just lip service. It's real. How is it real? You can look at Health and Human Services (HHS) and the Office of Disability and see the crossover with how they service the issues with regard to children with what we call complex needs. Many children with complex needs are being kept alive because of the advances in the technology that the wonderful people here in the world of science have created. We have other

issues in implementation in policy that must be responsive to these children with complex needs. It's a health issue, yes. It's an education issue. It's a training set of issues as far as skill-building. It's a parent support issue. It's an economic issue. It's a burden on the family issue. And, on the other hand, it can even be a spiritual issue. All of those facets have to be woven into approaches, and the way to create visibility is for the agencies, the Executive Branch agencies, to come together. I was in Government during the first Bush Administration, left in 1993, worked internationally for 10 years, came back, been here about 2 years now. And I can tell you the degree of interagency collaboration that I see now did not exist in the fullness and the richness and the genuineness that it does now. It didn't exist in anything from '89 to '93. But now people are very much more together, and I do believe we can credit the New Freedom Initiative for that.

- **Get rid of disincentives to work.**

On the sort of negative side, we must tackle disincentives to work, loss of benefits for people with disabilities. In the disability community, there is an enormous fear of reduction in benefits—health insurance, mainly—if a person goes off Social Security disability status and begins working. A huge disincentive exists for people with disabilities who are in the workforce and,

for whatever reason, are getting out—maybe it's a late acquisition on a disability—or for people on the outside seeking to get in. Fear of no healthcare coverage is a huge driver. Understandable, logical. I will tell you, even the Social Security Administration understands this. We must give people with disabilities incentives to work and employers must provide healthcare that is comparable to what was received prior to joining or rejoining the workforce. Healthcare is especially important to people with disabilities, as you can imagine, and their needs and fears must be addressed.

Bio:

Steven J. Tingus, MS, CPhil, has led the National Institute on Disability and Rehabilitation Research (NIDRR) since 2001. Tingus also chairs the Interagency Committee on Disability Research, the Federal committee that coordinates disability and rehabilitative research across Government agencies. Prior to joining the U.S. Department of Education, Tingus was Director of Resource Development and Public Policy at the California Foundation for Independent Living Centers and the Foundation's nonprofit project, the Assistive Technology Network. He earned his MS degree and is a PhD candidate in physiology from the University of California, Davis, where he studied muscular dystrophy and the effect of anabolic steroids on skeletal muscle regeneration.

For a full transcript of the breakout session on Workforce Education, please visit our Web site at <http://www.vard.org>

Breakout Session Reports

Research and Technology Development

RESEARCH AND DEVELOPMENT TEAM		
Dinah Cohen, Dinah.Cohen@tma.osd.mil	Director	Department of Defense Computer/Electronic Accommodations Program
Patrick Crago, pec3@case.edu	Research Scientist	Pittsburgh VAMC, Department of Veterans Affairs
Gilbert Devey, gdevey@nsf.gov	Program Director, Biomedical Engineering	National Science Foundation, National Institutes of Health (NIH)
Eileen Elias, Eileen.Elias@hhs.gov	Deputy Director	Office on Disability, U.S. Department of Health and Human Services (HHS)
Robert Fletcher, rfletcher@thenadd.org	Founder and CEO	National Association for the Dually Diagnosed
Karen Flippo, kflippo@nacdd.org	Executive Director	National Association of Councils on Developmental Disabilities
Margaret Giannini, Margaret.giannini@hhs.gov	Director	Office of Disability, Department of Health and Human Services
Cheryl Bates-Harris, Cheryl@napas.org	Disability Advocacy Specialist	National Association of Protection & Advocacy Systems (NAPAS)
Florence Haseltine, Fhaseltine@aol.com	Director	Center for Population Research, National Institutes of Health (NIH)
William Herman, wah@cdrh.fda.gov	Director, Physical Sciences Division	Food and Drug Administration (FDA)
Robert Jaeger,* Robert.Jaeger@ed.gov	Director, Interagency and International Affairs	National Institute on Disability and Rehabilitation Research (NIDRR)
Vernon Lin, Vernon.lin@med.va.gov	Chief, Spinal Cord Injury Service	VA Long Beach Healthcare System
Wentai Liu, wentai@soe.ucsc.edu	Research Scientist	University of California, Santa Cruz
Toby Long, longt@georgetown.edu	Director, Division of Physical Therapy	Georgetown University
Irene McEwen, Irene-mcewen@ouhsc.edu	Director, Department of Rehabilitation Sciences	University of Oklahoma Health Sciences Center
Celia Merzbacher, celia_merzbacher@ostp.eop.gov	Project Director, Technology Transfer Office	National Science and Technology Council
Emily Munson, munson@ncd.gov	Intern	National Council on Disability

