

Interagency Committee on Disability Research

Public Meeting

Tuesday, August 5, 2008

>> Hi. Good morning, everyone. We're going to get started here. I really want to thank you all for joining us this morning. I'm Jennifer Sheehy, I'm the acting chair of the ICDR, Interagency Committee on Disability research, and acting director of the National Institute on Disability and Rehabilitation Research at the Department of Education.

This is a very important gathering for us, and we really appreciate that you have taken the time and the interest to provide comment to us on coordination of disability and rehabilitation research. I will let our panel members introduce themselves. Actually no, I won't, I'll just do it myself.

Dr. Art Sherwood is next to me, and he is the science and technology advisor for NIDRR. Mark Leddy is with the National Science Foundation. Connie Pledger is executive director of the ICDR. And we have, as you can see, a lot of technology in the room recording your comments, letting people participate by phone. We will be summarizing the comments in a document and sharing it with all of the ICDR members. We use all your comments and input in our planning. We very, very much want to reflect comments from organizations and individuals with disabilities and families in our strategic planning and in our activities. We are also required to do it by statute. So you can be assured that we take this very, very seriously. And I do want to let you know that we will have people here all day until noon. I will not be able to stay the whole time, but we -- I also have Dick Fisher, who is the special assistant to the assistant secretary at the Department of Education who will sit in for me, and of course Art, Mark and Connie will be here until noon, as well.

We also have a session next week on the 13th in the afternoon for others that were unable to come today, and you still have opportunities to submit written testimony, should you desire to do that.

We will not be commenting today on your testimony, but we will be discussing it with our membership in future meetings. So again, thank you very,

very much.

>> Thank you, Jennifer. I'm Connie Pledger, the executive director of ICDR, as Jennifer indicated, I will be serving as the moderator today. We do have people participating by teleconference call, and the proceedings are available through webcast. So welcome to those on the telephone as well as those participating by webcast. We'll get started. The way we'll operate today is that we'll go back and forth between the individuals on the telephone and the individuals participating here in Washington, D.C., and the panel will also read comments of those individuals that will not be present today.

Probably portions of some of those comments, because they're pretty lengthy.

All right, our first speaker today is Catherine Gottfred.

>> Hello.

>> Good morning.

>> My name is Dr. Catherine Gottfred, and I serve as president of the American Speech Language Hearing Association, ASHA, the professional scientific and credentialing association for more than 130,000 speech language pathologists, audiologists and speech language hearing scientists qualified to meet the needs of children and adults with communication disabilities.

Effective communication skills are central to a successful life for all Americans. Communication disabilities greatly affect education, employment, and wellbeing. ASHA believes that more treatment efficacy and effectiveness studies related to indirect and direct intervention procedures are needed to help determine the most appropriate speech language pathology and audiology services. Questions related to intervention, what techniques are effective, with whom, for how long, and in what context, remain largely unanswered for certain populations. Such as children with autism, children with apraxia of speech, adolescents with literacy needs, and adults with traumatic brain injury. ASHA's written comments identify specific ways to improve future research for individuals with communication disabilities, including the areas of early intervention for speech, language, and hearing difficulties as well as literacy and service delivery in schools and various health care settings.

I would like to briefly highlight some of these areas.

Hearing loss continues to be one of the most common birth defects in America. In 1999, only about 22 percent of hospitals screened newborns for hearing loss. Due to combined federal and state efforts, today almost 94 percent of babies are screened for hearing loss before they leave the hospital.

For early hearing detection and intervention, EHDI services, research is needed on the impact of time between identification of hearing loss in infants and the intervention.

Further evidence is also critically needed on the impact of mild hearing loss in speech language delay and the resulting reading and other educational problems. We believe that further committed research in this area will not only radically change life opportunities for these children, but have a very significant effect on reducing long-term costs for school districts.

We also believe that federal research efforts related to early intervention in speech language and literacy should more precisely identify risk factors and generate prognoses. It is important that we clarify the interaction between risk and resilience factors that affect the likelihood or severity of early communication difficulties.

This includes developing methods to increase the accuracy of detecting children in need of these services, and carrying out scientifically sound studies to quantify the efficacy and effectiveness of current intervention approaches to prevent and treat speech, language, hearing difficulties, and resultant reading and writing problems.

With the dramatic influx of seniors anticipated over the next decade, much additional research is needed in the area of swallowing and feeding disorders. Key questions include what are the neurophysiologic relationships between speech and swallowing, and what is the relationship between dysphagia, malnutrition and dehydration.

Neuroplasticity is an important area of disability research because it may be the means to restoration of function in a variety of communication disorders associated with neural injury or disease including stroke, neurodegenerative diseases and neural trauma including traumatic brain injury. The potential for

progress rests in part on the current capabilities to use functional neuroimaging techniques to determine how the regional activation of the brain changes in response to disease, stimulation, or intervention.

We are committed to advancing the knowledge base in prevention, early detection, identification, diagnosis, treatment, and rehabilitation of communication disorders. We are dedicated to providing services that are based on the highest quality of evidence available to make effective communication, which is a human right, accessible and achievable for all.

Again, thank you for the opportunity to provide comments on this important topic. Thank you very much.

>> Thank you. We're going to go to the phone now, please.

>> Mary, your line is now open.

>> Thank you, should I start?

>> Yes, your line is open.

>> I believe we have Mary Lamielle on the phone, is that correct?

>> Yes, should I begin?

>> Yes, Mary, go ahead, thank you.

>> Good morning. My name is Mary Lamielle, I'm executive director of the National Center for Mental Health Strategies. The center focuses on solutions to environmental health problems, with an emphasis on chemical sensitivity, also referred to as chemical intolerances and environmental disabilities as well as on healthy buildings and healthy people. People with chemical sensitivities are an underrepresented, underserved population who suffer greatly due to significant barriers to access to basic necessities of life. People with these disabilities have limited or no access to public or commercial buildings, to employment or educational opportunities, to basic consumer services. They're challenged daily with lack of accessible, affordable, and most significantly, nontoxic and healthy housing and the lack of accessible and appropriate health care and medical services.

People with these disabilities live a life of significant loss. Loss of health, home, family, friends, jobs, educational opportunities, contact with the community, and the American dream, if such a dream still exists.

People with these disabilities suffer because of the government's failure to address the public health problem to research policy development, patient support, public education.

People with chemical sensitivities are frequently not treated with respect. They face discrimination, whether at work, at school, in the community, and their families. They're mocked and ridiculed, many people with chemical sensitivities suffer active and subtle harassment sometimes daily that keeps them from conducting anything that may be considered a normal lifestyle. There's no protection from the ignorance rudeness or meanness. Even the preamble to the ADA recognizes those with chemical sensitivity as disabled on a case by case basis, there are no specific protections.

I would recommend that the ICDR work to catalog action on chemical sensitivities in the appropriate federal agencies to expand and enhance the rights of people with these disabilities. I recommend the ICDR facilitate the creation of an interagency committee on chemical sensitivities to begin to address the research policy development, patient support and public education necessary to meet the needs of affected populations, and to urge congressional authorization and funding for a comprehensive research policy development and education program to address chemical sensitivities and related disabilities, including funding for environmental medical research units.

Environmental medical research units are hospital based research facilities proposed to be used to investigate chemically induced or exacerbated illnesses such as chemical sensitivities, autism, asthma, and ADHD. Such units are also in use in Japan. Little or no effort has been expended to identify the needs of those with these disabilities.

I recommend the ICDR fund an assessment of people with chemical sensitivities, including a look at who is affected, the needs of patients populations, and what could and should be done to begin to address public health problems. I recommend that the ICDR propose people with chemical sensitivities be included as those underserved populations for the focus of the federal collaborative on health disparities research.

The chemical sensitivity community requires your immediate and

concerted efforts to make sure they are included in existing ICDR committees and projects so these issues can begin to get the attention they need and deserve. I recommend the ICDR employment committee focus its attention on workplace and employment needs of people with chemical sensitivities and environmental disabilities. Housing and healthcare are equally critical areas that demand disability research and could be effectively addressed in ICDR committee.

Examination of any or all these problem areas would clearly need to look at the intersection between indoor environmental quality and disability access. Improved indoor environmental quality or IEQ would improve access for all people with chemical sensitivities and be healthier for everyone. The U.S. access boards indoor environmental quality project report includes recommendation for research which would improve access for people with environmental disabilities. The project needs your support and its disability research recommendations could be advanced by the ICDR.

Thank you for the opportunity to provide public comment. I've sent detailed comments with attachments separately for you, and I'd be glad to answer any questions you may have. Thank you.

>> Thank you. I failed to introduce the person sitting next to me, to my left, it's Rana Linnehan, she is monitoring our callers on the phone to ensure everyone who is on the telephone has an opportunity to speak. Also in the audience we have a CESSI member Cheryl Mitchell who is timing. Each speaker will have five minutes to speak, when you get down to one minute a signal will be given to let you know you have one minute. We do have your comments in writing, so if you don't have an opportunity to fully read all of what you've submitted to us, your comments will still be taken into consideration in full by the ICDR. Thank you. Now let's go to Therese Wiley, I invite you to provide comments.

>> Good morning, can you hear me?

>> If you can pull it a little closer.

>> Hi. My name is Therese Wiley, I'm a management policy analyst for the Department of Health and Human Services Office on Disability, I've been

there the last year working on a special project looking at a traumatic brain injury national initiative. It's a very critical need right now with, number one, the injured soldiers coming back from Iraq and Afghanistan, both TBI and PTSD, post-traumatic stress disorder, and both these conditions require so many services and programs. And why I have been on the Office of Disability is to research what exists now, and we've done a very extensive analysis of what is offered through the federal agencies, the NGOs, and some of the private companies that have addressed TBI issues.

But first what I've submitted in writing to you, and you can refer to it with the recommendations at the bottom of the report, are the primary recommendations that we have concluded from this analysis, and what we think TBI survivors really need. But what I want to first summarize is why am I here, why was I brought on to be a special policy analyst in this program. In 1985, I survived a massive cerebral brain hemorrhage. And for those of you who haven't researched brain injuries, my mother, of all people, recently said to me, "Don't tell people you had one blood vessel burst in your brain and you therefore have a few problems happen. It wasn't just one blood vessel bursting," she said, "it's a burst that the blood spreads throughout your whole brain." It's massive. There's a reason it's called a massive cerebral brain hemorrhage, it affects everything.

You have to learn everything. I learned how to walk, I learned how to talk, I had to learn how to swallow, that was the first test I had to get down. If you don't get down that barium swallow test, you're not going on.

So what I'm trying to emphasize is that you just need to learn so much in every regard, depending on what portion of the brain is injured. And when these soldiers come back, they're called, oh, so often, mild brain injuries. There's no such thing as a mild brain injury. Mild just means it impacts perhaps one function, maybe you can't walk for awhile. I was in a wheelchair for two years, they told me you will never walk again.

I said never walk again? This doesn't seem right. My sister said I don't believe it, either. She took me in my wheelchair and dumped me in the first indoor pool she could find. My mother again said don't use that word dump.

She gently took me out of the chair and taught me how to swim again.
Everything takes time.

How did I become a computer programmer? The last 20 years I've been working for the Department of Agriculture as an IT specialist. It doesn't happen like that. It takes training, it takes programs, it takes services. And that's what I'm here to address.

How did I learn to become a computer programmer again? Okay, I have a great family, I've mentioned my mom. My dad was my first computer programming teacher. He said I will teach you again. I said, but dad, the State of Virginia Department of Rehab Services says I am totally nonfunctioning, I don't have to work again another day in my life. Here's my disability check. And it was a pretty penny based on my previous jobs.

But I wanted to work. People want to work. And so he started teaching me on his home computer, COBOL, Fortran, Basic, languages I learned from him in high school.

Do you hear what I'm saying? You may not know those languages, they're kind of antiquated at this point to most programmers, but it's high level programming I was doing. This was after being told you will never work again, you are useless, you are not too smart anymore, baby. You know, that kind of hurts. When you're a determined soul and you have the right support network, you can move on.

>> You have one minute.

>> Thank you. And so I just want to emphasize please consider the outpatient programs that are critical to these soldiers and to anyone like me or anyone in the civilian community. They need OT, they need PT, they need speech pathologists. And then you need training to get back to work. Funding for education is mandatory in this problem we're discussing.

And so I'm sorry I focus on myself so much, but I want you to learn by example. People say you can't. Don't believe it. We just need people like you all that are taking time to say what kind of programs and services can we fund and support those who really need it the most. And everybody here really needs it. So thank you very much.

>> Thank you.

>> Now I invite Sarah Weir.

>> Good morning. My name is Sarah Weir, it is an honor to be here today to testify on behalf of the National Down's Syndrome Society. We are grateful to have an opportunity to speak on behalf of the 400,000 individuals with Down's syndrome and their families. We thank the committee for its continued leadership in various research areas for children and adults living with intellectual disabilities, as well as to allow individuals, stakeholders and parents to provide a variety of input to inform disability research during this forum.

As a result, a number of our parents from local Virginia, D.C. and Maryland affiliates will be testifying on education, employment, housing, and other issues over the two day session.

Down's syndrome affects people of all ages, races, and economic levels. Today individuals with Down's syndrome are active participants in educational, professional and societal aspects of our communities. There are more opportunities than ever before for individuals with Down's syndrome to develop their abilities, discover their talents, and realize their dreams. Each year, more people with Down's syndrome are going to college, finding employment, and living independently.

However, at the goal of our system is to create a society where people with disabilities are to capitalize on these opportunities, we must have a safety net of federal support services to help them achieve their goals. We have a long way to go before our system provides a seamless transition across the life span for people with intellectual disabilities.

There are still many challenges and issues facing our community today. I would like to address and highlight a number of these issues related to clinical care and research this morning.

