Peter Blanck: I am really honored to introduce our kickoff keynote speaker, Dr. Kate Seelman, who is the Director of NIDRR – National Institute on Disability and Rehabilitation Research—which is a major sponsor of why we are here today. Kate Seelman has taken, I think, somewhat of a leap of faith with us. This is the first conference, that I’m aware of, of its kind with the particular focus on rigor in qualitative research. And all of us in the room, I know, believe that it really is kind of a false dichotomy between quantitative and qualitative research. Either both can be rigorous or both can be a bunch of garbage. And we can approach each task with scientific rigor in a way which brings multiple perspectives and, frankly, perspectives which heretofore have not been brought to the table; notably a disability perspective and other perspectives in this area. It’s with great pleasure that I introduce now Dr. Kate Seelman as our honored guest to kick off this conference.

Kate Seelman: Well, thank you colleagues, friends. Now, so many of you I’m looking at are dear friends and it’s an opportunity to see you. It’s a pleasure to initiate the work of the Summer 2000 researchers’ symposium and the institute sponsored by NIDRR’s funded research and training center on workforce investment for persons with disabilities. I want to express my special appreciation to Dr. Blanck, to Michael Morris and to other symposium faculty. I also have to say that your drivers are way over qualified. I got a lawyer one time. I got an assistive technology person. Very impressive. One of the nice things also about coming to hear about all of you, one of you gave me your latest book which is on the ADA… happy birthday, of course. We’re having a wonderful time around the country, aren’t we, with the ADA?

I have to say a few things about NIDRR. We’re not NIH, we’re not NSF, we’re a little applied research institute and I think that just to give you the kind of mix of NIDRR I think it was the night before last, I was on the Vice-President’s lawn. We had set up an extraordinary technology tent attached to the Vice-President’s main tent. You walked into the tent, just before you went in you had virtual golf if you wanted to play it. You went in… we got an interior designer to do the tent so the tent was in the theme of the Americans with Disabilities Act which is, we live our lives. So, you walked into the tent, you walked into a living room. And, you had an entertainment center, you had this, you had that. You had a child’s area, low-tech, high-tech. And, then, a dinner table with low-tech and so on and so forth. And then, in another area, office…which was one of the most modern offices you’d ever hope to…… We had a lot of machines there. Judy Heumann’s husband, you know, is Mexican, so all the machines could talk at least in English and Spanish. But, you know, we beat that one by the guy… we did a technology event in the grand foyer of the White House last year. And one of the small business technology research things was the conversion of music score to Braille. And, so, I had the President and the Vice-President, ten minutes all to themselves playing with all this stuff. They walked up to Dancing Dots and the smart researcher had that computer programmed and it started playing Hail to the Chief. So that was even better than what we tried to do with Jorge [Pineda] and Judy Heumann. So, anyway. The kind of things that NIDRR does, and that you all do because we’re all a part of the same research community. You have these very complex, often very complex, technological kinds of problems confronting us. Anita and I were talking about genetics but really, you know, at the moment… I’m talking a little bit more about IT, information technology. On the other hand, we’re having the first international disabilities studies conference in October. And in January or February will be the release of a book on disability studies that is an international textbook on disability studies. So, these are the kinds of things… and in either case, I would say that we’re talking rigor and we’re talking relevance. And, for an applied research center or institute you have to somehow blend and take care of both sets of values.

There aren’t many NIDRR’s around. So, I thought as the end of this administration approaches, down at Rehab International, I would invite all of the representatives from all the NIDRR-like research institutes in the world… of which there are very few. But, they are all applied research and they help people with research in living in society and communities. So, we’re looking forward to international information
exchange. And all of you should be a part of that also. It’s a very exciting thing. It’s the first panel of its type, ever. And, that’s going to happen in Brazil next month.

So, in any case, this shows, you know, as a community, the variety of our work and the demands of our work. We’re in a time of a fast paced innovation yet we always must be attentive in our research to literature review, to research design, to identifying a problem that is researchable and to then bringing the methodological tools to that. There is no doubt in employment, and I might add in many other areas, that a combined quantitative and qualitative approach can make data come to life and have a powerful effect on our understanding of change. And, that qualitative research has six characteristics: concern with meeting people attached to the things in their lives; inductive…developing results from patterns in the data rather than collecting data to assess preconceived models, hypothesis or theories. And… this is very important. That point is very, very important in the time when disabled people’s opportunities are really blossoming and changing. A holistic view of settings and people. Concerns with how people think and act in their everyday lives. Emphasis on the meaningfulness of the research. Nonetheless, whatever research methods we use we have to first of all clearly identify a problem and go through the kind of scientific orientation and we can never be too far from that.