Vivian Owusu, Vivian.A.Owusu@ed.gov	Staff Member	National Institute on Disability and Rehabilitation Research (NIDRR)
P. Hunter Peckham, pec3@case.edu	Director	Department of Veterans Affairs (VA) Center of Excellence in Functional Electrical Stimulation, Cleveland VA Medical Center (VAMC)
Roger Smith, smithro@uwm.edu	Professor, Department of Occupational Therapy	University of Wisconsin-Milwaukee
Lena Stone, lstone@acf.hhs.gov	Program Analyst	President's Committee for People with Intellectual Disabilities
Rick Weidman, rweidman@vva.org	Director of Government Relations	Vietnam Veterans of America
Michael Weinrich, [†] mw287k@nih.gov	Director	National Center of Medical Rehabilitation Research, National Institutes of Health (NIH)
Celia Witten, cmw@cdrg.fda.gov	Director, Division of General, Restorative and Neurological Devices	Food and Drug Administration (FDA)
Stacie Yuhasz, yuhasz@vard.org	Editor	Journal of Rehabilitation Research & Development

*Session facilitator

†Session cochair



Dr. Michael Weinrich

Director, National Center for Medical Rehabilitation Research, National Institutes of Health (NIH)

Thanks very much. Our last group was on research and development. I chaired that, and Bob Jaeger was kind enough to act as the facilitator.

We had a very diverse group. Our group did, however, have quite a number of academics in it. So, being good academics, we of course didn't decide anything. What we have is a whole set of what we thought were opportunities and roadblocks, and a few recommendations. I'll just quickly run through them.

Difficulties in research and technology development

- **Lack of resources.** Not surprisingly, adequate resources for research are scarce. The budget for assistive technology (AT) research is quite small compared to the overall research and development (R&D) budget of the country. A lack of consensus exists on what should be done, given the problem in allocating scarce resources.
- **Information, please.** There's a problem with awareness and affordability of what really

is available. So again, we need to make information available to individuals with disabilities. Also, ATs are useless if a disabled person does not have the means to pay for them. We also see a dearth of awareness from both developers and deployers of technology. And we need better information from end users. That was brought up in several sessions. Again, information from R&D efforts doesn't get to the ultimate users of technology, and there's a problem in dissemination. We get the sense that translation research in AT may lag behind other translational efforts.

- **Technology development is not sexy.** Another impediment is peer reviewers at funding agencies may not have such a favorable view of technology development as opposed to hypothesis-driven research. It's a difficult job, selling the need for long-term research in disability to the general public, many of whom believe they will never become disabled. Some university faculty typically prefers to do basic research rather than applied development. This has to do with university culture and reward systems.
- **Where's the village?** It is in interdisciplinary teams in the academic world, and inter-agency programs in the Government world. We must streamline and integrate the process from basic discovery through to development.
- **Inferior research methodologies.** We need better or validated research methodologies for small

sample, low-incidence conditions in populations. Again, there's a problem of prejudice and negative opinion regarding individuals with disabilities.

- **Humanitarian exceptions are not promoted.** We need better enforcement and publication of the humanitarian device exception issued by FDA that allows development of ATs with exemption from some of the regulatory rules.

Strategies for research and technology development

- **Explore the world of universal design.** Research applications of universal design, with information and education, should also be explored, with an emphasis on the importance of early intervention.
- **Get there early.** Considerable discussion revolved around adequate resources for research and more research needed for diagnosis and early detection and prevention of disabilities.
- **Combine research whenever possible.** We detect an opportunity for combining research in regeneration and functional electrical stimulation (FES) for neurorestoration. Scientists need to find better ways of optimizing the number of electrodes needed for various bioelectric interface projects, such as retinal prostheses.
- **Draw better distinctions.** Helping disability researchers draw better distinctions between basic, applied, and clinical research would be of great benefit to all.

- **Compare injury outcomes.**

We discussed the identification of genetics and proteomics, the issue of natural variation between people who suffer the same injury. Some people recover well. Other people don't recover well. Some of this almost certainly is due to genetics. We need to understand how to turn people who would otherwise have a poor recovery into good recoverers.

- **Develop appropriate outcome measures.**

A brief discussion centered on appropriate outcome measures for AT. For example, if you look at some survey forms, they ask you how far you can walk. But they don't specify what kind of assistance you might need in doing that.

