Employment of People with Disabilities: Why Are We Losing Ground Webinar

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[Kathy Krepcio] Welcome this is the first series of the Virtual Leadership Institute under the NTAR Leadership Center. First of all I should say this is Kathy Krepcio from the Heldrich Center and also the project director for the NTAR Leadership Center and so welcome all participants to this first of five one-and-a-half hour webinar workshops designed to help state and local leaders who are members of our State Peer Leaders Network and State Leaders Innovation Institute meet the challenges of moving adults with disabilities into employment within their organizations and teams. I know all of you have registered for this Virtual Leadership Institute series, it is a series of sessions that focus on broad things, innovative ideas, and leading edge strategies that demonstrated to be effective in achieving an inclusive workforce for adults with disabilities in both public and private settings. Each of the workshops in this series will concentrate on critical performance requirements for today's leader in the disability, employment, and workforce arena and provide and develop a wide range of knowledge, skills, and insights necessary for systems change so we are very happy to have all of you register for this workshop and I'm going to introduce to you Steve Edelman who is the Rodney Sharp Professor of Human Services Policy and Leadership at the University of Delaware. Steve will be conducting today's workshop entitled, *Employment Of People With Disabilities, Why Are We Losing Ground*. Briefly this workshop will provide an overview of the demographic factors and public policy constraints that have contributed to less than acceptable progress toward assuring employment opportunities for people with disabilities in the U.S. Steve is a member of the NTAR Leadership Center's consortium as part of our institute and I'm going to talk a little bit on the next slide please about the institute. The NTAR Leadership Center was established in 2007 through a grant from the U.S. Department of Labor Office of

Disability and Employment Policy affectionately known as ODEP. It is a collaboration of partners with expertise in various areas workforce development, economic development, disability, employment, asset building, and leadership development of which the University of Delaware and Steve Edelman is an expert in this area. It was created for the purpose of building capacity and leadership at both federal, state, and local levels to enable change across various systems including but not limited to the workforce development and disability systems that helps increase employment for people with disabilities, next slide. The NTAR Leadership Center is built on five guiding principles as a result of some extensive research conducted by the U.S. Department of Labor. Briefly these guiding principles are, one, increasing partnerships and collaborations among and across generic and disability specific systems, a lot of you who are participants in today's VLI are engaged in an enormous amount of partnership and collaboration building and it's a key goal under our leadership center. The second principle is regarding increasing the use of self direction of services and integration of funding across and among systems, some of you may have participated in an earlier webinar we had done on blending and braiding resources which is I know for many of you a very important and critical component of your partnership development. The third principle regards increasing economic self sufficiency through leveraging things like work incentives, financial education, and other asset building strategies that promote employment and again asset building and income building. The fourth principle regards increasing the use of universal design and employment services and as a framework for employment policy, many of you are familiar with universal design in the physical sense and we're very interested in looking at the use of universal design in the service delivery system and finally our fifth guiding principle relates to increasing the use of customized employment and other forms of flexible work options for individual disability this is a critical area for us and really trying to promote customized employment and other kinds of work options that are important

in the work place, next slide. So without further adieu what I'd like to do is just go over the agenda a little bit, Steve is going to give an overview of the contemporary disability history, he's going to identify some of the leading issues, look at change management basics. We'll make things available for questions and answers so throughout the entire presentation we'll leave things open for questions and give Steve a break and ask him to extemporaneously discuss some of the really interesting and important things and the objectives of today's session are to provide overall background for all of you, to acquaint you with issues in the field, to develop a framework for systems change and again to answer your questions so without further adieu I'd like to turn it over to Steve Edelman.

[Steve Edelman] Well, greetings, good afternoon or whatever time of the day it may be when you're listening to this. Let me tell you a little bit about myself just so you'll know. I've been at the University of Delaware now for three years and I came here to develop our national leadership program for professionals in the field of development of disabilities like with many other fields there's a huge wave of retirements on the horizon and we've not developed people to lead systems for adults, everything has been child focused yet most people's disabilities are adults. So that's what I do, I spent six years in state government and three years in county government so I have I think some idea as a state government agency director how things work and had the good fortune of working with, in my capacity as the state DD Director with the Mental Health Director, the labor industry folks who ran both rehab and special education to try to do some of the things that we're talking about today. We're on slide number 6 and one of my favorite quotes from [inaudible] I think it speaks for itself. One of the things we've learned about employment of people with disabilities is just when we think we understand what's going on some new information comes to light who forces us to question our understanding, next slide please. Let me give you a general overview and of the five presentations that Kathy mentioned

this one is the most general, it's designed to give us an overall framework and the ones that follow this will be much more specific in terms of technique and strategies. I want to talk just a little bit about the more things change and more things stay the same, some recent milestones in the system, some ideas that have been coming up, some future possibilities, what some of the constraints are and especially in this economy and then one of the things that we can do, we being people who work in government, work in universities, work in private organizations, to effect the issues that confront us, next slide please. So let's look back on the last 100 years and this will be breathtakingly fast. The twentieth century really started out with optimism about what was possible, people with disabilities had been treated as defective and inferior or people who needed protection and this was when there was a huge rise in institutionalization sometimes called asylums around the country. It really wasn't until 1930 there was a White House conference on child health that really started talking about societies responsibility to support mostly children with disabilities but in large part that's because especially for people with significant disabilities it was not until fairly recently that people were living to old age, many people died young and changes in health care and changes in living conditions have actually presented ourselves with the first generation of elderly people with significant disabilities in possibly the history of the world. During the great depression things obviously changed, unemployment was rampant and while we're facing a period of relatively high unemployment today, it pales by comparison to what happened during the Great Depression. There was a movement started out at the Cold Spring Laboratory in New York by some of the major foundations in the United States and curiously enough the American Breeders Association, the same people who focused on breeding race horses and breeding cattle to see if there was a way to breed out these undesirable characteristics in the human race. That went on for quite some time and for those of you who are students of the history of eugenics actually led to the strategies that the Nazi's used in