In the employment area, which is a major focus of rehabilitation and disability research and a major point of stress, I might also add, for all of us, Tony Coehlo said, “Many Americans with severe disabilities are still unemployed,” I am sure that all of you have seen or will be discussing some of the new reports, certainly the research and training center here is very aware of them. We live in a time of opportunity that encompasses economic prosperity, technology and innovation. Government policy that focuses on employment for persons with disabilities; civil rights protections that prohibit discrimination against workers with disabilities. But there are many, many challenges. And, perhaps, the one that gives us the most pause is the employment trends that suggest that workers with disabilities may be the only group that is not experiencing job growth in the cycle of prosperity. And that gives us great pause.

Technological innovation that creates barriers for persons with disabilities. Many of you may know that it was the NIDRR research engineering center that helped to support the development of accessibility features in Microsoft Windows. And, I think you can pretty well feel that the engineering capacity within the disability community has gone from zilch to 95. We want the same thing in our social science and in our real capacity for research. And, I know that you are about that today.

Government initiatives that may be duplicative and lack valuation data to determine impact, legal challenges to the civil rights protections related to employment, especially in the area of state government. And, we are going to have quite a Supreme Court season coming up. I know that this is so legally orientated that we have our most brilliant, or many of our most brilliant scholars right around here in the legal area.

But, in terms of background, what is the background for people with disabilities in the past 25 years. Treatment advances in areas such as spinal cord injury, traumatic brain injury, severe burns resulted in a steady rise in the life expectancy and functioning of individuals with disabilities. Improved medical diagnoses, treatment methods and behavioral protocols as well as enhanced rehab engineering technologies have contributed to preservation and restoration of function. We stand at the threshold of regenerative medicine that holds the promise of reversibility of injury and impact. This is extraordinary. We are in a period on the threshold in both science and engineering that’s very important that we keep touch with the basic sciences, with NIH and NSF and we’re working very hard at NIDRR to make sure that we are in touch with these areas and in touch with these agencies. Because we are living in revolutionary times. Our view of disability, and you all have contributed so much to this, during this time period has, of course, changed. In the old paradigms of disability, disability was reductive to medical condition. This view may have contributed to societal attitudes that regard disability as the result of an
individual deficit that prevents a person from performing certain functions. The new disability paradigm maintains that disability is a product between the characteristics of the individual and the characteristics of the environment. The new paradigm may contribute to social attitudes that acknowledge disability in the mainstream of life through the availability of health care supports and universal design. This kind of approach, of course, is nested in, or is, the framework of the NIDRR long-range plan and the NIDRR long-range plan is a framework which invites the research community to state, “here are the problems that we need to address.” It is not something that is telling you what the research agenda is. This orientation is also very much a part of Enabling America, the Institute of Medicine Report, Healthy People 2010 and the ICIDH revisions which some of you, I assume, are working on.

In terms of going to this theme of opportunities and challenges, yes, there’s economic prosperity. The typical American family increased its net worth by 18% between 1995 and 1998 as house prices, stocks and wages all rose. Even the poorest fifth of American families saw their household incomes grow by an average of 2.7% a year between 1993 and 1980. There’s projection of continued job growth ensuring the professional specialty occupations will increase the fastest and add the most growth. I served on the Inter-agency Committee for the Commission on Equal Opportunity in Science Engineering and Technology for Minorities and Women. And we saw that disability was added. They just released their report and that concept report is on our web site and you should probably take a look at that. You see there is real concern about preparation of people in the sciences and in engineering and technology for disabled people because you have to, as you know, build access and many other things in an early age. I mean, kids can’t necessarily use the engineering or the laboratories that are available because they’re not accessible. I hope Iowa’s are. Are they? I don’t know.

Anyway, the projections supported by business reporting in an article raised alarm about the estimated 200 – 400,000 open computer software jobs. Our partial answer has been to go abroad in the United States, not to look at our own students. It’s very important and I think that Congresswoman Morella and others, including the concept report that I’m talking about, agree that the recommendation is to put more emphasis on developing our minority students, our students with disabilities and women and bringing them in to these technical professions. So, in any case, these are certainly some of the opportunities economic prosperity brings and some of the conundrums. As you probably know the Census Bureau created great consternation within the disability community with its release of an analysis of employment data from 1997 SIPP. Findings from the report indicate a drop in the employment rate of persons with severe disabilities and we’ll all want to be very attentive to that analysis and we have certainly been briefing the Assistant Secretary, as I said to Peter this morning, and have kind of a statement about these various studies that are coming out.