- **Revise common Medicare diagnoses.**

We also talked about addressing the most common diagnoses that cause disability. For example, we don't normally think of congestive heart failure as a major cause of disability, but in fact it's the most common diagnosis in Medicare causing hospitalization. Immediately, when we brought this up, someone pointed out that miniature pumps to assist the heart are becoming available and could be a major improvement in the lives of this very significant population of individuals with a severe disability.

Solutions for research and technology development

- **Create a DARPA.**

Our first solution was to create a Defense Advance Research Projects Agency (DARPA) for disabilities, to provide the "mezzanine" funding, middle-level funding that other people at this conference have talked about. This is yet another option; instead of a Fannie Mae option, a DARPA-like option could be instituted to pick out promising technologies and fund them under a contract.

- **Make cognitive and psychiatric issues a priority.**

Cognitive and psychiatric problems should be a research priority, with research beginning on patients as young as possible. An example of this would be developing research applications of AT

for individuals coping with stress who have communication deficits, i.e., cannot verbalize what problems stress is causing.

- **Establish grand challenges.**

We suggest new initiatives to create interdisciplinary teams at universities with stable, long-term support. For example, what about grand challenge workshops in disability and technology research? The idea is to really publicize grand challenges for rehabilitation and AT that can serve as moon-shot kind of programs, programs that galvanize the national will to put the funding and resources necessary to solve these problems.

- **Broaden AT applications and training.**

We must investigate larger applications of AT. We've heard this from several groups, the importance of broadening the market and the appeal of AT approaches so that they're more usable by the general population. Training for everyday providers of AT on state-of-the-art developments must become a priority.

- **Combine therapies.**

A lot of discussion concentrated on the opportunities of combined therapies—microfluidics, advanced sensors, and simulation. And this included research on tissue engineering, especially the hybrid materials such as biotissue, mechanical interfaces, and nanotechnology and hybrid materials. Researchers could focus on practical applications toward variable geometry sockets for amputees, as well as research on bladder and bowel control.

- **Increase TBI and PTSD research.**

We talked about disabilities resulting from traumatic brain injury (TBI), especially post-traumatic stress disorder (PTSD), and long-term endocrine disorders. This brought up the issue of the physiology of blast injuries. As many of you know, body armor is now saving many soldiers who would previously have died, so they're exposed to much higher blast forces. We need to understand a lot more about what these blasts do, especially to the nervous system, and how to help people recover from these kinds of injuries.

- **Build a better battery.**

Improved battery technologies are necessary for implanted devices, prosthetics, and wheelchair/mobility devices we're going to be bringing to the marketplace—perhaps using MEMS (micro-electro-technological systems) technology or sensor technology. Databases of what we actually have available in AT must be improved and expanded.

Bio:

Michael Weinrich, MD, is Director of the National Center for Rehabilitation Research in the National Institute of Child Health and Human Development at the National Institutes of Health (NIH). He graduated magna cum laude from Harvard College and received his medical degree from Harvard Medical School. Dr. Weinrich trained in medicine and neurology at the University of Chicago Hospitals and Clinics and in neurophysiology at the National Institutes of Health. While on the faculty at Stanford University, he developed a computer system to help stroke patients recover speech and language. He was recruited to the University of Maryland to develop a rehabilitation program. He served on the Maryland faculty as Professor of Neurology and Medical Director of the University of Maryland Rehabilitation System until January 2000 when he moved to the NIH. He was awarded the 1998–99 Health Policy Fellowship by the American Academy of Neurology and American Neurological Association and worked in Congressman Ben Cardin's office in Washington, DC, on health legislation.

For a full transcript of the breakout session on Research and Technology Development, please visit our Web site at <http://www.vard.org>

Breakout Summary

Research and Technology Development

The research and technology group focused on ways assistive technology research could be applied to disability issues. They examined the notion of including cognitive and psychiatric disorders in assistive technology research and the importance of looking into research applications of universal design. Considerable discussion centered on more adequate resources for research and more research needed for diagnosis and early detection of disabilities. Their chief findings were as follows:

- **Creating a DARPA.**

A variation on the Defense Advance Research Projects Agency (DARPA) could be created for disabilities, to provide the “mezzanine” funding, middle-level funding that other people at this conference have talked about. Promising technologies would be chosen and then funded under a contract.

- **Devising grand challenges.**

One way to build interdisciplinary teams at universities with stable, long-term support is through grand challenges in disability and assistive technology research.

- **Combining therapies.**

Myriad opportunities exist for combined therapies—microfluidics, advanced sensors, and simulation. These included research on tissue engineering, especially the hybrid materials such as biotissue, mechanical interfaces, and nanotechnology and hybrid materials. Researchers need to focus on practical applications towards variable geometry sockets for amputees, as well as research on bladder and bowel control.