First and foremost I would like to emphasize the need for a coordinated interagency strategy to address these challenges. We must identify a blueprint to support systems provided to our children, adults and families that create interagency bridges for our community. Science provides a vehicle to better help us understand both clinical care and research associated with individuals

with disabilities, as well as offers an avenue for potential therapies, treatments, and cures.

In order to effectively serve the Down's syndrome community, there must be a coordinated Department of Health and Human Services strategy to bridge research and clinical care treatment across the life span.

Working with DHHS agencies and programs we must determine a holistic clinical care approach to serve children and adults with Down's syndrome. For instance, we have a number of patients who at the age of 30 and beyond still see their pediatrician for a number of conditions. Our patients with Down's syndrome are likely to have a variety of other illnesses. Thyroid disease, diabetes, depression, obsession compulsive disorder, hearing loss, and Alzheimer's disease. We have 33 Down's syndrome clinical care centers in 21 states. However, there are still a large number of regions across the country with no specialized care in Down's syndrome. Working with these agencies and programs within HHS we must expand the network of clinical care centers that provide specialty care; develop and evaluate clinical treatments, best practices standards of care; and ultimately develop and evaluate health care professional training.

The Down's syndrome community is far behind many other conditions. Many who have aligned with this 20th century patient community empowerment movement. We have no patient registry, no biobank, no tissue repository. Without such mechanisms our progress in science is being obstructed.

We need these instruments to help us collect, gather, and analyze data to better inform translational research. Our community often relies on basic science to explain the causes of Down's syndrome and the ways of intervening and treating conditions associated with Down's syndrome.

>> You have one minute.

>> Thank you. There's a need to identify the barriers to care, which would permit development of interventions to eliminate racial disparities and further improve survival of all persons with Down's syndrome.

According to a 2001 MMWR article, major advancements in medical care have developed persons with Down's syndrome live longer. A study found that

this increase is much greater for Caucasians than other races. CDC researchers found no difference between the groups frequency of life-threatening malformation. The difference in care received by persons with Down's syndrome might explain racial disparity and survival.

In summary, federal appropriations for research and surveillance, support services for Down's syndrome activities are quite small compared to other diseases and disorders, some with less prevalence in population.

The National Down's Syndrome Society strongly supports the work of this committee and encourages the continued emphasis on the need for disability research.

>> Your time is up. Now we'll have Mark Leddy read one of the comments that was submitted to the ICDR.

>> I'm going to read a portion of the comments from the Association of University Centers on Disability, from the executive director George Jesien. The Association of University Centers on Disability is highly supportive of the efforts of the Interagency Committee on Disability Research, abbreviated ICDR, to strengthen coordination of disability research. We are pleased to have the opportunity to provide input and identify some areas where we foresee future research needs.

The first heading is greater collaboration on long range research plans. The ICDR is poised to provide a platform to foster greater collaboration among federal agencies when developing long range plans for research. Research efforts within one agency could be enhanced by building upon efforts of other agencies and organizations.

It is also important that across agencies a balanced portfolio of disability research is funded that includes not only randomized controlled trials but also survey research, qualitative research, evaluation research, descriptive and population studies, and other ways of creating new knowledge that will drive policy and provision of effective supports and services.

The next heading is translation of research into practice. Another area where greater collaboration among federal agencies is needed is the translation of research into policy and practice. It is common for individuals with disabilities

and family members to express frustration at the gaps in applying knowledge to practice.

The next category is disability statistics and research registries.

The ICDR could also play a leading role in promoting the inclusion of individuals with disability related problems in many large generic population based studies and databases. This would lead to a better understanding of the status of people with disability and their families to guide policy.

And the last section is trends in emerging areas. Finally, AUCD would like to highlight a few key areas where we foresee trends in future research needs. First, there is growing demand among individuals with disabilities and families to address the transition related needs of individuals with disabilities from adolescence to adult life. Second, coordinated efforts are needed to address the needs of a growing population of individuals with autism spectrum disorders. Third, there are broad demographic trends occurring in the U.S. and globally that will influence the future of disability in multiple ways.

Finally, a fourth area AUCD would like to highlight is disability and health. Significant needs remain for to reduce health disparities for individuals with disabilities, prevent secondary conditions, and improve the overall wellbeing of individuals with disabilities.

Thank you for the opportunity to provide comments and suggestions to the ICDR. AUCD commends your efforts to improve coordination and enhance disability research. We would welcome opportunity to engage with the activities with the ICDR and its subcommittees. We look forward to providing additional suggestions and working with you in the future.

>> Thank you, Mark. I've just been told that we have participants on the phone from Montana, Florida, Maryland and Michigan, thank you for joining us. And I'd now like to invite Lawrence Plumlee to come forward.

>> Good morning. I'm Lawrence Plumlee, a physician and graduate and former faculty member of the Johns Hopkins University School of Medicine. And I'm here as president of the board of the Chemical Sensitivity Disorders Association. Part of my background was as a federal employee in the Environmental Protection Agency and the Public Health Service, where I served

on the committee to coordinate toxicology and related programs, a federal interagency committee.

For over 20 years, the Chemical Sensitivity Disorders Association has worked to encourage research on chemical sensitivities, disseminating clinical and basic science information to scientists and physicians, and providing such information and support to those suffering from chemical intolerances.

As the editor of *The Environmental Physician*, the scientific newsletter for physicians of the American Academy of Environmental Medicine, I work to ensure that physicians caring for chemically sensitive patients ground their medical practices in science.

I've also advised the access board on indoor air pollution initiatives necessary to assure accommodation of chemically intolerant patients.

Significant barriers to access to the basic necessities of life are encountered by persons with chemical sensitivity. We develop symptoms of toxicity from many common chemicals used in workplaces at much lower levels of exposure than healthy people do. Standard setting committees for occupational settings have long recognized that the standards are not sufficient to protect sensitive, but for matter of convenience have often kept the standards higher.

This is reflected in -- state and territorial health officers. Our needs are not being represented, and they're not being accommodated.

The Chemical Sensitivity Disorders Association endorses the recommendation to your committee of the National Center for Environmental Health Strategies. You've already heard Mary Lamielle, the director of that organization this morning. Her extensive comments which were submitted to this committee on the 21st of July recommend in part that ICDR facilitate the creation of an interagency panel or coordinating committee on chemical sensitivities and intolerances. To promote research, policy development, patient support, and public education, that the ICDR urge congressional authorization and funding for a comprehensive research program for chemical sensitivity, including funding for environmental medical research units, that is, clean environments where people can be studied.

The Center for Environmental Health Strategies also recommends that there be a call to access the numbers of people affected, and their needs in the areas of housing, employment, and health disparities issues, consistent with the authority of ICDR.

People with chemical sensitivities often find their lives in upheaval and long for a time when others will understand that these health problems and the very essential need to minimize or eliminate exposures that cause or exacerbate the myriad of reactions that come with exposure to everyday substances and --

>> You have one minute.

>> The access board funded last year a report on an indoor air quality report that makes a number of research recommendations, and recommends that standards be reevaluated for the volatile outgassing of materials from building materials.

So we already have some specific research recommendations that we would like to see funded. And so thank you for your time and attention, and I wish you success.

>> Thank you. I'd like Peter Thomas to come forward.

>> Good morning.

>> Thank you very much for the opportunity to testify today, I'm glad to be here. My name is Peter Thomas, I'm with the law firm of Powers, Pyles, Sutter and Verville in Washington, D.C., and I'm testifying today on behalf of the Orthotic and Prosthetic Alliance, which is a coalition of the four of the major orthotic and prosthetic groups functioning in this country.

I also am general counsel of the National Association for the Advancement of Orthotics and Prosthetics, and that is a group that also belongs to a coalition called the Disability and Rehabilitation Research Coalition. And they will be testifying at your next hearing on the 13th and taking a much broader view than the testimony I'm going to present today. Many people will come today and talk about specific areas of interest, that coalition will present a much broader testimony that applies across disability and rehabilitation research.

But today I'm talking about pretty much the world of artificial limbs and orthopedic braces, and the importance of those, considering the demographic

changes taking place in this country. The significant number of increasing patients that need such care as a result of everything from the war in Iraq, although I must tell you that the number of amputees is much less than you might expect coming back from Iraq. Many people with musculoskeletal and neuromuscular conditions as a result of that service. But more to the point, the demographic changes in terms of age in this country, and in terms of peripheral vascular disease and obesity leading to diabetes, leading to kinds of problems that require orthotic and prosthetic care. Demand is clearly on the rise, and I detailed some specific examples and data in my written testimony.

We strongly support the ICDR's mission to coordinate, collaborate and to -- well, to communicate, coordinate and to the extent possible to collaborate between the federal agencies that engage in the disability and rehabilitation research. And we're thankful and cognizant that there has been some real federal efforts targeted to orthotic and prosthetic research in the recent past, and throughout the past I'd say 15 years at least. NIDRR has been a leader in that area, funding some significant research. The NCMRR and NIH has been funding research in that area. Is my mic on? Should I speak louder?

>> It's ringing in the room.

>> Okay. And so we do, however, feel that the need is much greater than the attention that's being paid to this field.

I think probably most people would say that, only because they are representing and I am representing a specific area of the population. And of course, the problems that exist in the field of orthotic and prosthetics are replicated throughout many different areas, and frankly, as a person who has lived for 34 years with artificial limbs, I can tell you there's a lot that still needs to be done in this field.

And research is a key to that. So we have five recommendations, I'll move through them quickly. The first would be to adopt the IOMs the Institute of Medicine's recommendation to work within the administration to try to propose a significant increase of funding for rehabilitation and disability research across the federal agencies. Not just one specific agency, but to try to take, you know, the IOM in 1997 suggested \$100 million increase in funding for disability and

rehabilitation research. It's going to take that kind of an investment to really gain -- get the gains that you'll need in order to really materially move forward in this area for the benefit of people with disabilities.

The second recommendation is the need for efficacy research and outcomes research in the area of orthotics and prosthetics.

>> You have one minute.

>> And that's a key area, because frankly, there are not very many measurement tools, there's not a lot of efficacy research, there's not a lot of comparative research between the different types of orthotic and prosthetic interventions. There's over 100 different prosthetic feet on the market, and there's very little science that dictates which type of foot belongs to which amputee.

The third recommendation is to really focus on some key items that need addressing in the area of orthotic and prosthetic research, and I've listed a number of those that have already been accomplished by various federal agencies, including energy storing and releasing feet to name one, but there's the state of the science conference that was held that developed a comprehensive list, and that's in the testimony for your perusal.

Finally, the education and training component is very important, and we would hope that the ICDR would take a more active role rather than a less active role in trying to coordinate research across the federal agencies. Thank you.

>> Thank you.

>> Thank you very much.

>> Now, we'll have Dr. Sherwood read some comments for us.

>> Good morning. I'm going to read comments from the American Association of People with Disabilities submitted by Jennifer Simpson. The American Association of People with Disabilities, AAPD, welcomes this opportunity to submit some comments into the record to the ICDR, to suggest specific ways to improve future disability and rehabilitation research to benefit individuals with disabilities.

AAPD advocates for accessibility and useability of all telecommunication devices and services so that people with disabilities are not left out, left behind,

or otherwise excluded by technological barriers, products and services commonly used in everyday life. We address our comments specifically to the research topic of access to assistive technology and universal design.

I'm going to read the titles of the 14 recommendations from the AAPD.

Based on some work conducted at Gallaudet University in support of their recommendations, we believe the following 14 topics should be considered for investigation and research. One, development of techniques to make mainstream technologies used for notification and communication usable by people with disabilities. 2, inclusion with next generation notification technologies. 3, development of accessible communications devices for persons who are deaf-blind. 4, development of methods to apply advanced technologies such as intelligent agents, to automatically ensure emergency information generated in one format is available in all formats.

5, conduct lab and field tests of promising technologies for improved accessibility of emergency communications, working with partners in the public and private sectors and involving people with disabilities.

6, continue to develop technologies for conversion of text based information to auditory information such as text displayed on television screens during emergencies.

7, determine the most effective ways of making EAS television alerts accessible to people who are blind. 8, research techniques for getting local alerts while listening to national or satellite radio.

9, accessibility of NOAA weather radios. 10, study accessibility to planned changes in 911 architectures. 11, demonstrate and evaluate methods of connecting and call handle to 911 using IP text and IP based relay services. 12, research effective and accessible methods of communicating egress or shelter instructions in buildings and building complexes.

13, study human factors issues around alerting people who are deaf-blind. 14, study and disseminate information about accessible user interfaces in video programming and play-back devices.

Presented Jennifer Simpson, senior director telecommunications and technology policy initiatives.

>> Thank you. We time for one more, if you could read one more for us.

>> I'm going to read the recommendations from the American Physical Therapy Association, APTA. On behalf of the 70,000 members of APTA, we thank you for the opportunity to provide testimony to ICDR. APTA appreciates the efforts of the committee and its commitment to public input through these testimony sessions.

Introduction. Rehabilitation research is essential to physical therapists and to the patients we serve. This research creates the evidence with which physical therapists provide interventions to hundreds of thousands of individuals on daily bases. The work of ICDR has and continues to contribute to rehabilitation research that improves the quality of life of individuals with disabilities. Physical therapist researchers have a substantial opportunity to improve the health and safety of Americans through scientific investigation of efficacious and effective treatments and strategies that address impairment, functional limitations and disability.

APTA believes with our nation's changing demographics and overall health status and emphasis on effective rehabilitation intervention supported by evidence will continue to be essential.

As leaders in the field of rehabilitation research the contributions of physical therapists scientists to the mission and work of ICDR should not be underestimated. We appreciate our growing partnership with each of the federal agencies that comprise ICDR.

APTA would like to focus its comments today on issues outlined in the recent Interagency Committee on Disability Research report to Congress on physical rehabilitation research, as well as other issues limiting rehabilitation interventions with persons with disabilities. This report published in March, 2007, is the most comprehensive to date that highlights accomplishments and current state of rehabilitation research among federal funding agencies.