World War II and the first people to be exterminated were the people with disabilities before any one else. Going rapidly forward right after World War II institutions just were at a peak of capacity, they were very overcrowded the conditions were in most public institutions, not something we would accept today and that pretty much lasted through the 50's and a curious thing happened, mostly men, but men and women came back from World War II, started having families and parents of children who had disabilities at that time started saying wait a minute the country is doing all these wonderful things, what about me, what about my child and that sort of dovetailed into the election of John F. Kennedy, and as you may know Kennedy had a sister with intellectual disabilities and pressed largely by his sister, Eunice Kennedy Shriver, he introduced many pieces of legislation and executive orders to get the federal government involved in everything from employing people with disabilities to training professionals in the field so that was really the beginning of the modern era from where I sit. Then from 1970 to the present just rapid increase in medical and rehabilitation technology, increases in survival, any of you have ever been to a neonatal intensive care unit you see babies that are very, very small that two decades ago, three decades ago were not surviving. We also have things like seat belts and air bags in cars and people who might have not survived trauma that way have in fact survived sometimes with significant disabilities and then one of the benefits, if you can call it that, from war is that we learned how to save people who have been wounded and injured and we're expecting a spike in adults with acquired brain injury and people who have lost limbs and are using prostheses as a result of what's going on in Iraq and possibly Afghanistan so that in about five minutes is the one semester course in disability history, next slide please. Some of the interesting things that have happened in the disability field that don't exactly have parallels in other fields, one is the whole engagement of the courts in state systems, advocates using mostly 14th Amendment ideas of equal access and equal protection started in the early 70's giving

children with disabilities the right to go to public schools and at the same time litigation was started concerning conditions in state psychiatric hospitals, state institutions for people with disabilities, state rehabilitation centers, a lot of that led to federal policy makers being directly engaged not only as a result of the Kennedy administration initiatives but of these court cases saying there's something here, the right to education for all handicapped children act which is now called the Individuals with Disabilities Education Act, IDEA, actually emanated from a law suit in Pennsylvania brought by parents of kids with what was then called mental retardation, we don't call it that any more, to give their children access to the school systems and the ruling of that case led very directly to the passage of the first special education law. Families have also undergone remarkable transformation as have people with disabilities, when I started doing this work long ago people talked a lot about shame and chronic sorrow and people kept their kids at home literally in the house and now when you deal with advocates and you deal with families and people with disabilities, there's a whole disability pride movement, parents are proud of their kids with disabilities. They talk about what they've been able to accomplish and again people with disabilities themselves are very vocal as to what they want and one of the things that's almost universal among people with disabilities is they want to work, in a real job, in a real setting, not in a sheltered setting, not for subminimum wage but they want to work. There's an incredibly strong work ethic with people with disabilities. At the same time in the mid 70's institutions started to close, the numbers have gone down dramatically in part first with children because when the right education for handicapped children passed in I believe it was 1974 you saw a rapid decrease in the number of children in institutions once parents had someplace their children could go during the day, they could care for them the rest of the time. That movement continues today, there's still over 40,000 people left in institutions, there are ten states for people with disabilities that have none, we've seen a similar thing in state

psychiatric hospitals and we've seen both litigation and legislation to get people with physical disabilities out of nursing homes. The movement went from one of programs, you send somebody to a place and do things during the day, one of individual support, it's called a lot of different things and I'll talk about that a little later, but basically a way of saying what does this person want and need and how do we figure that out with them, not for them but with them. Instead of a cookie cutter, we're going to put ten people in a room approach, it's one person at a time even if you end up with ten people in that room together. At the same time there's been an increasing emphasis on outcomes, most of our evaluation and our licensing regulation and funding mechanisms measured process, how many units of service, how many days of service, how many staff did so and so...how many of the goals in someone's plan were implemented and the current emphasis is on what happened as a result of all that. Whether you use two staff or five staff, what happened did the person get a job, how much money did they make, how many hours a week did they work, how long did they stay in that job and then I'll talk a little later about self determination and I have a slide on that as well. Next slide please. So here's what I've learned over the last 30 plus years of my career, people with all kinds of disabilities do better outside of big places whether they're psychiatric hospitals or DD institutions or nursing homes or rehab centers, they do better outside than in and that applies to all level disabilities. In fact there's some evidence that people with the most significant disabilities actually thrive more out than in. We've learned that we can develop community support in a cost effective manner, we used to say it was cheaper and I think we shot ourselves in the foot by saying that, it's mostly cheaper in the beginning because we paid staff less and we were serving people outside who had less significant disabilities, as that's changed what we've found is that state legislature frequently have responded to that it's cheaper and not heard the other things that we need to do to build infrastructure and capacity and support. We know on a total cohort approach