- **Increasing TBI and PTSD research.**

Disabilities resulting from traumatic brain injury (TBI), especially post-traumatic stress disorder (PTSD), and long-term endocrine disorders need to take priority in research areas. Body armor is now saving many soldiers who would previously have died, so they’re exposed to much higher blast forces. We need to understand the physiology of blast injuries and how to help people recover from these kinds of injuries.

- **Building a better battery.**

Improved battery technologies are necessary for implanted devices, prosthetics, and wheelchair/mobility devices we’re going to be bringing to the marketplace—perhaps using MEMS technology or sensor technology.

Technology Delivery

The technology delivery group looked at ways to effectively move technology from the laboratory to the marketplace. They addressed the urgent need to make the process more efficient and to promote the commercialization of assistive technologies. The group’s suggestions included:

- **Creating a Government incubator.**

The Government incubator could follow the original Fanny Mae model, acting as a “middleman” to coordinate the tech transfer process as well as the transition to the private sector. This incubator would be a partnership between the public and private sector.

- **Emulating the Alfred Mann Foundation model.**

The government cannot do much more other than to encourage the notion of commercialization. Philanthropists need to emulate Alfred Mann and create foundations that would raise awareness about assistive technology needs, stimulate innovation, and bridge the critical market capitalization

- **Centralizing information.**

America has more than 700 Federal laboratories, several hundred major research universities, and dozens of individual research departments in the country, making it extraordinarily difficult to find out who is working in specific areas. Research information on new technologies needs to be centrally accessed and streamlined so that the industry can be made aware of potential technology transfer opportunities

- **Developing incentives and accountability protocol.**

Federal agencies should also be held more accountable for assistive technologies. Incentives should be created for Federal laboratory research teams for successful technology transfer.

- **Eliminating barriers.**

In order to tap into key foreign markets, trade barriers for international export must be banished. The United States assistive technology industry must be able to export their products in a fair and free-trade relationship.

- **Initiating tort reform.**

Legal and regulatory reform will allow new technologies to move most effectively to the marketplace. In particular, regulatory reforms in the area of reimbursement are urgently needed.

Transportation

The transportation group developed two proposals worthy of consideration and implementation. Discussions involved the issues facing the disabled in transportation, highlighted technologies that can aid mobility, and assessed ways to promote research and implementation. The two proposals were to coordinate research and implementation of assistive technologies nationally and to promote ongoing awareness of the technologies and accommodations available to the disabled around the country, and how to use them. The group devised these strategies to realize the two proposals:

- **Establishing a national committee.**

The United States should establish a national committee of experts to review this panel’s findings and coordinate assistive technologies in transportation nationally. The committee would review the progress of emerging technologies to ease widespread adoption, set guidelines and foster creation of pilot programs, and assess funding and resource needs.

- **Developing a national information center.**

A national information center on assistive technologies in transportation should be created to provide a one-stop resource for information and guidance on assistive technologies to anyone, anywhere, at any time. An institutionalized process needs to be established to ensure everyone is aware of new and existing technologies and accommodations, as well as how to use them. Greater awareness of available technologies, systems, and accommodations should be fostered through outreach and user education.

Workforce Education

The task of the workforce education group was to look at special education and workforce curricula for people with disabilities. They examined how people with disabilities can be trained and/or educated to be able to fill the emerging jobs/skills gap. The group also discussed how assistive technology could aid in education and training, as well as for adding more disabled employees to the workplace. The group devised the following proposals:

- **Forming incentives for research on affordable technology.**

Incentives for research on topics like affordable assistive technology need to be established. The assistive technology research should include applications for inclusion in the workplace that would be eventually called to the attention of employers.

- **Reaching out to small business.**

The fastest growing segment in the world of employment is the small business, defined here as 250 employees and fewer. The training and retention of employees with disabilities needs to focus on opportunities in small businesses.

- **Promoting distance learning.**

Greater awareness of the potential and effectiveness of distance learning must be promoted.

- **Establishing preferences for end users.**

The end users of assistive technologies—children, youth, reentry workers, teachers—should be polled as to their needs and preferences. Employers should be asked what assistive devices and methods of workplace support make a person a better employee. This links the outcome directly back to workplace productivity.

- **Eliminating roadblocks.**

Roadblocks in interagency collaborations need to be knocked down in order for the New Freedom Initiative to become successful.

- **Getting rid of disincentives to work.**

On the sort of negative side, we must eliminate disincentives to work, loss of benefits for people with disabilities. Fear of losing healthcare coverage is a huge concern for a disabled person thinking of entering or reentering the workplace. We must give people with disabilities incentives to work and employers must provide healthcare that is comparable to what was received prior to joining or rejoining the workforce.