In terms of technological innovation, Mary Pat Ratabout, of IBM stated long ago, 1988, “For Americans without disability, technology makes things easier. But, for Americans with disabilities, technology makes things possible.” And, we live in an era of rapidly developing technology and it is all around us and as I said to you, NIDRR is very much involved in it. We have many, many concerns. Access is a technological problem. Access is also a policy problem. Doug Kruse, an economist at Rutgers University, recently found that although disabled people are more likely to work at home, they are less… actually less likely to use computers. In a recent NIDRR funded disability statistics report, computer and internet use among people with disabilities, Steven Kay observed that computer technology and the internet have a tremendous potential to broaden the lives and increase the independence of people with disabilities. Kay concludes that the computer revolution has left the vast majority of people with disabilities behind. Very important. He found that only one quarter of people with disabilities owned computers and only one tenth ever make use of the internet. These findings get worse when age, income level and educational attainment are factored in. And, of course, older people and those with less income and people with less education are less likely to use computers. Computer usage rates, of course, have implications for employment on several levels. The BLS data, the Bureau of Labor
Statistics data indicate many jobs, especially those with good income potential involve technology. So, we put a lot of emphasis on technology. I’ve always looked on technology as a social tool, not as hardware, because technology is changing our social relationships. And, that’s the way, I think, we look at technology at NIDRR.

In terms of new government initiatives, as you know Section 4733 of the Balanced Budget Act authorizes states to provide Medicaid for working people with disabilities by creating a new optional eligibility category. The legislation will allow states to provide health insurance to individuals with incomes up to the 250% of the Federal poverty level. In 1999 Ticket to Work and Work Incentives Improvement Act signed in ’99 further addressed work disincentives inherent in DI and SSI and it will be up to our community to understand the implications of that as it goes on and that certainly is an important piece of our work. And we want to know how the relationship between changes in TANIFF and changes in AFDC and so on and so forth and the employment rate. We have to know these things.

Research efforts are also underway to identify factors contributing to employment, unemployment of persons with disabilities. In 1998 NIDRR funded six employment rehabilitation research centers including this one and Cornell. We also funded a rehabilitation engineering research center on ergonomics in work. I wonder if any of you ever thought about how these standard doorways were established. What the standards for size… You know… why do we have these standards. So we asked the ergonomics center to begin to look at and create an anthropometric database. I, myself, have been delving into anthropometrics and find that a lot of the standards go back to the Second World War pilot who was 20 years old and male. And so, that’s a very interesting undertaking, kind of innovative in the NIDRR research community.

Civil right protections… I want to discuss the Americans with Disabilities Act. The ADA was a culmination, as you know, of many of years of our efforts. And, in recent years judicial decisions have both narrowed and extended the scope of the ADA. On the one hand the courts limited interpretation of ADA coverage to conditions not corrected by assistive technology. On the other, in the Olmstead case, the courts declared the states must provide the least restrictive setting for persons with disabilities. Currently there is a serious challenge to Title II of the ADA in Garrett v. Alabama. Very important. This case pending before the Supreme Court will address the constitutionality of the ADA as a state rights argument and I assume I need to say no more about the legal areas because you all are very conversant.

The implications of these opportunities and challenges for the research community, as indicated in the NIDRR long-range plan published recently. The agency supports efforts to enhance the capacity of the field to conduct research that is scientifically excellent and relevant to the concerns of disabled individuals and other stakeholders. Research training should be based contextually, I think, in the new paradigm of disability and should explore the strengths and weaknesses of cross-disciplinary efforts as well as participatory action research which is an approach to research that has very little grounding. I would love to see the philosophers get to work a little bit more on participatory action research, as well as the social scientists and the political scientists. Qualitative research, of course, allows us to focus on specific disability populations, delineating characteristics that allow in-depth discussions specific sub-populations. All research allows us to tailor our research questions to issues that may be newer and innovative and we’re all in this field because we like that. It makes us… you know…. It’s exciting. And, to fulfill it’s own promise, qualitative research must be rigorous in its approach.

So, in conclusion, I think our job as researchers is to choose research problems that are relevant and that meet the high standards of science. This is not easy. But I will tell you that when I became Director of NIDRR I was slapped with the Institute of Medicine report that said NIDRR’s peer review was poor. It was quite a bit of criticism of NIDRR’s science. And I do not believe that our community cannot do both,
and it must do both. It must be rigorous and it must be relevant. Now, NIDRR is receiving...well let me
just tell you that yesterday the President signed an executive order on tech transfer which gives the
inter-agency committee on disability research implementation power and I chair the inter-agency
committee on disability research. It is a statement that the scientific establishment now reposes a
certain amount of confidence in our science. It will always be, and I always have said, that our research
community is in a state of tension between rigor and relevance. That is our situation and it will be our
situation. But, nonetheless, we have unique opportunities as an applied research institute with this little
bit of money that we hold together as a public trust. So, again, I want to commend you, Peter, and all of
you and thank you for the hard work and productivity as we move through extraordinary times for those
of us in the disability field and we are continuing to be challenged. So, what with that, if there are any
questions I’d be glad to field them. None? Ok.