that it still is less to support people in the community than in institutions but that includes supporting lots of people who are living with their own families and their families assuming lots of the day-to-day responsibilities for care. Then finally work as a desired outcome lags way behind community and independent living, it's been the one nut as it were, very tough to crack and in part we have this sort of Oedipus complex, we have people with all kinds of disabilities in institutions and when it came time to do work we ended up focusing on places for them to go and those places weren't jobs they were called different things, sheltered workshops, or enclaves, or day activity centers but they weren't real work and people with disabilities knew it and know it. Next slide please. A few other achievements to talk to one of the things we've learned is that the systems are capable of offering sort of diverse and flexible services and supports, it's not necessarily easier to run systems like that it's just better this whole idea of person centered support has really been embraced if not totally implemented, there's been a massive infusion of dollars into the community. Several years ago we crossed the line as to where people were, more people in the community than in institutions but the increase in cost and an increase in government support has been phenomenal, in DD alone it has been about 700 percent in 25 years, adjusted for inflation. Then one of the things that keeps some of us up at night is this whole issue of heightened expectations, people with disabilities in families now expect we're going to give them what want and need, I think a large part of that is what they want and need is a job and we promised, we said you're going to have a decent place to live, something to do that's meaningful, people who care about you and I think we were all taught no matter where we grew up not to lie and some of us are worried that we may have lied to people, next slide please. So here's sort of the three ideas that have driven the field, the first was a Scandinavian principle called normalization, Wolf Wolfensberger who is a professor at Syracuse University spent some time in Scandinavia and then in Canada and the whole concept in the book by the same

name drove a lot of what happened in services for people with disabilities around the United States. Things like the independent living movement can sort of trace their conceptual framework back there and the idea was well let's set up a pattern of somebody's life, somebody's day, that's the same as a pattern of a person similar situation, similar age, background, geography, someone who doesn't have a disability. Let's not do these congregate things because that enhances peoples perception that people with disabilities are different and the inference in different is inferior. Starting in the 1980s we really started talking about inclusion, how do we include people in regular places, regular schools, and regular classrooms and then regular places to live so not a house with 20 people but two people in a condo and then the ultimate inclusion really is having a job for real wages and a job that needs to be done, not make work. Then in the 1990s we started looking at this whole idea of self determination is really a term that came out of developing democratic governance in the former Soviet Republics but how do we look at people with disabilities and help them figure out what they want and need and then control the resources that allow them to get what they want and need. That ideology has spread around the country, it has spread around the world, we talk about it more than we do it and it's harder to do than it is to say because most of our systems have been built especially with our heavy reliance on public funding and then Medicaid in particular have been built around the relationship of the government agency and the vendor, not the relationship around the person with a disability controlling services and supports. Next slide please. So doing normalization this is just going to go back a little bit during the whole idea about normalization that we expose these large institutions, t's just inhuman and I can still, there's a place that's closing right now that I won't mention the name but I was there as a high school student as a volunteer and even today 40 plus years later when I shut my eyes and it's real quiet I can smell it and I can hear it and those places largely don't exist today, the places that are out there are far

superior in terms of cleanliness and quality of care and oversight and accountability than the institutions of old but they're still not places where people should live. Next slide please. We went through this whole era of homelike and joblike, we had 12 people living in a house but we made it homelike and we had people doing work that was in a very segregated environment and many times it was make work, you can still see today ten minutes from where I sit places where people will put nuts on bolts in the morning and then in the afternoon they'll take the nuts off those bolts so they know it's not real work, next slide please. Then self determination came to the floor and the people had the life that they choose and interacting with people with and without disability allows you to be really part of the community as opposed to being separated from your community by virtue of your disability or by virtue of the way the program supports you. But the key concept again is people have to have control over the distribution of the sources, it goes by many names but people have to be able to say I want this, I don't want that and the reality is if we want a market-based system and I know that term has gotten sort of battered lately with what's going on in the stock market and policy areas but the idea is the same, if people with disabilities can choose what they get, those people who provide what they want and need will be more responsive because people can take their money and walk and we're seeing it happening in some places around the country in small levels and small quantities, it's still not a dominant way of delivering support, it's the dominant way of talking about them but not the dominant way of doing them, next slide please. There will be another idea during the careers of people who have listened to this presentation perhaps during my career. and I think the job of people like yourselves who are in leadership roles is to make sure you're ready to receive it and to adapt to it and I can't even predict what it's going to be, are we going to repackage things what are the impacts and the opportunities of the current economic situation on how we deliver services. We just saw something

from one state that it struggled for two decades with a few institutions that are just horrendous and expensive and at the same time there are people who need lots of services in those states and get none and a governor took the imitative to say I've had enough we're going to close these places, reprogram the money, help the people who have self-determination and a person centered process get what they want and need and that's pretty spectacular use of a crises to produce something positive. Next slide please. So again what comes next, what is it, I couldn't tell you, got some ideas but when we've had futurists in to conference to present things the one common theme in there has to do with the use of technology and people with disabilities not only assistive technology to help negate some of the things that are challenging for people with disabilities but information management technology and prove their management technology, so we'll see how all that plays out, next slide please. So my office is in a building called Alison Hall and those of you who know me, fashion is not my strong suit, but my office is right next to a fashion design studio because we share Alison Hall with the fashion folks and there was a very passionate argument, this is going back now maybe two years with a bunch of young students about brown being the new black and I had to ask some of my own students just what that meant. It really is a color thing, that black is apparently a very fashionable color and brown is becoming that fashionable color and so what in the world does this have to do with people with disabilities, let's go to the next slide please. The reality is sheltered workshop to activity center enclaves pre-employment segregated schools those are a new institutions with the old standards of black, these things are the new standard and again what they have in common is they keep people separate from the communities and they make it really hard for a person with a disability to be included because they're somewhere all day long that labels them a deviant and different, next slide please. Again we live in this very high tech age, this presentation that we're doing today, this technology wouldn't have been possible five or six years ago yet now it's