And I'm going to just summarize the recommendations, because there are quite a few.

APTA would like build on its testimony and recommends that ICDR focus its efforts in the following four areas. Increased funding for studies describing

effective dosages of physical rehabilitation therapies, enhanced opportunities for training of new scientists in rehabilitation and disability research, collaboration with nonresearch based federal agencies on evidence of pressing public dilemmas, support for development of a national outcomes database to support rehabilitation research.

In summary these four recommendations complement the areas that APTA recommended in its previous testimonies before this committee. We encourage continued efforts in these areas cited previously, as well as the four priorities we outlined today.

In closing, we compliment ICDR for its March 2007 report, which raises the awareness of the need for physical rehabilitation research. We also encourage the ICDR and the federal agencies that comprise this committee to maintain activities to assure the continued viability and credibility of disability related research.

With the current economic challenges facing this area of health care, APTA is committed to its responsibility to individuals with impairments, functional limitations, disabilities, and changes in health status, and requests that the committee develop and fund programs of rehabilitation research, and train the cadre of researchers that will improve the quality of life for these individuals.

>> Thank you. I'd like Charles Mosley.

>> My name is Charles Mosley, I'm the associate director of the National Association of State Directors of Developmental Disability Services, and we thank you for the opportunity to comment on research this morning. State governments collectively spent almost \$19 billion in the 2006 fiscal year on services and supports furnished to individuals with intellectual and developmental disabilities and their families. When combined with federal matches funds from Medicaid and other programs as well as local revenue dollars, total spending approached \$44 billion in the 2006 fiscal year.

As state developmental disability systems expanded over the years to meet increase demands, services have changed, moving away from segregated institutional models to integrated community settings. 10 states have closed all their institutions for individuals with ID and developmental disabilities. In other

states, the number of persons in large segregated programs has declined rapidly as large static programs based on older institutional models are replaced by flexible service arrays built on networks of public and private provider agencies.

Driven by consumer demands and decreasing revenues, states are increasing relying on family homes as the setting of choice for residential services. The percentage of individuals with DD receiving publicly financed services who reside in the family homes has increased by 45 percent in recent years, from about 392,000 in 2000 to 569,000 in 2006

Significantly the proportion of individuals receiving support in the family's home as a percentage of all service recipients has grown steadily during this period from 51 percent in 2000 to 57.3 percent in 2006.

This shift has had significant impact on the character of the developmental disability service delivery system which has seen the average number of individuals with DD per residential setting in the U.S. decline from 22 and a half in 1977 to only 2.7 in 2006.

State developmental disabilities agencies are only beginning to grapple with the impact of this change on the structure and functioning of their existing service delivery infrastructure.

Research data needs. In this rapidly changing delivery environment, state and federal policymakers urgently need relevant, valid and reliable data to, A, form the development of appropriate and effective public policy, B, guide implementation of effective and appropriate supports, and C, track current performance outcomes and accomplishments.

Frequently in the past decisions regarding deployment of federal research and developmental dollars have seemed to ignore issues of greatest relevance to the service delivery process,

Program administrators as well as practitioners routinely express concern over the lack of clear evidence documenting program designs, models, operational strategies and funding methodologies that have a positive impact on the lives of people receiving support. State developmental disability programs administrators as well as people receiving support, service providers, advocates and family members urgently need information describing and evaluating

effective support, training and funding strategies currently being used to assist individuals with developmental disabilities secure and hold employment in regular community jobs, develop and implement statewide employment first strategies that articulate a clear policy preference towards full employment of persons with developmental disabilities regardless of the intensity of their needs.

Fund and incentivize local job development, on the job training and long term employment supports. Support people with disabilities living in the community in their own homes or the home of a family member. Transition individuals with developmental and other disabilities from school to adult services, to employment. Improve the skills and competencies of the direct support staff and front line supervisors. Ensure individuals with disabilities have access to adequate and appropriate physical and mental health services, housing and transportation. And improve the quality and responsiveness of publicly financed services and supports.

In conclusion, state policymakers need quantitative data on population demographics.

>> You have one minute.

>> Costs and utilization trends over time, as well as empirically sound information evaluating the effectiveness of specific training, treatment and support strategies. Equally important is data describing the impact of the service system on the lives of people receiving support. Policymakers need access to carefully perform qualitative investigations, providing rich descriptive data documenting the meaning, quality and responsiveness from the point of view of the service recipient, analyzing different perspectives on service delivery held by consumers, providers, families, and detailing the specific outcomes received. Thank you very much.

>> Thank you. Barbara Raimondo.

>> Good morning, my name is Barbara Raimondo, I'm a staff attorney at the National Association of the Deaf. Thank you for the opportunity to be here today.

There are many areas that affect the deaf community that deserve research, but I'm going to focus on two today.

One is mental health. It is fair to say that there is almost -- you know, virtually no research on the mental health issues facing the deaf community. When we put the word out to researchers about what the priorities should be in studying mental health issues, the word came back that pretty much any topic you pick is something that has not been addressed sufficiently. And some examples that were given to me are we have almost no epidemiological data regarding base rates of mental illness or mental illness disparities in the deaf population. We don't know with any reliability how mental illness may manifest differently in the deaf population, as compared to the hearing population.

We have almost no tools specifically designed and validated to aid in the assessment of mental illness or health for the deaf population. We don't know which treatments for specific disorders are more or less effective with the deaf population. Very often when deaf consumers are being seen in the mental health setting, they use a sign language interpreter, but we really don't know what the impact of use of sign language interpretation is on mental health services. We don't know how sign language interpreting in a mental health setting affects the sign language interpreter him or herself.

So basically, there are just many, many, many unanswered questions in the area of mental health in the deaf community, and we hope that the agency will consider looking into those issues.

The second topic I wanted to address is emergency notification and communication, and the accessibility of that to people with disabilities. And you heard from -- about this a little bit already from the American Association of People with Disabilities. I will echo our support for those recommendations.

The document that those recommendations are taken from is called Accessible Emergency Notification and Communication, and a copy of that was forwarded when I sent my comments in.

I wanted to highlight just three items in that. One of the items is to study methods of awakening people with hearing disabilities while sleeping in case of an emergency. Now, that's a really basic thing, I mean, for a hearing person if there's a hotel fire, for example, there is an audible alarm that is heard, there may be a strobe light, there probably is some kind of a strobe light. A deaf person

may have some kind of a vibrator on their bed that is intended to help them wake up. And there is really an assumption, there has been certainly in the deaf community, that a vibrator or some kind of flashing light will wake that person up.

But recent research has shown us that that is not necessarily the case, and this is, you know, a real basic problem that needs to be solved, how we wake deaf people in the case of an emergency.

So that's one issue I wanted to highlight.

Another is the concept of streaming text over radio, and there has been some research in this area done by NPR and other webs, and when you look at the lists that you're given from different government agencies or private entities in the case of emergency you should have, and there's a list of things, and almost always they include a radio. And that's a great idea because radios are portable, you can change the batteries in them, and certainly emergency notification information will come over the radio.

Of course, if you're deaf, that's not going to help you too much. So it's very important to look at the research that has been done in captioning radio and improve upon that, so that that kind of information is available to the deaf and hard of hearing community in an emergency.

The third item that I just wanted to highlight this morning is development of accessible communication devices for people who are deaf-blind. Obviously, the purely auditory systems are not going to work for this population, purely visual systems will not work for this population. We really need to look into what needs to be done to make sure that people who are deaf-blind have the same access to emergency information.

>> One minute.

>> As everyone else. Thank you very much.

>> Thank you. And now we'll have Mark Leddy.

>> I'm going to go ahead and read a written comment from Susan B. Matt, Ph.D., JD, MN, RN, the initials after her name. She's from Mercer Island, Washington.

As I am unable to travel to Virginia to attend the public meeting I would like to submit my comments regarding the ICDR research agenda. I find that

much of the funded research today focuses on individuals with serious disabilities. Which is understandable. However, I have seen individuals with mild and moderate disabilities who face challenges in the workplace that merit investigation on a large scale.

I have begun to research specific groups of health care workers who have disabilities and work in hospital work environments as part my dissertation research. Now that I have completed that, I would be interested to learn how federal agencies are supporting additional research into barriers for this population in various workplaces. I am particularly interested in access to assistive technology and universal design for workers with moderate disabilities in the health care industry.

While I understand the goal of promoting employment of people with serious disabilities, I strongly believe that by conducting research focusing on the working population of individuals with disabilities we can solve issues on a large scale and thus improve conditions for this neglected worker group.

I have begun to look at workplace disability climate, specifically within the nursing workforce which I believe prevents integration of nurses with disabilities in hospital workplaces. My goal is to open this profession to individuals with disabilities who are ready, able and willing to work in the field, but who have been rejected based on their disabilities.

To summarize, I would like to see more research focused on worker groups with mild to moderate disabilities, and organizational factors that facilitate or hinder their integration into the workplace. Thank you for allowing me to contribute my comments. Susan Matt.

>> Thank you. Now, I invite Bonnie O'Day to come forward.

>> I would really appreciate if someone would take a moment to tell me who is at the head table.

>> Rana Linnehan, CESSI.

>> Connie Pledger, ICDR.

>> Mark Leddy from the ICDR, and I work at the National Science Foundation.

>> Art Sherwood from NIDRR.

>> Dick Fisher from the Office of the Assistant Secretary.

>> Great, thank you very much, I really appreciate that.

Thank you for the opportunity to present suggestions to advance disability and rehab research to benefit individuals with disabilities. I work for Mathematica Policy Research, and we recently initiated a center for studying disability research, which brings together scholars with backgrounds in a variety of areas like health care, aging, employment, education, et cetera.

And our purpose is to inform disability policy formation with rigorous and objective research and data collected from the people disability policy aims to serve.

And I have in the past 15 years conducted research on employment, health care, independent living and assistive technology, and I've also worked at Centers for Independent Living. And all of these issues are really important, but for brevity I'm going to confine my comments to employment.

Increasing employment opportunities was one of the major research and advocacy issues when I became involved in the disability movement in the early 1970s. And today, we spend about 300 billion on the four federal cash assistance and medical programs, SSI, SSDI, Medicare and Medicaid. But the employment rate is still -- hovers right around 30 percent, as it did in the 1970s.

ICDR recently held a national conference to develop a cohesive research agenda to promote the employment of individuals with disabilities, and it seemed clear that the reason a cohesive research agenda is lacking is that there's no cohesive federal policy to promote integration and productive employment of individuals with disabilities.

Progressive laws and policies such as the ADA and its regulations are adopted, and then we have some so-called work incentive programs, but the majority of federal dollars are still spent on cash assistance and medical programs that often discourage employment. And until our federal programs are more focused on enabling all individuals with productive capacity to become self-sufficient, our research agenda will remain fragmented and disjointed.

We need a research agenda that focuses on 21st century jobs and 21st century employers that takes into account the new realities for people with

disabilities.

It should lead to 21st century policy change that truly promotes independence, productivity and employment.

Well, that's pretty broad. So I'm going to try to give you nine, and that's probably too many, specific ways that I would like research to be focused.

First, it needs to be grounded in the social-political rather than the medical model of disability. Although medical research is very important, ICDR's role is more the social political rather than the medical research.

Secondly, research should focus on outcomes. Outcomes research that measures program results such as employment, educational attainment and increases in independent living should be emphasized.

It's often deemphasized in favor of process oriented studies due to the difficulty and expense of measuring and tracking outcomes. Process research is of course very important, but should be conducted as a way to find out how the outcomes are achieved.

Thirdly, the research agenda should focus on randomized controlled demonstration projects that provide enough statistical power to draw strong conclusions. They should include enough people to evaluate effectiveness by gender, ethnicity, and to the extent possible, type of disability.

Fewer, larger, well designed and adequately funded studies are preferable to a multitude of small, inadequately funded ones.

Number four. A research agenda should include cross-agency demonstration projects that provide a single point of entry, make work pay, offering meaningful choices in rehab, and expect people to be substantially self-sufficient.

They should be funded at the federal and state level but implemented locally. Development of such demonstrations will require executive leadership, cross-agency collaboration and funding, and relaxing of federal regs.

ICDR seems the appropriate body to encourage the development of such demonstrations, and some examples are the supported employment program for people with psychiatric disabilities, that research, and the youth transition demonstration conducted by Social Security.

Number five, I suggested a centralized repository of evaluation of existing research, the What Works clearinghouse funded by the Department of Education provides an online source of independent reviews of research that is relevant to education policymakers, and practitioners.

It provides independent reviews of research studies, demos and evaluations to inform practitioners about what really works.

Number six, we need more research in collaboration with employers to test and employment best practices. Once these programs have been identified and rigorously tested we should increase TA, technical assistance, to employers provided by employers who wished to recruit and retain employees with disabilities.

>> Bonnie, your time is up.

>> Okay. I'm sorry?

>> Your time is up.

>> Time is up? Okay, I'll just quickly say that seven, research should identify training that prepares people with disabilities for positions with employers. Number eight, research should explore the reasons for the drop in employment in the federal government. And nine, finally, we need more extensive regular reporting of statistics on the status of people with disabilities. Thank you.

>> Thank you.

>> Thank you very much.

>> And now we'll go to Dr. Sherwood to read comments.

>> I'm going to read a letter from -- and apologize in advance for pronunciation of her name. Emily Angelcyk, A-n-g-e-l-c-y-k. Thank you for taking time to read this letter. I'm a 37-year-old woman who was born with congenital glaucoma, worked most of my life, but am now extremely vision and am considered legally statutorily blind.

My three year old daughter was born with a different and even more rare condition called Peter's anomaly. She had emergency bilateral corneal transplant at nine days old, due to her lens prolapse. She now has artificial corneas, but due to scar tissue growth and retinal detachment due to the rupture

she has light perception and maybe some shape and shadow.