Closing Remarks



Dr. Mindy L. Aisen

I thought I might close with a song. Actually, I would like to thank Susan Parker [Office of Disability, Department of Labor] not only for her eloquent comments but also for making the point that we at the VA are going to publish the proceedings from this conference and put them online.

We are not authorized to come up with formal recommendations. However, we can reference the key points, the questions this group felt begged investigation, and the important issues. I would like to summarize what I heard throughout this conference.

I would like to particularly thank the White House people for hosting us in the lovely venue last evening, along with the Office of Science and Technology Policy (OSTP). The departments of Transportation and Health and Human Services, participated in so many ways. The Department of Labor was a vibrant part of this program, as were the departments of Education and Commerce. Indeed, we brought together many different agencies that seem to have very distinct agendas, but actually we all have a commitment to people with disabilities. People with disabilities are important. Everyone talked about the significance of people with disabilities throughout the conference. Those of us who do not have a visible impairment that makes us conventionally disabled are the temporarily able-bodied. Disabilities touch everybody's lives.

In my case, it's my work, and I have a nephew with cerebral palsy. We are struggling with the public education system and such issues as where do we get electrical stimulation for him, how do we treat spasticity, where do we find organized care in a high-powered university town in this country. So, I can't thank everybody enough for coming here and for your endurance in lasting until the end. I thank you for expressing your opinion, whether you are consumer, an advocate or a formal member of an advocacy organization, or if you represent the Executive Branch. We had representation from Congress yesterday. Clinicians, researchers, academia—we're all partners in this area.

"Clinicians have become very risk-averse. It is important to expand our horizons and think creatively, and not subscribe to old, probably outdated notions about what is possible for our patients."—Dr. Mindy Aisen

I think we need to think about how we can make the issue of disability important to everybody all the time, not just those of us who are disabled or related to somebody who's disabled, or work in the disability community. Peg Giannini [Director, Office of Disability, Department of Health and Human Services], offhandedly suggested that maybe our Government needs a disability czar to constantly remind everybody about how vital this issue is. What do I see that we might have provoked one another to think about throughout this conference? Engineers, once again, need to focus on what is relevant. They need to be more grounded in clinical reality. They should be creative. They should reach for the stars. The presentation by Dr. Donoghue [professor of neuroscience, Brown University] was amazing. That would have been science fiction a year ago.

We must ground these amazing developments in clinical reality, and therefore, a constant dialogue must flow among clinicians, consumers, and engineers. What do clinicians need to do? If you'll excuse the expression, we need to think outside of the proverbial box. We need to follow best practices and guidelines and consider what therapy payers will cover.

We also need to sometimes be creative and imaginative and be willing to participate in the clinical trial that doesn't have absolutely every element that will fit within guidelines we already recognize. Clinicians have become very risk-averse. Risk is not a good thing when a patient is at risk, when the person you're caring for is at risk. Yet it is important to expand our horizons and think creatively, and not subscribe to old, probably outdated notions about what is possible for our patients.

Policymakers, our goal is not cheapest healthcare. Our goal is best healthcare. I hope that the policymakers who are here today will convey that we really must promote innovation, support development, and bring the most current, cutting-edge possibilities through technology to our patients, consumers, and veterans with disabilities.

We need to bring inventors, clinicians, and industry together, probably through more effective incubator and development programs. The three entities that perform research and development in this country—Government, universities, and industry—must work together more efficiently and effectively. Roadblocks to interagency collaboration must be eliminated for the New Freedom Initiative to be successful. Those of us who are the civil servants entrenched in bureaucracy, we need to help more. Our hearts are in the right places, but we have to be less risk-averse. Change is not necessarily bad, hard as it is.

Development is absolutely necessary for rehab technologies to succeed because they aren't an obvious moneymaker. Not yet. Perhaps they never will be for some groups of people with impairments that do not affect large segments of the population.

We have to remember it is our obligation as the Federal Government to step in when the private sector cannot or will not act. For example, the Federal Government needs to get involved in a clinical trial that industry wants to conduct because they know that this information will help them better fulfill their goal, which is essentially to get products to market and to answer to their stockholders and boards. We do need to help every orphan product, every orphan condition. If an appropriate mode for development isn't available, I don't know if we need to replicate Al Mann's very creative, clever, and apparently successful idea. We need to do something and it can't be soon enough.

With that, I would especially like to thank everyone who helped organize and support this conference—my colleagues, the participants, thank you all. Now go home.

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