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readily available and inexpensive but there's still significant movement of people supporting old models, I subscribe to several news clipping services and it must be once or twice a month I'll get a clip that someone has opened a new workshop, someone who has gotten a grant to expand their segregated employment capacity. I get many fewer stories about successful programs that help people with disabilities get meaningful jobs and meaningful wages in the cities and towns where they live, next slide please. So there's some big factors that are facing you as state leaders that limit change and they're not insurmountable but we need to recognize them in order to deal with that and one is it's the people who are currently in leadership roles who have developed the old stuff. Some of the things we are doing today, and we're trying to get away from what we were incredibly proud of one professional generation back, and so we need leaders. We will have at a later one of these webinars, someone who has done this statewide in Washington state and I heard her do a presentation once that said well if we can't change the hearts and minds and practices at least change funding policies and people will follow the money, organizations will follow the money. For those of you who don't recognize the cartoon it's an early 1970s cartoon from Walt Kelly who had this cartoon called Pogo and probably the most famous quote from a couple of decades that cartoon ran, we have met the enemy and he is us. Next slide please. So this is really a human service story and as in many of the slides you've seen today [inaudible]. Human Services Research Institute first used this in a presentation first and got permission to sue, but what happens when the horse dies well you dismount and this really is a human service story so just hang with me please, next slide. But it's not what we seem to do, we don't follow that advice instead we buy a stronger whip, or switch riders and move the horse to a new location, change the fee schedule for riding a dead horse and I've seen some of those human service things just in the last couple of weeks, appoint a committee to study the horse or create dead horse riding standards. Next slide. I think you can read that for

yourself, well maybe we reorganize the stable or develop a training course for riding a dead horse. My favorite is we blame the horse's parents, the problems is often breeding but for employment of people with disabilities we can't just repackage old strategies that have failed, we can't rename them and we label them, we can't say it's the fault of people with disabilities that the employment numbers aren't what anyone would like, we've got to figure this out, next slide. The title of this thing probably should have been rewritten if I had been thinking about it, the question is are we losing ground and the answer is I'm not sure and this was developed for the current crash in the stock market and labor market and capital markets so if this recession is in any way similar to others we've seen people with disabilities lose their jobs at disproportionate rates in the beginning, don't know whether that will be true here or not, but the quality of the data in the data sets out there is such that I'm not sure we can draw that conclusion, we do know that it's not due to the Americans with Disabilities Act. Most of the modifications that employers estimate because of the ADA are very low costs, they are not expensive, it's not forced people to hire people they didn't want. In fact the way the ADA is written and this is from an article by Robert Silverstein who was Senator Harkin's disability policy specialist when the ADA was going through the Senate and it was specifically written so that a person had to be qualified for the job, you don't have to take someone who can't do the work. It's not due solely to changing demographics, it's not just because there are more people with disabilities and that the workforce in generalization, and it's not due to the economics of the workforce, there are large number of jobs that people with all kinds of disabilities can do. Again before this recession, employers were hungry for employees who would show up everyday and do the job and we'll see what impact this has now. The supply side efforts have not produced large scale results and we have very good technology that can help people with all kinds of disabilities be successful in a job and they've been run by human service agencies, by state vocational rehab agencies, by mental

health agencies, by DD agencies under contract with private vendors. Many of them have been very successful, customized employment, supporting employment has worked for some people, yet the number of people in segregated employment keeps on going up, not down. Most significantly unemployment data, our national unemployment data doesn't include people with significant disabilities so if you have a significant disability regardless of the cause, regardless of the etiology and you've not yet worked you're not included in it as being unemployed, if you're in a day program you're not counted as being unemployed so we really are not sure just what's happened over time in terms of number, next slide please. Again I think I said part of this before, it's not the cost of the accommodations in 2055, the average cost is less then $600, and it's not just because of the recession the numbers in the booming 1990s were very poor, next slide please. This is from the National Association State Director of Development of Disability Services, they had a project going on with select states to help people with developmental disabilities get real jobs and yet the charts show that the numbers have stayed flat for people with real jobs, integrated employment, and facility-based service options. I said before they are increasing in many places and this is their goal, real jobs for people and I think their policy statements say well working in a shelter workshop is not a real job, next slide please. So they did some research and this project called T-Tap at Virginia Commonwealth University in the Web site is referenced below to see people's preferences because what we know from creating programs that help people get and keep work if people do things that they want to do, if they have the kind of work that they want they're more likely to continue in a job and the answer is most people don't want to be in segregated settings and most of their families don't want them to remain in those settings. The numbers are under 30 percent and then 63 percent, that's like two-thirds want real jobs outside and some people just didn't know because they didn't have experience but not a huge number of people said I want to stay here and I want to do this. I had