I have learned to deal with my disability because as I was growing up my vision was better and there were not all the agencies available now. My concern is now for my daughter, Angelina. She's extremely smart, being what they call garden variety blind, meaning there's no other developmental issues with her. Her memory is extraordinary. For example, she can already count to 10 in English, French, German, Spanish and Japanese. I must continue challenging her.

Here are the obstacles that I've already run into, and I'm going to summarize these because it's quite a long list. The shortage of vision therapists is extremely critical, and most therapists that have orientation and mobility certification are contracted out through government agencies. This prevents me using my private insurance to get additional VT, and O and M training as recommended by her eye doctor and pediatrician, as people who need PT and OT can.

They cut her all therapy for summer except for three sessions in July and shortened the time frame for PT and OT, I had to fight and keep her VT and O and M through the summer. How does this make sense. They're not providing any family support or education such as Braille training and organizational skills. They refuse to have our household evaluated for adaptive technology. They do not provide education loan on request, and even at that it is incomplete. There need to be requirements a patients bill of rights for disability education be sent to families before transitioning, and I mean more than just the procedural safeguards, or have more advocates that can go to the homes on a required basis to explain what is available and what is expected.

Everything that I've done I've had to do on my own. Though I met a great number of people trying to help, there are many people with disabled children who do not know where to start or do not have the resources or understanding of how to advocate. Regulations and laws are being blatantly ignored because there's no oversight.

I believe the government should not have the monopoly of vision therapy and O and M training. Since I was first denied services through the IU and

couldn't get the proper services via outpatient, my daughter was denied proper care. For blind children who are mobile, O and M is absolutely critical, and this should be set up a different standard. My daughter only truly started walking six months ago, they wanted to stop teaching her how to walk. This service needs to be mandatory without even discussion for mobile children. This is like taking a wheelchair away from another disabled child.

People of disabled children need to be spending time with their children, not reading manuals and fighting government agencies or hiring lawyers. If they want these children mainstreamed, then more than legal minimum needs to be provided.

Disabilities do no discriminate, so neither should the care, grants or adaptive technology. Especially when availability is based on income. We're just above the low income marker, so we get no extra assistance. However, there's no doctor within a 500 mile area that can treat my daughter, so what little we have goes directly into medical travel expenses, which we barely get a fraction back on our taxes. Add to it my husband is the only one who drives, so he misses work on FMLA. Therefore not only do we have the expense but we also have the loss of pay. These factors are never taken into account, but they put us well below a low income household. I could go on for hours.

Thank you again. Emily.

>> Thank you. I'd invite Debra Ziegler to come forward.

>> Good morning. My name is Debra Ziegler and I'm the associate executive director for policy and advocacy at the Council for Exceptional Children. As a nonprofit professional organization, CEC's mission is to improve educational outcomes for individuals with disabilities. I'm pleased to be here to share with you CEC's recommendations, and thank you for the opportunity.

While my comments are rooted in the employment of individuals with disability, CEC believes that the issue of employment cannot be justly discussed without analyzing programs and investing in research that helps individuals reach employment

My comments today only reflect a small component of CEC's research priorities and is in no way intended to be an exhaustive list.

CEC believes that when considering employment of individuals with disabilities it's critical to evaluate existing programs in place in schools and communities to help prepare, guide and advise individuals with disabilities to enter the workforce. While CEC agrees it's critical to examine through research barriers and best practices for individuals with disabilities in the workforce, CEC believes it is equally as important to ensure that education and community based programs have the evidence base and resources needed to fulfill the mission of preparing individuals with disabilities for challenging and fulfilling employment.

Unfortunately, we know that students with disabilities drop out of school at significantly higher rates than their nondisabled peers. High dropout rates coupled with low percentages of students with disabilities graduating with a standard diploma have dramatic ramifications on the futures of individuals with disabilities, including their employment and ability to be productive citizens. Therefore, CEC believes perhaps the best way to tackle some of the employment challenges for individuals with disabilities is to research best practices in education starting from birth.

Early childhood development. Recent advances in the science of early childhood development suggests that early years constitute a unique period in which to alter children's developmental trajectories, it is widely accepted that investments in comprehensive and coordinated early intervention services will generate long term benefits for children and families.

Specifically, CEC in its partnership with the Division on Early Childhood believe there must be an increased investment in research in the following areas. Further development and evaluation of methods that promote early identification and timely intervention, and those that help practitioners link assessment of intervention practices as part of an integrated system. Identify and evaluate the most effective models of family supporting collaboration, and the conditions under which these interventions are most effective. Identify and evaluate research based practices for addressing the needs of children and families from diverse groups and for creating highly qualified personnel to work with these children and families.

Identify and evaluate the policy and organizational mechanisms that

support effective services and practices. Identify effective mechanisms for supporting the adoption of an evidence based approach in applied settings, and evaluate the effects of early intervention on children and family outcomes.

As member of the national universal design for learning, task force CEC is committed to supporting and promoting the framework and principles to provide all students equal opportunity to learn, which is described by the Center on Applied Special Technology.

As you know, much like universal design principals and architecture, UDL seeks to minimize curriculum barriers by ensuring meaningful access to the curriculum and accurate skill and knowledge assessment.

Therefore, CEC believes that there must be an increased investment and research to advance the principles of UDL, and further investigate the impact of UDL driven curriculum on the performance of students in school.

Career development and transition. As students with disabilities move through the education system, it is critical that transition to post-secondary activities, whether it is to pursue higher ed, career vocational ed or employment, play an integral role in students with individualized education program.

>> You have one minute.

>> Okay. To that end CEC together with its division on career development and transition believe that additional research is needed in five key areas. Effective coordination integration research, research that leads to ready use of evidence based practices, research that addresses social relationships and social barriers to inclusion, rigorous academics at the expense of quality transition planning, and interagency collaboration and family involvement. Our last area is recruiting and retaining special educators, and we believe that extensive research needs to look at this area around preparing and recruiting and retaining qualified personnel, who can ensure that our children have the knowledge and skills they need.

In addition, some concluding thoughts. CEC believes that ongoing research be conducted beyond a single type of research methodology, such as randomized experimental group design, and include other methodologies such as experimental group, correlational single subject, and qualitative designs.

CEC has just put together a publication on these very recommendations, and we encourage you to take a look at that.

Additionally, in order for research to be utilized by the public, it is critical that the research to practice gap must be properly addressed, and research must be meaningful to practitioners, disseminated broadly, and easily identifiable.

Lastly there's a critical need to invest more at the federal level. CEC continually advocates for special education. However, investments in research has not and continues not to be a priority of the federal government.

While I understand that the focus of today's hearing to broaden the research methodology, accessibility and investment, I do not believe -- I do believe that I would be remiss if I had not mentioned these issues here today. Thank you for the opportunity to share with you CEC's broad membership base ideas, and we believe that the future of ICDR should hold, as it moves forward, to ensure that research is available and accessible to practitioners. Preparing our youth with disabilities to be engaged citizens is of critical importance and must start with intervention as early as birth.

I commend the council for its initiative and for soliciting stakeholder input, and thanks for the opportunity.

>> Thank you very much.

>> Thank you. We're going to go to the phone now.

>> Robert Beckley, your line is open.

>> Good morning.

>> Good morning.

>> I'd like to thank the Interagency Committee on Disability Research to accept my public comments. My name is Robert Beckley, I am a federal employee, I am also an employee with a disability, and I'm a union member. I'm a member of the National Federation of Federal Employees, which is an affiliate of the International Association of Machinists and Aerospace Workers.

The issue I wanted to bring forth before the committee today is federal employees who become injured and disabled on the job. As a federal employee who was injured and disabled on the job, I know problems that employees within our own federal government face, having become a permanently disabled

employee.

Federal employees disabled on the job are covered under the Federal Employees Compensation Act, which is administered by the Department of Labor. The Department of Labor allows individual federal agencies to administer the Federal Employees Compensation Act. Unfortunately, the way many agencies administer the employment act, or the Federal Employees Compensation Act, is detrimental to the health and well-being of those employees who have sacrificed their health and their well-being in the service of their country.

Employees who become injured and disabled on the job often face discrimination. They're placed in low wage, low grade jobs, with little chance of advancement. And quite frequently, they're forced onto an OPM disability retirement.

A federal employee who becomes disabled on the job is entitled to retraining and accommodation. Yet those expenses are often charged back, those expenses are charged back to the employing agency. In an effort to cut costs, federal agencies will often take the low end of accommodating employees. Which means rather than retraining them or allowing them to participate in their chosen field, they will assign them to a position, call that accommodation, and quite frequently, those employees then leave federal service.

As they leave federal service, they leave with a great deal of wealth, and the numbers of employees with disabilities in the workforce also drops.

One of the problems that the union has uncovered in looking at federal employees who are injured and disabled on the job is how that affects that family. And quite often we find drug and alcohol problems, broken marriages, suicide, and in some cases we've uncovered the potential for workplace violence. This is all the result of how those employees are treated once they become injured and disabled on the job, and the lack of accommodation and help they get.

Sacrificing their health for the agency for the federal government, for the United States, should not lead to more problems for these employees who get hurt on the job.

The Department of Labor, the Federal Employees Compensation Act, is in

dire need of being updated. The Department of Labor, the Secretary of Agriculture, has the ability to change the CFRs under which the Federal Employees Compensation Act is regulated

One of the problems that federal employees face is the lack of attending physician rule. In many cases a civilian employee has greater rights than those of federal employees. An injured employee in federal service, their doctor may not have the final say as to what they can do in their condition. Workers compensation can send them to one of their doctors, who inevitably finds that employee fit for a duty that their attending physician may not agree with.

>> Caller, you have one minute remaining.

>> That employee then needs to -- or that workers comp doctor then overrides the attending physician rule, and that employee usually suffers for it.

Employees take a disability retirement through OPM, Office of Personnel Management, and that's really a substandard retirement system.

The Federal Employees Compensation Act needs to be updated, and those employees who cannot return to work should be placed on a true retirement system, not OPM disability retirement. And those employees who can return to work need to be accommodated.

This can all be done through rewriting the CFRs under which the Federal Employees Compensation Act is administered.

I'd like to thank the community and you have our paper on the issue.

>> Thank you. And now we'll go to Art Sherwood for comments.

>> I'm going to read the comments from Karen Wong. My name is Karen Wong, and I'm a post-doctoral researcher presently completing a fellowship grant at Kessler Medical Rehabilitation Research and Educational Center.

I'm also a spinal cord injury survivor, so I have investment in rehab research from in both a professional and consumer perspective. I am presently conducting an online survey on voting among the disability population. The survey presents a brief unscientific overview of the voting preferences and priorities of voters with disabilities.

The survey has been up since mid-July and will be open until August 15th. Anyone with a disability who is over 18 can participate in the survey at

<http://www.surveymonkey.com>. Oh, dear, I'm not going to try to read the rest of this, it's too complicated.

Preliminary results so far indicate that voters with disabilities are heavily invested in disability related interest areas to the extent that many, almost 50 percent, indicate that they would consider voting for a candidate viewed as most disability friendly even though they might not agree with the candidate in other areas.

In terms of voters' number one priority area, access, coordination and quality of health care services received the most endorsements, 37 percent, with nearly 91 percent rating as major or primary importance. Also significant priority areas were housing and personal assistance support, 73 percent. Employment, 71 percent. And Social Security 66 percent.

The survey also asks about the sources from which people receive their disability related news and information. Over 77 percent reported getting information over the internet, although this may be overrepresentation due to the online format.

Other important news and information sources were newspapers and magazines, including disability targeted publications such as New Mobility, and national disability interest groups such as Adapt, or AAPD, 50 percent and 48 percent respectively. Based on the poll results, I would recommend as a priority area for investigation, number one, systematic investigation of access, coordination and quality of health care services for people with disabilities, including how experiences of health care services affect health care seeking behaviors and health outcomes.

Two, demonstration projects aimed at increasing the levels of community based housing, consumer directed personal assistant services and employment, including special awards for innovative strategies to achieve same.

Three, investigation into the various media channels in which consumers with disabilities receive information. Areas seen as easiest to access, most unbiased and most credible, and ways in which to use these channels to disseminate important information most accurately and efficiently.

>> Thank you. Mark, if you could give us comments.

>> I'm going to read from the National Association of Rehabilitation Research and Training Centers. The National Association of Rehabilitation Research and Training Centers, NARRTC, is pleased by the opportunity to provide testimony to the ICDR regarding ways to maximize the scope of disability and rehabilitation research, and the possibility of achieving real world benefits and results.

The ultimate mission of the National Association of Rehabilitation Research and Training Centers is to promote the full inclusion of persons with disabilities in American society through applied research and training.

The NARRTC has a commitment to full community work integration, participation, and access for all persons with disabilities, and supports the rights to self-determination and choice.

I'm going to read portions of this.

The next section is the disability and rehabilitation issues we face today have no regard for the specialist boundaries of our fields, agencies, and institutions.

ICDR was created as a result of that realization, and no entity is better positioned to foster the partnerships these problems require.

If the issues facing us do not fall under one purview, it follows that the solutions must be as adaptable, agile, and multifaceted as those issues require.

In this context, NARRTC offers the following recommendations for ICDR's continuing mission. Number one, we recommend that ICDR continue to support and coordinate existing interagency agreements and other joint funding mechanisms. Joint funding programs have been under threat in recent years. Any regression in the implementation of the current interagency agreement process would seriously limit the development of new knowledge designed to further positive outcomes for persons with disabilities.

Number two, we recommend that ICDR work cooperatively to propose new cross-agency increases in funding for disability and rehabilitation research.

Given the success of the joint funding programs in the past, we urge ICDR to take leadership in creating new opportunities for joint funding programs across more federal agencies to address the serious concerns of the disability

community. It would be a major setback to the disability research community if new and innovative joint agreements are not developed to foster the interagency efforts that are needed to benefit today's Americans with disabilities.