an interesting experience this past year, a course I was teaching had undergraduate students go out and look at three different kinds of settings, one was the state institutions in three states, one was a community group living, and one was sheltered workshops. They all came back from the sheltered workshop and said the exact same thing, the absolute exact same thing, you know people seem bored and they said is it always like that and my response was well I don't have data on that but I've been going for 30 yeas and I've never been when people aren't bored, let's go to the next slide please. This is just graphically presenting what the people, their families and staff said and there's not huge differences except you'll sometimes encounter this if you go through a systems changeover where families and people with significant disabilities their families are frequently involved well into adulthood, families are somewhat more cautious about people getting real jobs than are the people with disabilities themselves but that's the only place you see this kind of difference, next slide please. So sme research asked why are they in these places, in part this is what was there, this is what was offered and in part it was about transportation and most of the work we've seen around the country of employment transportation comes up right at the top in terms of barriers to people getting jobs. There's a lot of concern with families about safety, about convenience of work hours, many jobs in the economy are not nine to three yet many segregated programs will run that system and it serves as respite for families. People are worried about benefits and we'll have more on that later in the series plus there are strategies for managing the benefits that make this issue quite manageable and then this whole social environment especially with families saying gee my son or daughter has friends there they like it there, no one picks on them there but for every story of someone being picked on in the community I can tell you stories about people who with very significant challenges have become a full part of their employment setting and part of not only the work but the social setting, next slide please. Again the whole issue here is most people don't have experience with

paid work and so they were projecting based on not knowing. One of the consultants we work with on another project when asked what's the indicator, if you can only pick what is the indicator that shows that people are going to get jobs and keep jobs and the response was the strongest indicator they had was getting paid work during your school years, not an internship but while you were in school regardless of the disability having real work for real pay and if you look back on most of us who don't have disabilities you know we had jobs in high school, and we learned a lot from those jobs. Next slide, there's been a very high degree of consensus about what does success mean, this whole outcome issue, again these are not process issues and here are the indicators again according to Silverstein who looked at what other people have said, increased percentage of people who are employed, increased the number of hours worked per week or month, increase income, health benefits, increased satisfaction from work, improvement in work schedule flexibility, and if you have the ability over time to modify your schedule to accommodate your life and money. It's sort of funny that we've shied away from that in the past but the reality is the reason that most people work perhaps is money is a big part of that and with people with disabilities somehow that hasn't been part of the equation but we've got lots of studies showing that people even with the most significant disabilities can make more money, have increased satisfaction, increased income, work more hours with the right kinds of supports. Next slide, please. So how do we do this, how do we change the culture in our states and one of the things we all know from working in the state government is that there's a relationship between families and family organizations, the service provider community and community leaders who serve on the board of organizations who provide services and state government as the funding agency and that as you go forward to try and change the culture in your state from one of keeping people from real work and real life to a culture that supports and honors that you're going to encounter all sorts of resistance and sometimes at

least when I worked in state government the baseline assumption, the thing that local elected officials, people in the state legislature, people in county government reacted to was you're from the state you must be wrong, you're just doing this to save money, you're just doing this because you don't like our provider because they challenge you and so on an so forth but that's not true in my experience. The things we have to ask ourselves is how do we get what we know are proven practices we'll have a person from Washington state who did it statewide there, not a small state, not the biggest state but not a small state, how do we incorporate things that are proven to work into old models and have those old models change, again with the goal being full paying jobs with the community. How do we learn sort of systematically, hear the wisdom of people with disabilities, so you get either an individual or groups of people with disabilities together they'll tell you what they want, those previous slides I presented was one approach at that. Successful policy makers have learned to incorporate the thinking of people with disabilities into their work and their state and use that whole approach to force change in the systems. Then with the vendors that we use, whether we call them providers or vendors or whatever, now how do we change their organizational cultures because unless they change you're constantly fighting an up hill battle. So how do we change their cultures and the things that they may be very proud of what those things they're proud of will produce long term independence, pat of it is going from the concrete to the abstract, a day activity program whatever you call it for a shelter workshop or a residential center. You can see it, you can feel it, you can touch it, and what people with disabilities and what leading edge policy makers are now saying is well that's not what we want, we want things that are open and inclusive and real jobs and but you can't see those things. One of the things I certainly learned in closing institutions is that families will say show me where my son or daughter is going to live and I've seen this in psychiatric hospitals and in DD institutions and the answer is well we're going to find and

apartment in the neighborhood that your son or daughter wants to live in and as soon as we figure out what your son or daughter wants and needs we'll go out and find that apartment whereas the facility the person is living in they can see it, it's been there it has the appearance of solidity and stability even though it may be neither of those things. Now you've got to change cultures to say the goal of our culture is to make people as independent as possible, not dependent to make people supported in an inclusive environment, not segregated environments to help people get real work not pretend work, next slide please. One of the other things we're seeing around the country as the systems have grown whether it's for people with psychiatric disabilities or physical disabilities or DD but as the systems have grown it's become more challenging to manage large agencies and lots of the small and very flexible innovative organizations that were in existence have merged into larger organizations and so provider organizations then end up with a lot more power and they have a vested interest in doing the right thing but they also have a vested interest in doing what it is they know and the first golden rule of government is that I was here when you came in and I'll be here when you're gone and that kind of waiting game takes place a lot in state systems. One of the other things we look at there's been this incredible advocacy around closing institutions and getting people access to services but the advocates, especially the family advocates, are aging and the systems aren't hard like they used to be. Big general statement but the horrible abuses of the 50s, 60s and 70s we generally don't see and so my favorite expression from the entire Bush administration was during the debates around No Child Left Behind they talked about the bigotry of low expectations and I think he was referring to minority students but the same thing takes place here. The expectation is people can't work, people can't do these things, people can't progress, they're not going to. We have got to have some sense that people can make progress and move forward so how do we translate that into systems level thinking, next slide.