And the third and final recommendation, we recommend that ICDR sponsor the creation of a government-wide database on federally supported and federally conducted research, as has been suggested in the 2007 Institute of Medicine report, the Future of Disability in America. With this comparatively simple tool, unnecessary research overlap could be better prevented and the funds saved as a result would doubtless create opportunities for new avenues and approaches to rehabilitation. Thank you.

I'll now read another one from Christine Rover at the Center for Autism and Related Disabilities of University South Florida.

The Center for Autism and Related Disabilities of University of South Florida receives input from families and professionals, and here is a summary of some of their comments. Please look at individuals with disabilities and coexisting mental health concerns, and how to bridge the physical and treatment gap that exists between these systems of care.

I would want to look at researching, whether there's any benefit to one-stop shop type services versus the current system of care, where we operate in a more fragmented way.

Is there evidence to support whether one type works better than another? How about technology in disabilities to promote social decision making. Thank you, Christine Rover.

>> Now we'll go to Art Sherwood.

>> I'm going to read a letter from Robert Simms. VOR is a national nonprofit advocacy organization represented individuals with mental retardation and developmental disabilities and their families. VOR supports a continuum of care options from family home, own home, community based settings, and facility based care. We are especially concerned about the impact of deinstitutionalization when forced upon an individual and his or her family. Often research relating to quality of care is focused on resident satisfaction, which is assessed by asking subjective questions such as what you want for dinner, and

are you happy.

While satisfaction is a fundamental indicator of quality, alone it does not offer a complete picture. More research relating to objective indicators of quality following deinstitutionization is needed.

For example, one, mortality. Research currently exists that shows a higher risk of mortality prior to move out of an institution and immediately following such a move. But it is limited to one state, California.

Mortality is the tip of the iceberg when it comes to assessing quality. Higher mortality rates signal problems with abuse, neglect, staff training, staff turnover, inadequate funding, inadequate monitoring and oversight, and inadequate lack of access to health care after a person leaves, and a higher level of depression, anxiety and fear when faced with leaving a long established home.

National studies relating to mortality rates across service settings are desperately needed.

Two, obesity. Community placement does not always equate to integration and inclusion. Some individuals residing in community settings find themselves watching television all day and/or without adequate attention to recreation, exercise and diet. The same could be said for individuals living at home with family, where job opportunities are limited and supervision is not always there.

Research is needed to track the rate of obesity in individuals with developmental disabilities and mental retardation across all placement options.

Three. It is well documented that people with mental retardation and other developmental disabilities generally have a difficult time accessing health care in community settings. Some solutions are being pursued, including legislation to improve the accessibility of physician offices, training medical students to encourage empathy and experience, and utilizing intermediate care facilities for persons with mental retardation as outpatient clinics, making the expertise at the facilities available to nonresidents in surrounding communities.

Most of these solutions are used only sporadically. The best practices should be studied with a focus on how to expand successful models of service delivery. Thank you for your attention to these research suggestions, please

consider VOR as a resource. Sincerely, Robert Simms.

>> Art, could you read one more, please.

>> This letter is from Susan Rough of Southern Tier Independence Center. Thank you for the opportunity to address the committee as you look at ways to improve future disability and rehabilitation research. I have worn several hats in my personal and professional life. I am the parent of a young adult with multiple disabilities.

Working at an independent living center over the past 13 years, I have directed three programs, supported employment for early childhood direction center, and systems advocacy. I would like to see research funds directed toward the following areas.

Supported self-employment. While there are notable employment of successful programs, for example University of Montana Rural Institute, it is extremely rare for state rehabilitation agencies and providers to pursue this option when working with people with disabilities.

This vocational option could stand a boost from vocational rehabilitation dollars, but evidence based studies can have an impact on those dollars. Could you envision any studies that would measure the factors that contribute to the success or failure of this vocational option.

Dual diagnoses in young children. We're noticing increasing numbers of young children with dual diagnoses, developmental and mental health disabilities. Why. People are very puzzled by this trend. What is disrupting the normal neurological development of our children? Is it a result of increasingly polluted environment, more poverty and reduced health care, or less available parental support and time? There may be many contributing factors.

How will these factors be affected by public policies, what's causing it, and what can we do about it.

SSDI determination. The average amount of time needed to establish eligibility for Social Security disability, SSDI, is over two years. It is longer in some states than others. The long wait has put people at increased risk for further health deterioration, loss of income, bankruptcy. What helps the process and what hinders it? Again, as we are an aging population, how will this factor

into future economic imperatives and societal needs.

Community based services. People want to live independently in their own homes, and in their own communities. Over the last few years, since the Olmstead decision, some states have made a larger financial commitment to community based service dollars as opposed to maintaining longer term institutional care. Some states are doing a better job than others at providing waiver services. For example, traumatic brain injury nursing home transition and diversion, mental health home and community based. As an ongoing issue that is very troubling to the low rate of pay received by caregivers who work in these programs. Are any states doing a good job in caring for residents with disabilities? How does one define good? Accessible and integrated housing, available transportation, skilled, committed and sensitive workers, all play a part in how easy or life will be for people with disabilities.

Where are the model programs, and what contributes to their success? People have basic needs: Food, place to live, friends, a positive valued social role. As we anticipate difficult economic conditions over the coming years, the amount and distribution of research dollars will shrink. Before approving a research request, ask yourself how will this help people with disabilities. I hope that the areas you recommend for future research expenditures will ultimately result in greater independence, greater self-sufficiency, and greater dignity for people with disabilities. Thank you for your consideration. Sincerely, Susan rough, director of advocacy, Southern Tier Independence Center.

>> Thank you. Now we'll go to the telephone.

>> Frederick Menz, your line is now open.

>> Good morning, my name is Fred Menz. I was director of research and directed a number of national disability and research projects over the past 35 years. Now I'm coming as a stakeholder with interests in advocacy and increasing the impact of research on the employment of people with disabilities.

As a family member, as a person with disability, and as somebody who has spent an awful long time trying to figure out the answers, I'm going to offer two suggestions at this time for research.

My first suggestion is that you design a research agenda from the

recommendations of the 2008 ICDR ISE conference that was recently conducted in Arlington, Virginia. This looked at the issues of research from both the demand side and the supply side. And while I was chair for the planning committee for this conference, my observations are my own, they're not anybody's from the federal government or any other agency or entity except that.

I think this was an important event, an important milestone for the identification and gathering of input for research around an issue that seems to be unending and unchanging.

In my closing comments I voice the message from participants that if we are serious about changing the status quo, the unemployment of people with disabilities, an interagency research agenda needs to be formed, piloted and directed towards achievable impacts in a few areas of need that can yield evidence-based -- on evidence base, relevant and applicable to our communities, to our employers, to individuals, and wrapped around jobs that will have importance in the 21st century and businesses that will be derived in the communities of the 21st century as well. I think this is the way we can have measurable effect and impact in our programs, policies and practices.

The many presenters at the conference were asked to speak towards needs for research around four important themes. I think these four themes are pillars for the development of a research agenda, and development of a research to application package that would come out of such an integrated agenda.

The four themes are the goals of globalization and technology, and creating 21st century businesses and jobs that include individuals with disabilities.

Second, the issues and needs and consequences of disabilities affecting full participation in economic development and employment in 21st century businesses.

Third, help gauge disparities and assurances for American workers in creation of sustainable businesses and competitive workforce in a global economy.

And fourth, the role, implementation and consequence of government policies, programs and practices intended to support full participation and

employment and sustained competitive businesses and employment.

Proceedings are in the process of being prepared at this time, and I hope that the committee, the folks that are listening to this input today, focus attention to that as a primary source for developing a research agenda.

My second recommendation is a little broader. This comes from having perhaps struggled with the issue of trying to figure out ways to cut unemployment for people with disabilities, and also trying to figure out what disability is in the context of the 21st century.

My standpoint, and from the work I've reviewed to date, there's a need for a contemporary theory of disability. I think a federal investment in developing an inclusive theory would be in the public interest, and would certainly help base policy, concepts, theorems and practices that have a better chance to improve the future status of people with disabilities in the American populace.

>> Fred, you have one minute.

>> Okay, I'll get down to this. We've looked at a variety of different theories over the time where we've moved socially from the point of seeing disability as a curse, to one as being a social phenomena, to one of being a medical rehabilitation phenomena. And my suggestion is that we develop our research to help create a theory that will account for the fundamental issues that people face in disability, and develop research policy off of that. I've submitted my comments more thoroughly in writing, and I'm open to any questions. Thank you.

>> Thank you. Mark will now present two comments.

>> The first comment I'd like to read to you is from -- I'm not sure I'm going to pronounce the name correctly, but Kashay Araya, K-a-s-h-a-y, first name, and last name A-r-a-y-a. I am pleased to submit my comments or report for improving future disability and rehabilitation research to benefit individuals people with disabilities. In this letter I want to emphasize on the issue of equal employment opportunity for people with disabilities. In the last 18 months I have been interviewed by a number of software companies and experienced the following problems.

Number one, fear or ignorance of employers in hiring for individuals with

disabilities resulted from misinformation or lack of information. Most employers don't have enough knowledge or understanding on the reality of what a great asset in hiring people with disabilities would be.

The fear that they have is lack of resources, of accommodations, or training for people with disabilities. Employers need to be convinced or educated for the available resources and training stipends that exist for individuals with disabilities. Representatives of people with disabilities need to deliver sufficient information or awareness to employers, especially of those who never hire any disabled individuals.

Number two. The obstacle the disabled person most often encounters is loss of confidence and lack of knowledge on disability rights and responsibilities at the time of the hiring process. Individuals with disabilities need to be trained after college to handle job interviews and processes in conjunction with their rights and responsibilities to empower their confidence.

And number three, government security clearance issues for peoples with disabilities need to be discussed to allow at least interim or temporary clearance for people with disabilities. This would allow individuals with disabilities to prove themselves, how honest and reliable they are to handle sensitive government information.

Example would be naturalized disabled U.S. citizens face with big challenges on having non-U.S. citizen resident parents or relatives in the U.S.

This is like a natural phenomena that cannot be avoided by a disabled individual and the clearance need to focus on the disabled individual requesting that security clearance, and not his parents or relatives.

In addition, the disabled person need not be treated differently as a result of his parents being U.S. residents and not U.S. citizens.

The disabled individual need to have an opportunity to prove himself or herself how the honest and reliable he or she is to handle sensitive information just by being in the workplace

Thanks for giving the opportunity to write comments, Kashay Araya,
Aurora Colorado.

>> We're going to go to the phone now, we have one presenter joining us.

>> Michael Morris, your line is now open.

>> Hello,

>> Good morning.

>> Can people hear me.

>> Yes, we can.

>> Oh, great. Good morning. My name is Michael Morris, I am the chief executive officer of the Burton Blad Institute, BBI, at Syracuse university. BBI was established in 2005 and has as its core mission the advancement of the specific economic participation of persons with disabilities worldwide with students on public and campus, and private collaborators around the world. BBI is building leaders in law, education, business, communication public policy, the social science, engineering and technology. They're fostering higher expectations about the benefits of the inclusive workforce, the impact of technology access, and the advantages of valuing individuals with disabilities for their productivity and participation in the economic mainstream.

We appreciate having the opportunity today to talk to the ICDR to ensure with your goals that research efforts lead to solutions for identified needs for individuals with disabilities, and to increase collaboration among federal agencies. My testimony to you is to provide first a context for identification of research priorities, and to offer four priority areas of focus for the future.

Approximately one week ago on the 18th anniversary of the signing into law of the Americans with Disabilities Act, the U.S. Census Bureau released new findings on the status of people with disabilities in the United States. The statistical report identified 41.3 million Americans with some level of disability representing approximately 15 percent of the civilian noninstitutionalized population.

Only 44 percent of people with nonsevere disabilities reported working full-time year round, and only 13 percent of people with a significant disability reported working full-time year round. 26 percent of people with severe disabilities reported living in poverty, as compared to 8 percent of the general population. The median earnings for those with a severe disability was reported at \$12,800 annually, as compared to \$25,000 for those without a disability.

In a post-ADA era individuals with significant disabilities are more likely to be unemployed and living in poverty, with limited income.

Only one in five are reported to be college graduates. Despite the millions of dollars federal agencies are spending to improve the economic status of individuals with significant disabilities, whether through research or demonstration initiatives, these current results are distressing. GAO, NIDR funded RRTC's, CMS funded Medicaid infrastructure grants, Presidential appointed commissions and work groups, all have reached similar conclusions.

Number one, cross-agency collaboration at a federal, state and local level is inadequate, with service delivery systems fragmented and difficult to navigate for the end user. Number two, public policy across federal authorities are not aligned and conflict with the priority of promoting work, advancing self-sufficiency and strengthening individual choice and community participation. And three, there's a lack of unifying vision that values and rewards collaboration within the public sector and across the private sector interest that promotes saving and asset building outcomes and that promotes persistent knowledge translation activities that support the movement from knowing to doing at an individual and systems level with the expectation that researchers have a responsibility to move beyond knowledge creation to accelerate its use in policy and practice.

ICDR members continue to focus on strategies to improve employment outcomes without a focus on the underlying problems of siloed government, the lack of cross system solutions, the problems of conflicting policies that perpetuate a status of poverty for people with disabilities, and inadequate resources and commitment to advance the gains of new science and knowledge to change individuals and systems actions.

Four priority areas for you to consider for future focus.

A, cross system collaboration. ICDR is in a unique position to engage multiple federal agencies to identify, document and analyze cross-system collaboration at all levels of government, that is advancing the self-sufficiency and community participation for people with significant disabilities.

>> Mike, you have one minute remaining.

>> Okay. My testimony provides you more information about

cross-system collaboration. The second area I think deserves your attention is public system customer relationships, looking at self-determination leading to self-directed budgets and individual direction and control of public resources. As we move forward across systems, how can policy be aligned to provide more consumer control of funding decisions, in terms of goals who provides the support, at what costs, and how do we measure success.

An ICDR led work group could coordinate such efforts.

Issue three, public assistance and poverty you've heard me talk about many times. We need to align policy in a way that supports savings and asset building, and advance self-sufficiency.

Limited federal research priorities have been on looking at opportunities to advance savings and asset building, and there's a great opportunity across federal agencies to focus in this area.

Finally knowledge translation. If we're so interested in researches really impacting policy and practice, we've got to change the point structures on grants across the federal agencies. A minimum of 40 points on 100 point scale has got to focus on knowledge translation to policy and practice. Researchers should be expected to document activities and outcomes of past and current knowledge translation efforts, as well as cost and benefits.

We're at an age of exciting new approaches to knowledge translation, communities of practice online, web based libraries, distance learning. ICDR could pick the ball up across federal agencies and really promote researchers having to be more actively involved in knowledge translation.

Thank you for the opportunity to share our views with you. On any of the issues we've raised I hope you will have a chance to read my full testimony, we welcome the opportunity to talk with you in more depth. We appreciate your efforts to come together across the federal spectrum of agencies, benefits, systems delivery and research priorities to work together to advance meaningful and effective economic participation by people with disabilities in the United States. Thank you.

>> Thank you. We'll take the next caller. It appears that we don't have another caller on the line, so we will hear more comments, if we could have Mark

go through the next comments.

>> I'm going to read from a comment that came from the Zaro Center for Learning Enrichment at the University of Oklahoma. It's written by Vincent Harbor, who is a doctoral student. The Zaro Center for Learning Enrichment is located on the campus of the University of Oklahoma. The center engages in research focused on the development of innovative instruction and educational practices for successful transition of youth with disabilities from high school to post-secondary education, employment, and/or independent living settings.

In response to the ICDR's request for comments on specific ways to improve future disability and rehabilitation research to benefit individuals with disabilities, we believe emphasis on the following research topics would significantly improve secondary youth with disability success, transitioning from high school to employment and independent living.

Number one, provide transition education for secondary schools and rehabilitation professionals on the various types of transition assessments, and how to use transition assessments to develop effective transition plans for youth with disabilities.

Number two, develop flexible collaborative processes for integrating interprofessional service delivery systems responsive to the unique demands and the cultural needs of the local settings in which service professionals operate. And number three, identify effective strategies for increasing student and family participation in the development of individualized education programs, and transition, and vocational planning.

Thank you for considering the Zaro Center staff's comments on this extremely important and relevant issue, we hope our recommendations prove useful to the ICDR.

>> Thank you. We'll continue to read through the comments that we received in writing for those individuals who are not participating on site or through teleconference call. As individuals join us on the phone or here on site we will invite them to present their comments. Dr. Sherwood, if you could give us two comments, please.

>> I'm going to read from comments presented by the Research Institute

for Independent Living, RIIL, which I'll refer to as "real." Physical movement to ameliorate functional limitations implications for a disability research agenda. One of the goals of RIIL is to facilitate implementation of evidence based programs that lead to independent lives of people with disabilities. Disability is currently recognized by the Americans with Disabilities Act through disability theory from the World Health Organization and Institute of Medicine as a multidimensional concept that involves both the individual and environment.

The CDC indicates that disability has not been defined, measured or analyzed in a consistent manner. Thus interventions to ameliorate, maintain health status, or reverse disabling functional limitations has had little direction. The recently published CDC document, July 2008, clearly identifies conceptual theoretical measurable elements of disability that can guide research to ameliorate and reverse elements of disability.

I'm reading selected portions of the document. There are many elements to health and many avenues of research to disability. However, the suggestion for ICDR research is focused on general health, of prevention of chronic health condition and functional limitations associated with disabilities that involve physical movement.

Physical movement plays a role in prevention and amelioration of chronic health conditions that diminish health that result in functional limitations and disability. Addressing disability research through chronic health conditions associated with obesity, of which one precursor is a physically active leisure lifestyle, may be fruitful in ameliorating disability. However, functional limitations related to disability can be task-specific and require specific training of movement functions associated with disability.

Chronic health conditions, obesity and physical activity. There is impressive evidence that health benefits from physical activity results from a lifestyle of leisure physical activity. While there is widespread evidence of short-term interventions to address overweight through physical activity, there are few interventions that have been replicated that address outcomes of physically active leisure lifestyles. These interventions need to be developed in detail for reproducibility and widely distributed to address overweight and obesity.

Interventions of physically active leisure lifestyle are needed because of the unprecedented epidemic of childhood obesity.

Evidence based research practice. Evidence based interventions are needed to enhance physically active leisure lifestyles as addressed -- and address obesity associated with chronic health conditions and functional limitations that involve physical movement. Evidence based procedures require validated curricula or programs of behavior that can assess where participants are in the program and to measure progress as they obtain program goals and objectives.

There are five components to the evidence based model associated with measurable outcomes that can be replicated. A description of the model which can be applied to physical movement, aspects of obesity, and functional limitations follows. If you use these activities curricula, so progress can be measured, and task analysis that have been validated, under these conditions, time in program, intensity level, financial resources, community resources, et cetera, with personnel trained in these ways, protocols from behavioral, social and management sciences, you will get these results: Improvement on progress of specific physical movement parameters of functional limitations or measures of physically active leisure lifestyles. With these persons: Racial ethnic minorities with a variety of disabling conditions from different socioeconomic levels, ages, health status, et cetera.

Needed research. The central focus on research should be on replicable interventions that produce socially valid outcomes for persons with disabilities that develop, ameliorate, maintain or improve physical movement functions and physically active leisure lifestyles for independent social living. There is an abundance of medical research that addresses the biology of health conditions, and a paucity of research in applied settings that employs protocols that link processes of intervention to measurable socially valid outcomes.

The procedures established in the mid-1970s with initiation of the Individuals with Disability Education Act are in particular applicable to addressing the physical movement aspects of functional limitations of physically active lifestyles.

I'll read the second one.

This is a letter from Linda Mayer. I'm Linda Mayer of Temperance, Michigan. I'm a 57-year-old widow with multiple sclerosis. I developed the MS help group in Monroe County in 1993, and in 1994 I was asked to be on a committee to bring a center for independent living to Monroe. My husband died suddenly shortly after that group was formed.

I was told by the union reps from General Motors that I would have to pay \$500 for my health insurance, and was not certain how I would survive. I continued to move forward and did continue to be active with this committee and others in the county and state such as Tech 2000. I attended every program in continuing ed regarding anything pertaining to disabilities. This CIL office opened in late 1994 and it was a satellite office of the Ann Arbor Center for Independent Living. After taking some computer classes I was asked to replace the counselor, then took a job at voc rehab. I started one person in a small office and it grew over the years. The Monroe Center for Independent Living gave me worry, heartache, pain, laughter, uncertainty, knowledge, abilities, joy and honor to serve the disability community for all these years.

I will continue to advocate on behalf of people with disabilities as long as I can speak. I have been active with housing, education, employment, accessibility, benefits, advocacy, IL skills, and support.

Before I wrote this note I called John Dingell's office and thanked him for his support on health care issues such as HR 676. Awareness is a big issue, and a lot of individuals are not being served properly. Today I was let go from my position at the Monroe CIL, and I feel like a part of me died with the conversation I had with my boss. He also serves as a state director and faces many cutbacks. I happen to be one of them.

My sadness today is not only for myself, but my contacts in the disability community.

I will continue with the Michigan chapter of the MS Society.

After I read this e-mail I felt a need to write this letter. Sincerely, Linda Mayer.

>> Thank you. Mark, if we could have two.

>> I'm going to start with one from Kenneth Curry, who is the executive director of the National Association of State Head Injury Administrators, and I'm going to read portions of this.

Dear members of the ICDR. The National Association of State Head Injury Administrators represents state governmental programs administering an array of services and supports for individuals with traumatic brain injury. Abbreviated TBI.

And their families include rehabilitation, vocational rehabilitation, home and community based services and supports.

Most of the states also receive grant funds through the U.S. Department of Health and Human Services, health resources and service administration's federal TBI grant program, to help improve service delivery and access.

There is very little research and information on TBI best practices that span the range of services needed to improve employment and independent living outcomes. In addition, research to help support best practices for outreach to identify individuals with TBI in general populations is needed. Such as returning service members, homeless, victims of domestic violence, corrections, substance abuse, and behavioral health.

It would be very beneficial for research and best practices related to screening instruments and administration to help with outreach and identification of individuals who may have TBI and co-occurring conditions, and for facilitating these individuals to appropriate treatment or rehabilitation services that would result in productive outcomes.

State policymakers in today's environment wish to have information validating that services and supports for individuals with disabilities, including TBI, are cost-effective and lead to productive outcomes. It would be extremely helpful to have studies that show cost-effective or societal value or other outcomes, especially with regard to service coordination or case management services.

Research in the area of prevocational, vocational strategies, and models specific to TBI to lead to better employment outcomes would be beneficial.

While traumatic brain injury can happen to anyone at any time, it most

often occurs to individuals 16 and older. This means that these individuals were functioning without a disability during their developmental learning years. Students who receive their disability in high school often will drop out of school, or obtain any missing credits to receive a diploma, but fail to advance to vocational or college training or program.

Research and information on how to help these students to transition to other goals and be successful would be helpful.

Often, adults with TBI held high level jobs, i.e., doctors, lawyers, CEOs, and not being able to assume their former lives after a brain injury is indeed traumatic. Research in this arena to help with transitioning from life without a disability to life with a cognitive and behavioral disability would be extremely valuable to those of us who are working in this field.

As with other disabilities, the array of housing and supports is vitally needed, yet funding is lacking for individuals with TBI.

Research to help direct funding for services and supports to meet the critical needs of individuals with TBI is of utmost importance. Any research conducted to assist with developing outcomes and best practices would be welcome, but needs to be transmitted to state governmental programs involved in TBI service delivery.

Sincerely, Kenneth Currier.

I will next read a portion of a letter from Julie Ward, who represents the Arc of the United States, United Cerebral Palsy, based in Washington, D.C. United Cerebral Palsy is pleased to submit written comments in response to the Interagency Committee on Disability Research request for input about future research priorities.

For three years now UCP has researched and provided an analysis of Medicaid for Americans with intellectual and developmental disabilities. Medicaid is the safety net program that can assist in supporting individuals with their acute and long-term care service needs.

The report entitled A Case for Inclusion ranks states by analyzing data to determine what the program outcomes are for people with intellectual and developmental disabilities.

In doing so, UCP has discovered that some of the most important outcome data is not nationally collected or regularly reported. For example, to more completely assess key outcomes, additional research and reporting is needed in the following areas.

Number one. Are services self-directed, and how many individuals are participating in self-directed services.

Number two, are individual budgets used.

Number three, what is the pay and turnover rate of direct support staff.

Number four, what school-to-work transition programming exists for this population.

Number five, what are the detailed results of standard client satisfaction surveys. Number six, what is each state's long-term plan to close large institutions, both public and private.

In addition, in the area of emerging technologies, UCP is currently partnering in a research effort to understand emerging technologies that will impact on independent living across all forms of disability and aging-related function limitations. The project will forecast trends and summarize results in following areas. Trends in emerging technologies, impact on patient and client experience, impact on settings of care, impact on information and communication technology requirements, impact on service needs and costs, impact on workforce needs, impact on operations for service organizations, facilities and clinical providers.

As we move forward with this project, we will undoubtedly discover additional areas needing research that ICDR will promote. And that's from Julie Ward. Thank you.

>> Thank you, Art, if we could have two.

>> I'm going to read a letter from Lance Wright of Wright Choice, Inc. As the CEO of a supportive employment company in Virginia and current researcher working on my Ph.D. dissertation on occupational commitment of job coaches, I have noted a paucity of research on the profession of job coaches. To increase the quality of services and decrease dollars spent for supported employment, turnover of job coaches needs to decrease. The crux of successful placements

for persons with disabilities resides in the abilities and longevity of being a job coach. Research needs to focus on how to recruit and retain quality job coaches. Regards, Lance Wright.

And I want to read a letter from Tony Temple, the Ohio Network for the Chemically Injured. She's titled this deceived, disabled, dejected, dismissed and dying, the widespread dilemma of multiple chemical sensitivity disability. By Tony Temple, founder and president of the Ohio network for chemically injured.

I'll read portions of her letter. My name is Tony Temple and I'm a nontraditional self-appointed poster child. I'm nontraditional because not an adorable child with Shirley Temple curls standing on crutches that you might have seen growing up on March of Dimes or polio prevention ad campaigns. Heck, I'm not even a child, I'm 63 years old. And I'm self-appointed because the disease from which I suffer is not recognized or acknowledged by significant portions of medical and health care communities. I am a victim of multiple chemical sensitivity -- the housewife and ordinary people like you, who may have had jobs that exposed them to harmful toxins, took pharmaceuticals for health issues, or just happened to be in the wrong place when the toxic event occurred.

Toxins can be ingested, for example dyes, preservatives, pesticides and other food additives. My MCS disability was caused by an exposure to zinc chloride being emitted from oxidized galvanized metal in my home furnace ductwork. I learned from the zinc toxicological profile that zinc can replace iron in your body and cause dangerous iron deficiency anemia. The zinc apparently also mimicked iron in the CBC blood tests I had been given. I was not diagnosed with anemia until after I gave my physician the zinc profile and he desired to take an iron level blood test. It showed I was in imminent danger, and iron transfusions were ordered for me.

In short to the short term effects in chemical poisoning, there are long term effects particularly when people cannot get away from everyday exposure. For example, exposures at the workplace, schools or homes.

Long-term effects include neurological problems, peripheral nerve damage, anemias, diabetes, arthritis, chemical cellulitis, vascular disorders including life-threatening blood clotting, nutritional deficiencies, asthma, and

sometimes even cancer.