So some other challenges and stages for people in state policy making positions, one is increased power to people with disabilities, giving people control of resources, making them the people who have to accept plans and signs off, not being told what must be but gaining control from what must be. There's going to be increasing de-evolution and decentralization unless we give individual people control of the sources our policy framework that says you must have x square feet of space that you must do things in this fashion, that the rules are such and such, have to go away, you can't control things at the very local and community level unless you're measuring outcomes, you can't control these prophecies, you cannot so the self advocacy movement is maturing and while we're concerned about the aging of parent advocates, the self advocates, the people with disabilities themselves are I think becoming much more sophisticated in how to change systems and if they're going to be changing systems then we better pay attention to them, what we don't want is for them to say wait a minute this system is not meeting my needs. We're going to see deconstruction of prefab services so instead of saying okay use a wheel chair you have limited mobility here are the five things you're going to get we're going to say okay you use a wheel chair, you have limited mobility, what do you want, what do you need, how do you want to live your life, and then how can we put a package together to help you do that. We're going to see integration of funding and we've already had the talk about braiding but from multiple revenue streams, maybe it's going to be bulk rehab, maybe it's going to be economic development dollars, maybe some of it's going to come from DD or mental health, maybe some of it's going to come from insurance, some of it's going to come from family resources and putting together those resource packages differently for each person because each person's needs and resources are different, presents a challenge to systems used to root [inaudible]. We're going to see continuing illumination of workplace incentive, it's now possible to maintain benefits as you go through this work process it's possible for policy to buy

into state Medicaid program it's possible to use resources from social security to develop and build your own business those things are there in place, there's still great fear about those work disincentives but gradually they've been withered away. The performance of the state quality systems see more translation of research into practice, one of the things that happened in the current information age there's no excuse now for state policy maker to say I don't know. In every state in the United States you have rehabilitation research and training centers, you have university centers of excellence, you have psychiatric rehabilitation centers, you have Google or whatever search engine of your choice, if there is an issue you're facing in your state about employment with people with disabilities or pretty much anything else in human services for that matter one click and you can find out the answer, you can find out someone who has encountered this problem and develop policy and programatic solutions to get around it and you can find the research that shows this is what works and what doesn't work and help translate that research into policy and practice in your state, next slide. So this is what I think and then I'll switch a little bit to talking about change management because it's part of what state leaders do but this is what it's all about there's no private marketplace and what we've done is we've sold people something we don't want to buy, we've charged them a lot for it except we've charged government a lot for it and then we're shocked when we don't like it and leading edge policy makers are changing that, they are creating a marketplace type environment where people can pick and choose and it's not unlimited, it's not open, there's a difference between what people want and what people need, what I want is a brand new Porsche convertible to get to work, what I need is a car that will get me back and forth to the university everyday. Two very different things and government is in the business of getting people what they need and maybe some of what they want but it's not a blank check, it's not open ended, never has been and just can't be, next slide. So it's all about change, it's all about changing what is and it's both

policy and practice and next slide please. How people react to change is different, people in top management roles either in government or in private companies or in nonprofits providing services to government you know top management feels isolated, they underestimate the reaction about change, they don't communicate, they feel people should just get along and they feel betrayed when there's opposition and middle management sort of feels pulled in all sorts of different directions, they lack information, they're pressured to make changes, they don't feel they have the tools to make those changes and then people in the rank and file feel caught off guard, anger frustration and afraid to take risks, what if I do the wrong thing. They feel confused especially in facility closures whether it's a work shop or residential facility or rehab center, all of a sudden the people you've worked with for the last 10 years side by side you're not going to see them everyday anymore, you're not going to see those folks because you're going to be out there helping people get jobs or maybe you don't have the skills to do that, next slide please. Lots of studies on change management but they basically show the same thing you know, 10 or 20 percent of the people be in favor in the change process and those people can be allies and champions, 10 or 20 percent will be opposed strongly and those are people you don't ignore but you don't want to spend too much time with them because it's going to take a very long time and a lot of effort and it's really the people in the middle the 60 to 80 percent who are on the fence about change maybe they think there's something here but they need to be convinced, show me, teach me, help me, and think government leaders and especially again with communication technology the way it is now or through web pages or webcasts, the government leaders have an opportunity to communicate change initiatives clearly and succinctly and to engage stakeholders in dialogue and discussion in a way we've never had before. Way back when I was in state government I remember many a night where I'd hop in the car at the end of the day and drive 100 miles to speak to a family group so I