From 5 to 15 percent of the U.S. population is affected by chemical sensitization in various degrees. When you also consider that chemicals cause other diseases including cancer, birth defects asthma and Parkinsons, the percentages skyrocket. As a society we've become careless and irresponsible about the production and use of chemicals. We have been lured into believing that there are safe levels of toxics, and that additives and pesticides in our foods will not harm us. It is shocking and inexcusable that most doctors have not been and are not trained to recognize chemical poisoning in medical schools, including those for occupational medicine.

Death from taking prescription drugs as directed occurs more and more frequently, and more have been permanently harmed. Toxicologists are appropriately trained and capable of recognizing how various toxins affect our health; however, they are not permitted to treat patients unless they also have medical school training.

As a result, many MCS patients are misdiagnosed and inappropriately labeled with psychological disorders, while anemia, nerve damage and other life-threatening harm takes place. Having Ph.D. toxicologists teach in medical schools would be a great start. I firmly believe in the adage seek and ye shall find. There is a cause for every health problem and disability. As a society we can fix some of the problems. We have to be responsible and appropriately educate ourselves, and then learn how to communicate with each other to find the solutions.

>> Thank you. Mark?

>> I'm going to read three of these, and I'm starting with one from Federica Barrow, Ph.D. I think there are two populations that need special attention. Children who grew up in the foster care system have special access problems because their helpers and caregivers are paid workers who change frequently. They have no ongoing advocacy, which I believe is essential to their growth and development.

The State makes a poor parent. Perhaps an external program which funds individuals and which carries with it a five year contract subject to

renewability when a child thrives might be an alternative to foster care worker turnover with children who have disabilities.

And second, the second population is the growing number of children whose parents are incarcerated. Thank you for the opportunity to comment, Federica Barrow.

I will next read one from Jane Burnett from the Independence Empowerment Center in Monassiss, Virginia.

Gaps in research where information would be helpful are as follows: Number one. There is little research on how general education and special education teachers can prepare students for state standards assessments. Number two, information on per diem employment for people with disabilities who can work sporadically would be helpful.

There is not -- number three, there is not enough information on white collar occupations for people with disabilities.

And the third one that I'll read is from Steven Chalmers. A dozen years ago I happened to move my family into a house which likely by a bizarre confluence of events poisoned all four of us in a way neither the doctors nor the industrial hygienists ever figured out. Leaving us with what is commonly called multiple chemical sensitivity, abbreviated MCS. 13 years ago, to be honest, I would have called me a crackpot or worse. For the last 12 years, I've been allowed to remain in the workforce in a high-paying knowledge worker job because of informal accommodations from a series of managers.

Over the last 12 years my son has gone through elementary school, junior high school, and high school. There were some years when they was poorly accommodated with teachers who ignored our pleas and saw his academic performance plummeted. But in most years with teachers and administrators who out of the goodness of their hearts listened, made simple accommodations and allowed him to shine.

We're still making working on his college experience possible.

What happened to us can't possibly occur given the basic theory behind the practice of medicine today and behind the research community as well. It's been well over 100 years since MCS-like symptoms were first reported. More, if

you look closely. And over 50 years since the Randolph study. The consensus against first Randolph, then the clinical ecologists, and now RIIA and environmental medicine is really a confluence of special interests, third party payers, meeting lack of understanding in the medical community as a whole. Can't possibly occur. So this has to be all hogwash.

I thought it was hogwash, too, until it happened to me. Let's turn the research machine back on. Stop denying that this is happening, or letting the lobbyists deny it's not occurring by arguing there should be no funding, until there is a case definition, but then filibustering the case definition. Let's do the research to figure out what's happening to people like me.

Why have, in electrical engineering terms now, the noise margins in our nervous systems collapsed so that parts per trillion of contaminants particular to an individual in the blood stream are suddenly impacting the nervous system's correct operation without any sign of physical damage. And let's make sure there's a safety net. I was able to spend hundreds of thousands of dollars, imperfectly and with a lot of waste, adapting our new house so we could live there and I could continue to work. Most folks in our condition can't.

We're having a very difficult time establishing a viable residence for our son at a university he worked very, very hard to get into. There are basic accommodations he needs that we aren't allowed to ask for. Medicine doesn't understand, only the fringes of construction understand, and campus housing apartments and apartment landlords certainly don't. So chemical sensitivity by many names is a real problem. Research is needed to get past. This can't possibly occur.

Compassion is needed so that people can stay in the workforce as I have, and in the academic world like my children have. And understanding and expectation of reasonable accommodations is needed so a class of housing can be designed and made available to people like me, and likewise work environments. Thank you. Steven Chalmers.

>> Art.

>> I'll read a letter from Ronald Hull of Houston, Texas. Spinal injury, 45 years. Caregivers.

I employ three caregivers to assist me with my basic needs and get me to work. Caregivers are not paid enough to attract the type of assistance I need to be a university administrator and novelist. Family members who dedicate their lives to help me should be paid according to their contribution.

Employment. Accommodation is more than physical workplace arrangement and a disabled parking spot. It is full acceptance of the disabled employee as an integral part of the organization's productivity. For the severely disabled, work with pay should help offset public assistance. Work fare is much preferred over listless welfare.

Research. Promising treatment like stem cells should be allowed to progress without restrictions imposed by the scientifically challenged religious right. The rapidly evolving field of wireless electronics should focus a portion of its development to applied solutions for the disabled.

I'll read a letter from Liz Smentowski, S-m-e-n-t-o-w-s-k-i, I hope I got it close. Thank you for the opportunity to give the ICDR a bird's-eye view of the challenges of life as a single, fully disabled chronic Lyme disease, environmentally ill, both highly electromagnetic hypersensitive, EHS, and chemically intolerant, CI, patient.

The majority of my fellow patients intensely long to return to work as soon as they are able. For me, having EHS from Lyme disease is the greatest hindrance to reclaiming normal life. The three areas I wish addressed below are I believe key to recovery for me and many others.

One, health disparities. Nonbiased research is needed. Most doctors are not aware of EHS, it took three years for a doctor to diagnose it. I have seen 40 doctors in the seven years of illness.

And even though two neuropsychological tests were run and show that I'm mentally stable, I was often mocked and discriminated against in grocery stores, motels, public libraries, apt complexes, et cetera. Because there is virtually no public knowledge and acceptance of this illness in the U.S., unlike Europe and Asia, appropriate and affordable medical care, housing, as well as employment opportunities are virtually nil.

Two, availability of accessible housing. One key component of

recovering from EHS is appropriate housing. When one is disabled, the bare necessities are addressed. There is no time or energy and often no cognitive abilities left to search for housing. During the seven years of illness I have lived in 16 dwellings, four places of my own and the remainder with friends or family. Accessible housing is incredibly scarce, and typical housing that is available is so overpriced, about \$3,000 a month, that most cannot afford. With the current proliferation of wifi, the homes I've lived in in the past are no longer suitable for me. Based on others' experiences if I had accessible housing and appropriate medical care two years ago, the potential for greatly improved health would exist. Instead as I write this, I am more EHS than ever, and have recently been doctor-confined to my friend's house where the only space I'm able to physically tolerate is a 3 by 10 area of their living room without developing migraines and resulting intensified fatigue.

I'm not currently able to use one of the last vestiges of modern day America, a speaker phone, an 8-year-old car, and an electric stove.

Three, employment of people with disabilities. Although I have an international MBA with impressive work history and in the recent past was able to use the phone, there were no organizations that could assist me with employment options. In an extensive search I found no national or government agencies or profit or nonprofits that had viable options. Even phone work now requires the use of a computer. Thank you for working to improve the lives of the environmentally ill. Regards, Liz Smentowski.

>> I'm going to read from comments that came from an organization called Access to Independence of Courtland County, Incorporated, and I'm going to read portions of it. Access to Independence of Courtland County, Incorporated, abbreviated ATI, was incorporated in 1998 as a not for profit 501 C 3 organization. ATI's roots go back to 1986 as a grassroots advocacy organization based in the city of Courtland, New York. In 2001 ATI became one of New York state's 40 independent living centers. As an independent living center, ATI is a community based consumer controlled nonresidential organization that serves individuals with a wide range of disabilities in and around Courtland county, New York.

In giving recommendations to the ICDR, the ATI identified five major topic areas. Employment of people with disabilities, health disparities, access to assistive technology and universal design. Transition of youth to employment and independent living, and availability of accessible housing, transportation, and recreation.

Throughout all of those areas, ATI first recommends that there be targeted research and analysis to rural areas and small cities.

Within the areas specifically of health disparities, ATI recommends four things, in addition to targeting research and analysis to rural areas and small cities.

Number one, begin implementing test programs that target specific disability populations to collect outcome based data relating to the successes or failures of innovative programming that aim to reduce health disparities among persons with and without disabilities.

Number two, evaluate the impact that increased community choice in health care would have on the quality of services provided and the health disparities that persist among persons with and without disabilities.

Number three, correlate the availability of accessible health and wellness programs in an area with the per capita disability population. The availability of accessible transportation, and the general health and wellbeing in those individuals.

And number four, evaluate the availability of accessible medical equipment throughout the country that is available to test for additional diagnoses. For example, equipment that is accessible to individuals with any kind of mental, physical or developmental disability.

In the area of availability of accessible housing, transportation and recreation, in addition to targeting research and analysis to rural areas and small cities, ATI also identifies some other recommendations. Number one, evaluate the impact that increasing college and university populations has on available accessible and affordable housing, especially in rural areas and small cities.

Number two, compare the levels of public assistance available to households that have individuals with disabilities, with the household areas' fair

market rent levels.

Number three, compare locations with available, accessible and affordable housing with the availability of accessible public transportation.

And there are more in that category, but I'd like to read a few from the category of access to assistive technology and universal design, and in addition to the previously mentioned targeting research and analysis to rural areas and small cities, there are three other recommendations.

Begin implementing test programs that target specific disability populations to collect outcome-based data relating to the successes or failures of innovative programming that includes the use of assistive technology to promote independent living.

Number two, evaluate the impact that increased community choice in assistive technology training would have on the quality of services provided and the related independent living outcomes for persons with disabilities.

And number three, expand the use of test programs, such as New York State's Department of Housing and Community Renewal access to homes program, to include local businesses and to collect specific outcome-based data relating to the successes or failures of innovative programming to facilitate increased accessibility in the community, and to promote the universal design concept.

I'd next like to read a letter that was written by Ronald Paul, who has had a spinal injury for 45 years. You read that? I thought you did, sorry about that.

I'm next going to read, then, a letter from Joseph Lyons from Quincy, Massachusetts, who writes, I strongly recommend that the ICDR facilitate the creation of an interagency panel or coordinating committee on chemical sensitivities or intolerances. To promote research, policy development, patient support, and public education.

And that the ICDR urge congressional authorization and funding for a comprehensive research program, including funding for environmental medical research units. Joseph Lyons.

>> I'm going to attempt to do justice to a very long tome presented by the American Occupational Therapy Association, Inc. AOTA. The American

Occupational Therapy Association represents the interests of more than 100,000 occupational therapists, occupational therapy assistants and students of OT. We appreciate the opportunity to present comments to the ICDR.

AOTA's overall research aim is to increase understanding of the factors that support everyday life and identify barriers that limit engagement in meaningful life activities and full social participation, with the goal of improving the quality of life for individuals and their families.

Occupational therapy researchers do their work across the life span as disabilities present challenges to children and youth, workers, and older adults that face the consequences of aging with chronic illness that can lead to disabling conditions. Because our focus is on everyday life, we offer resources to translational studies that seek to understand the impact of interventions on wellbeing and participation.

AOTA is an active advocate for increased funding and visibility for rehabilitation research for the benefit of people with disabilities. Our efforts are targeted toward many of the agencies, institutes and centers that are represented on the ICDR. Addressing this committee provides the opportunity to highlight rehabilitation research priorities important to occupational therapists, as well as other rehabilitation researchers.

AOTA believes there are critical research needs across the life span. This aligns with AOTA's Centennial vision, a plan that sets a blueprint to 2017 for our profession.

We consider the broad practice areas of productive aging, children and youth and disability rehabilitation and participation to be cornerstones of this vision. While our comments are divided between productive aging and children and youth, you notice the third practice area can be found under both categories as it is addressed across the life span.

I'm going to read selective portions from these topics starting with productive age. In regard to the aging populations we're seeing increasing numbers of older persons with disabilities living alone, many with cognitive problems, and in the oldest old age group many experience impairments that impact ability to carry out daily self-care activities, as well as home management

activities.

The impact of aging and chronic conditions is particularly acute for elderly people who live alone with minimal access to informal supports. Effective self-management strategies for this population with chronic health conditions and disabilities with a goal of preventing secondary conditions and improving health is an area that requires additional attention.

Cost-effective solutions for prolonging independence in the face of increasingly restricted budgets for elder care are essential. There is a need for research and development of technology that can offset the decline in health and self-care abilities and enable older persons with disabilities to continue to live at home.

Low vision is a condition that cannot be corrected by lenses or surgery but allows some usable vision and is a specific area of concern to AOTA. The Eye Diseases Prevalence Research Group reported that one in 28 Americans over the age of 40 experience low vision and blindness. This translates to roughly 4.3 million adults, a number that is expected to double within the next three decades as older Americans succumb to age-related eye diseases that cause low vision.

Although investigators have identified the prevalence and causes of low vision, research is lacking in areas addressing the effectiveness of rehabilitation, particularly the amount and type of rehabilitation approach that will enable older adults with low vision to continue to lead productive lives.

Community mobility encompasses walking, pedalling, driving and riding as passengers, and is an area of interest for OT.

Traffic related incidents for drivers, passengers and pedestrians results in one of the most significant causes of injury and death for many groups across the life span.