could make sure they got the information directly and clearly this was pre-e-mail and now you can push a button and give people your position, get people information and get people facts, it's a double edged sword of course because once you start communicating with people they may want to communicate back to you but again it's a tool and there are strategies to be developed to use that tool effectively, next slide please. Change isn't about structure and regulations and funding stream or policies, it's really about people and it's about behavior and those of you who participated in change initiatives know that when you've got someone leading a change initiative who's good at communicating with people and really treats people with dignity and respect you can move forward. Frequently change initiatives get stopped because of untoward remarks or comments or interactions that just become increasingly difficult or hostile but aren't characteristic of the people engaging in them, next slide please. Any kind of change process you end up with resistance and it comes in all sorts of different forms, is actually a good thing, it's a good thing if you can figure out what people don't like, are against, are opposed to, don't want to do, you can develop strategies to deal with this and in part people who are resisting the change may know something you don't and in part it may show that you've not communicated effectively. So it's an opportunity and again you just got to realize some people may never accept what it is you're trying to sell and that's reality but we have to find ways to get around those people, next slide please. There's some fantasies about change, it's not disruptive...well it is, it doesn't cost much and people who have done change initiatives will tell you there's a transition cost when you're both doing the new thing and doing the old thing and until you stop doing the old thing you've got to maintain that system or that service or that program. I have a friend who called it building the airplane while flying it. People say well it's quick to implement it, it's not and then again everyone will see the value, everyone will see what you as a state leader will see and that's truly a fantasy, they won't and

you're immersed in it the most effective state leaders I see are very passionate about these issues, very committed, and just work incredibly hard to implement them and sometimes it's hard when all this work and other people do not see the value in what's being done, next slide please. So when I show this is a regular PowerPoint all these little figures move up and around but here's during change initiatives people fear losing their job whether it connects into their competence or their passion or all these other things on the slide and these things are very real. I once had a person who worked at a big private institution say you know my neighbors drive by and they see where I work and it's a beautiful place, they know it by reputation, its had festivals and fairs and it has a community room that communities can use and now you're going to say I'm going to work in somebody's house, they're not going to see that and they're not going to see me, they're not going to see what I do is valuable. So it's very real, losing control is very real and going from centralized to decentralized systems requires giving up a great deal of control, next slide please. So here's why things fail, misunderstandings due to poor communications primarily, power plays, people saying over my dead body are we going to do that, people feeling they don't have a say, especially professionals who committed their lives to a field who the thing they're doing now was state of the art a decade ago or 15 years ago and now we're saying we're not going to do that any more. So people want a say in both the process and the outcomes and the inequality of resources or attention is part, as a state leader you're going to respond to those who buy into your change initiative and you're going to want to encourage and show case those people and it's absolutely a right strategy. Other people will then feel well wait a minute, that person is getting special treatment, they're getting something that I don't have and therefore they can do it and I can't, it's not fair. The whole issues around self interest you know this is my organization, this is my agency, this is what I do and it's what I have to protect first, and if I'm an agency executive director or board member indeed that's true, my response to those folks

has always been but you have to look both short term, intermediate term, and then again long term and if this is where the world is going if the world is [inaudible] for people with disabilities is going towards helping people get meaningful jobs, real wages in the communities where they live then if you don't do that you're swimming upstream and eventually putting your organization at risk. Fear of the unknown, change requires people to have faith and to project into the future and we can't always guarantee what it's going to be like and we can't always say this is what's going to happen when we get there because indeed we'll encounter things that we don't know and if I'm an organization exec or a board member who has worked hard to build what I have I'm very interested in certainty and predictability and yet what you're telling me as a state leader is some things are going to be different and not quite sure what it's going to be like, next slide please. Some other reasons why things fail, ego, whether its I've developed this program and it's terrific and don't you dare change it or on the state side of things I know what I'm doing and it's worked in other places, we're going to make it work here, I've had other successes don't bother me. Things going too fast, too slow, it's judgement issue, poor planning and implementation and the next slide we'll talk about that for a bit and then inappropriate behavior. The next slide is really about planning and implementation, you can't really do implementation without having an Einstein quote but it's really if I had an hour to save the world I'd spend 55 minutes defining the problem, planning for change is incredibly important and it's why contemporary communication strategies and technology are so valuable because you can get constant input in refinement as you're going forward because we have the ability to communicate quickly and inexpensively. The next slide please. And again some other 50 quotes, I am a college professor and you have to have 50 quotes and I won't read them to you, so the next slide. So what do we do now, we can't stay were we are because the numbers are dismal, the increase in the number of people with disabilities forces us to figure out what and where

people's increased life span so we can't stay so we've got to figure out as state leaders what's the value equation here, what are our values. One interesting thing in our society is that we argue about we're just coming up on an election but we argue about politics, we argue about sports, we argue about religion, we argue about family but one of the things as the people we don't seem to argue about is the value and worth of work. Work brings dignity and respect, brings money, as American we actually work more hours than anyone else in the world so we complain about that some, but people with disabilities have figured out hey this work thing is what people talk about and so that's our core and underlying value, work is meaningful, it makes you a better person, it makes you contribute to society, it allows you to exercise your talent and passion, next slide. Finally my favorite cartoon, so we've got all these constraints and if you can't read the cartoon it's two cows looking at a telephone, it's ringing and one says to the other well there it goes again and we just sit here without opposable thumbs, so given all our constraints now what do we just say it can't be done or do we figure out what it is indeed we can do. Two other quotes one from Yogi Berra, but he actually stole this from somewhere else, the future ain't what it used to be and he stole it from this philosopher that was French who published it sometime in the early 1900's and what we do next is really one of the things the entire project in its entirety is about. How do we move you in the case of state leaders our state systems to a point where employment is the primary outcome for people regardless of their type of disability that we move resources because we can't maintain parallel systems there's not enough money and I don't have to tell you, I'm watching it from afar you're experiencing it every day just how tight resources are now and are likely to be. I mean this is being recorded in the beginning of 2009 but everything I read tells me 2009 is going to be very hard, 2010 is going to be hard, we don't know yet about 2011. So we have these constraints, we have to reinvest funds, we have to work with other systems in our states as states are developing sector strategies for

employment and for training, we have to be part of that thinking, we have to be part of the economic development thinking, and there's lots of opportunities but it requires working differently than many of us have worked in the past. The next slide just has some resources that we pulled together that really talk about ones from the Department of Labor, ones from Diversity World, ones from Java Combination Network, which is a great place to go when you want to have a conversation about well here's a person with specific disability what do we know to do accommodate workplace for them. U.S. Chamber of Commerce has a very strong section on strategies for employment of people with disabilities, mostly written during the time when jobs were plentiful but they still see it as a very important part of their business growth strategy and then the Business Leadership Network in one of our centers in this series will be from one of the Business Leadership Networks, it's been very successful in bringing businesses together in a community, figuring out what they need to grow their businesses and figure out what it is that people with disabilities do to contribute to that and their goal and strategy and they'll talk about I think rather passionately is to make all this a win-win, this is not an either or, it's not a win-lose it's how do you make everybody successful in this enterprise of growing our economy. So with that final slide is just my contact information and I'm glad to talk to anybody on the phone or through e-mail to have discussions with you about anything you're facing and I think you'll find from the entire NTAR team a great willingness to be accommodating to individual state needs and to help think through issues and problems that you're encountering. It's a very exciting time despite the very challenging economy because I think that conceptually the tide is turning and saying yes people with disabilities of all kinds want to work, can work, and we can figure this out. So with that I'll see if there are any questions?

[Robb Sewell] Hi Steve, this is Robb Sewell from the NTAR Leadership Center and we do have a few questions, this first is

are there any tips you can give us as to how to get over the resistance politics that work to keep those old models in place?

[Steve Edelman] Part of my strategy has always been constant communication, finding someone in your state and especially in larger states this is easier. There's someone who's either doing what you want or who wants to do it and working with that someone, that organization, that group to sort of highlight what they've done and say see it can be done here. Another part of it is this whole issue of communication and finding allies, you're not alone in wanting to do this, I mean this whole project the Department of Labor has been very responsive to disability advocacy groups for quite some time listening to what they've said and they've heard the message loud and clear from people, we want to work so finding those people in your state and finding those groups and having them as a counterforce and then part of it is working and it's the whole interpersonal skill set or working with people around change and we've got consultants available who can work with people around individual change managements strategies, all those things on the slides are just a hint at some of the issues and strategies that are out there but like anything else you have to develop a plan, you have to have to test that plan and modify it over time and have to keep at it. One of the other things you have to do in government that you don't necessarily have to do in other settings is you have to look at who's behind you, is the governor's office aware of the strategy, why it's important, are they on board. If you're in a cabinet level agency the same question about the secretary, most people have advisory boards or governing boards or policy boards and so all those people have to be lined up and they also have to know that this is not going to always be a knife through warm butter and here's some of the things you might hear about what's wrong with the strategy and why it won't work. But given that and given a good plan and given flexibility to modify the plan as you learn as you go along and given good communication strategies you can overcome that resistance.

[Robb Sewell] Great the second question is in the culture that seems to want immediate results how do you balance the need to communicate outcomes with knowing that change takes time?

[Steve Edelman] Well, that's a great question, again I think technology is part of the solution and if you specify outcomes and they have a process in place that has validity in terms of measuring those outcomes you can keep a constant stream of information flowing out even when you're in the process of change. So people don't have to wait until next year's annual report to know they can look at your Web site tomorrow, they can be on your listserv and get an e-mail once a week that says this is what's happening and this is what's going on. Part of that is in the preparation and again dealing with legislative bodies and an appropriate process being absolutely straight forward about what's possible and what's no.t I can show you at another venue of what happens when you don't do those things.

[Robb Sewell] Great thank you and finally our last questions is I work with a lot of state leaders who want to do the right thing but have difficulty moving forward with change, do you have any suggestions?

[Steve Edelman] Yeah getting people together and bringing in somebody to help you strategize and develop a plan I mean most people like ideas but then putting those ideas into sort of concrete practice and sort of manageable, measurable steps so giving them something that they've contributed to that they can see, feel, and touch, going through X, Y, and Z, here's the order we're going to do it, here's what it requires you to do to make that happen and keeping that process ongoing and updating and again I can't talk enough about the use of technology to do that. But keeping people in the loop, keeping people informed and also being very public about what's happening and not disparaging but showing the data as to

here's what we've done, here's what we haven't done. But you need a plan and it frequently helps to have an outsider come in and help you develop that plan and then you need a champion, you need somebody who's in charge, who can help move that plan forward and some consensus about bench marks spelled out so you know when we get to this point we'll say we're almost there.

[Robb Sewell] Great thank you so much, that's pretty much it for questions for today, Steve we want to thank you so much for such an excellent presentation as we always do with our webinars the audio and web recording from this webinar will be posted on the NTAR Web site which you can access at www dot ntarcenter dot org. Also I just wanted to remind our participants that our next virtual leadership institute webinar will be held on Wednesday, February 4, 2009 at 3:00 p.m. eastern time and the topic will be *Public/Private Partnerships, Strategies for Meeting the Needs of Employers* and again thank you all for participating today and on behalf of the NTAR Leadership Center I want to thank you again and just wish you all a great afternoon.