AOTA is interested in improving mobility for seniors and people with disabilities and believes that research related to interventions directed toward improving community mobility is necessary. AOTA recommends that community mobility be given additional emphasis by the committee and the disability research community.

Another important area for research relates to elder falls and falls prevention. When evaluating an older person who has fallen or who is at risk for falls, the OT synthesizes information from three broad areas to identify causes and target interventions. The three broad areas considered by OTs are the person, the environment, and the occupation.

AOTA recommends an emphasis on the following. Frail elders living in the community have unique needs with regard to falls risks. Inclusion of research into the most effective strategies to address the special needs of frail seniors is needed. Falls prevention for people with cognitive decline is the most difficult and consequential problem faced by older adults and caregivers. We recommend consideration of inclusion of research priorities that address the interplay between cognition and fall risk and specific instruction such as OT that addresses these issues.

Physical activity programs have been researched heavily in recent years, a shift in research that leads to closer examination of the connection between engagement in occupations and fall risks with emphasis on activity modification in context as a fall prevention strategy is needed.

Children and youth. In regards to children and youth, AOTA would like to see more investigation into effective interventions to address the needs of young people with social, emotional, psychiatric, behavioral disabilities, especially in middle school and high school students. These disabilities can be a difficult barrier to engagement in meaningful age-appropriate activities, full social participation, and transitions to adulthood.

One such issue is autism. Autism spectrum disorders ASD are a group of developmental disabilities defined by significant impairments in social interaction and communication, unusual behaviors and interests, and unusual ways of learning, paying attention or reacting to different sensations. There have been more than 172 percent growth in individuals diagnosed with ASD over the last 15 years.

And there are many more points here, I'm going to try to skip down. Transition is a process of preparing to move forward from school setting to successful community living. Schools should prepare all students with or

without disabilities for life skills necessary in young adult. Research has indicated that student and family participation and self-determination has been the link to increased graduation rates, employment and achievement of positive post-school outcomes.

Other issues deserving greater attention relate to chronic pain. Barriers to functional ability, and ability to participate in normal physical activity need to be understood. There is a need to determine extent to which changes in catastrophizing or excessive negative thinking, effectively alter pain and psychological adjustment, especially in those youth who suffer severe pain or acute depressive symptoms.

It is important for the disability research community to examine what factors in the environment most influence emotional and physical health community living participation employment for people living with long term disabilities.

AOTA thanks the committee for the opportunity to share research recommendations in regard to people with disabilities. In 2006, AOTA submitted comments regarding the need for capacity building for research within the profession, and while that need still exists we recognize and appreciate the creation of two K-12 grants for junior investigators, training for occupational and physical therapy researchers. We remain committed to working with the committee and member organizations tasks in guiding the disability research agenda. We look forward to an ongoing collaboration with the committee to ensure that the unique perspective of occupational therapy is utilized to inform disability research in the area of function and performance for people with disabilities and functional limitations.

>> Thank you. We'll go to the line now.

>> Billy Weaver, your line is open.

>> Thank you very much. I also want to address federal employees disabled through on the job injuries. This is what our paper has to say about it, I'm going to read right from it.

Treatment, accommodation, placement and termination or retirement of federal employees permanently disabled through on the job injuries. Federal

employees disabled through on the job injuries who cannot return to their previous position are subject to harassment, intimidation, discrimination and nonaccommodation for their disabilities. Arbitrary decisions regarding medical treatment, career, placement and/or separation from service are often made by the employing agency and the Department of Labor office of workmen's compensation, with little or no involvement from the injured disabled employee.

Frequently these decisions are made without regard to the interests or needs of the disabled employee. Employees who become disabled through on-the-job injuries are often faced with traumatic changes in their lives. In addition to drastic changes in lifestyle, they are frequently displaced and lose control over their chosen careers. At the whims of the employing agency or the Department of Labor, these employees are often excluded from the decision-making process affecting their future and their health.

They are frequently harassed by BNOWCP, however should they return to work they are often placed in jobs for which they are unqualified, are denied adequate training, and are placed in jobs that do not meet their career objectives and/or in which their physical limitations are not accommodated.

Placement decisions that fail to adhere to accommodating guidelines and medical needs are bad for moral, lead to increased OWCP costs, are a poor use of agency resources, and are demanding to the employees who sacrifice their health for the agency, and now must face other challenges in health, lifestyle and career. Treatment of this kind has also led to drug and alcohol addiction, broken marriages, suicide, and in some cases workplace violence.

In many cases the employee leaves the agency, at a loss of both expertise and unrepresented employment group member. Often these employees feel they are being driven from the agency by placement in unacceptable positions and are then directed toward an office of personnel management disability retirement, which is really poor.

Employees often fight harassment and intimidation along with threats of termination. Employees who become disabled through on-the-job injuries should not be penalized for their desire to remain employed and productive, nor should an employee be harassed and threatened if unable to return to work.

Unfortunately, very often an employee is discriminated against if he or she returns to work, harassed and threatened if he or she remains on OWCP. The employing agency should do everything within its power to meet the needs, interests and career goals of those employees who became disabled through on-the-job injuries.

And I'm not going to continue all of this, because you have our paper in front out of, but I just wanted to say that I appreciate this opportunity to bring this forward, and I do hope that this is falling on some ears that want to take care of this issue. Thank you.

>> Thank you.

>> This is Mark Leddy, I'm going to read one from Pamela Williamson who works at -- or is affiliated with Southeast DBTAC is the abbreviation, frequently referred to as dib tack. And DBTAC is a southeast ADA center. And from a visual on the letter, it appears to be covering states in the southeastern United States.

And the letter reads: If research is to be translated so that various audiences can use findings to improve services and maximize outcomes for people with disabilities, researchers must -- and then there are four recommendations. Number one, convey information in a language that is suitable for the intended audience. For example, business, people with disabilities, disability service providers, legislators, general public, federal government agencies, state and local government agencies.

I would suggest that researchers utilize the services of individuals or agencies in the targeted groups to review any research findings and materials used for knowledge transition and dissemination to ensure it is understandable and meaningful to achieving specified outcomes.

Number two, identify appropriate networks for information dissemination. I would suggest utilizing the DBTAC ADA centers, and the web is given for that www.ADATA.org, as an information dissemination network. The DBTACs have 10 regional centers and work with over 2,200 agencies and organizations. These organizations include people with disabilities, state and local government agencies, private businesses, and service providers.

Number three. Provide guidance in the form of documents or tools that will assist in applying the research findings in a practical and usable manner in the field. Guidance documents or tools would also assist in replicating best practices that are identified as a result of conducting research.

Research has often been conducted in a vacuum, and the findings have not been applicable to the real world. Therefore, these documents and tools are critical to ensuring successful implementation of research findings.

And number four, include people with disabilities as equal decision-making partners in all aspects of the disability research agenda. For example, planning, identifying questions, data collection, and knowledge translation, et cetera. That was submitted by Pamela Williamson from the southeast DBTAC.

>> Thank you.

>> I'm going to read a letter from De Tobis, T-o-b-i-s. I'm a female who moved out of an ICS residential home for the mentally retarded and developmentally disabled into my own apartment. I have a physical disability which makes me unable to walk or use my hands, but for some things I can still use my mouth. After completing two years college I applied for a staff position at a sheltered workshop.

Later BVR, Bureau of Vocational Rehabilitation, set me up with my own computer and a workstation with adaptive equipment that I drove my wheelchair up to. One year after receiving assistance from BVR, since I competitively employed, qualified to receive PAS, personal assistance services through RSC, which reimburses me for the wages of a care provider to assist me with some of my daily needs and duties on the job. The changes I would like to see in the future for all individuals with disabilities are, one, families of individuals with a disability or the individual who lives in their own homes who needs adaptive equipment to allow them to live independently cannot find any help with getting the equipment.

Two. Individuals with a disability who are competitively employed and in need of assistance with purchasing adaptive equipment to better perform their work duties, or maybe the individual who is employed who do get assistance from BVR, but they assist one time with adaptive equipment.

Five, 10 years or more they may need their equipment upgraded. The nonprofit agencies that the individual is working for is unable to update their equipment. There needs to be a way that they can -- that they be able to get some type of assistance.

Individuals with disability who are in need of personal care to assist them with some of their daily care and their work duties. It would be good that the PAS would raise the amount of pay that they reimburse because of the rising cost of the price of life and the cost of gas. Thank you. Dee.

>> I'm going to read a letter received from Becky Barclay. Summarize it. Becky is appreciative of the opportunity to express her views. And she's writing -- she's in support of the recommendations submitted by the National Center for Environmental Health Strategies, Incorporated.

Among those recommendations, she requested to highlight the following, that the ICDR facilitate the creation of an interagency panel coordinating committee on chemical sensitivities and intolerances research, policy development, patient support, public education, and that the ICDR urge congressional authorization and funding for a comprehensive research program including funding for environmental medical research units.

Number two, the ICDR take action to assess the number of people affected by chemical sensitivities intolerances and their needs, as well as housing, employment, health disparities, issues consistent with the authority of the ICDR.

Sincerely, Becky Barclay.

>> I'm going to read a letter from Angie Sanders. I'm a person with chemical sensitivity, and more and more it is commonplace to find others with the same challenge. I am a professional in health care. Hundreds of times through the years I have had patients crying in my arms saying you are the only ones who understand and are helping me. About then a nurse with perfume will come waltzing in and the patient and I get sick with various symptoms, or the cleaning team enters and my patient's heart rate rockets up and needs a breathing treatment. Or it is time for the pesticide treatment. Or how about the time varnish was painted on the handrails in the COPD hospital. Oh, yes, the diesel

fumes from the generators every week. Sometimes I have to go home because I lose my voice. Sometimes my settings accommodate me by putting me in an isolated office, and it is very sad to be apart from my coworkers.

Mostly I just do not work anymore. I live on very little and stay healthy by reducing my exposures and just staying home. However, because there are so many people with chemical sensitivity I do have others I can visit who have safe homes. I wish doctors were better trained to recognize this and treat this. Personally, I can spot a sensitive person like a hawk on its prey. A lot of people who have this don't even know they have it or how to help themselves.

It is a gaping hole in the industry. I wish products on the market were safe, that Americans would recognize the common sense of staying healthy, using many nonchemical products.

As is often the case, we do not awaken to things until it affects us personally. It sure is a struggle to be at the beginning of a movement affecting all parts of my life. If you can help public recognition, federal oversight standards on safe nontoxic products, et cetera, et cetera, we can stop a situation from going from bad to worse. Thank you, Angie Sanders.

>> I have one from Sylvia Coris. People who experience mood swings, fear, voices, and visions are managing their health issues better under the social model of disability, and services are beginning to focus on recovery and wellness. Still, people have moved from mental patient to good mental patient, and are often continuing to live in a mental health ghetto.

I encourage more resources towards community integration and community participation, meaningful work, paid or unpaid, a valued place of belonging.

>> New Jersey Environmental Federation wishes to support the recommendation by the National Center for Environmental Health Strategies, NCEHS. The NCEHS comments in part recommends that the ICDR facilitate the creation of an interagency panel coordinating committee on chemical sensitivities intolerances, to promote research policy, develop patient support and public education, and that the ICDR urge congressional authorization and funding for a comprehensive research program, including funding for environmental medical

research units, EMUs.

NCEHS recommendations also call for action to assess the numbers of people affected and their needs as well as housing, employment, and health disparities issues consistent with the authority of the ICDR. Thank you for the opportunity to comment. Jane Nogaki, program coordinator, New Jersey Environmental Federation.

>> I have a letter from Ann Styman. Ann also supports the NCEHS recommendation that the ICDR facilitate the creation of an interagency panel coordinating committee on chemical sensitivity intolerances, to promote research, policy development, patient support, public education, and that the ICDR urge congressional authorization and funding for comprehensive research program, including funding for environmental medical research units.

Ann is a professor at the Department of Civil and Environmental Engineering at the University of Washington.

>> We're going to try to summarize from the Ecological Health Organization submitted by Elaine Tomco. My name is Elaine Tomco, I'm writing as executive director of Ecological Health Organization based in Connecticut. ECHO is a statewide nonprofit advocacy support education and referral organization for people disabled with multiple chemical sensitivity, MCS, and others who care about its prevention. Founded in 1992, ECHO was one of the first organizations in Connecticut linking environmental issues in public health. In her extensive testimony that she provided in writing, she is quoting often from Ms. Lamielle who presented for us earlier today, so I'm not going to repeat a lot of those comments. Instead, try to just present some of the unique material, here.

We wish to concentrate on two areas of vital importance in our community disabled by toxic chemicals which resulted in chemical injury. These areas are need for safe, accessible housing and the inability to receive adequate health care to meet our illness. In her book, Multiple Sensitivities, a Survival Guide, Comprehensive Help for Coping with Chemical Hypersensitivity, Chemical Injury and Environmental Illness, Pam Reed Gibson writes I believe housing is the singlemost important issue regarding environmental sensitivities. A safe zone

can help prevent further health deterioration and provide a place to detoxify after exposures received from the outside community.

On average, ECHO receives one phone call per month from people disabled from chemical exposures who need safe housing, free from asphalt street paving, pesticides, ambient wood smoke, or drifting fabric softeners from neighbors' clothes dryer.

Need for emergency housing for people with MCS is not being met by any federal, state or local agency in Connecticut. Emergency housing should be made a priority for HUD, and managers in HUD sponsored housing should be educated and trained regarding the health needs of people with MCS who reside in their facilities.

The HUD ruling regarding disabilities including MCS should be distributed to all such managers. Our time is quickly running out. We urge a survey of the MCS community be conducted as to the extent of the need for safe, affordable housing, and demonstration construction projects be funded.

>> Thank you. Thank you very much for joining us today, we greatly appreciate your input. And we invite you to join us again on August the 13th from 1:00 to 4:00 for public comment, and also that session will be webcast. Thank you very much, and we'll see you on the 13th.