

NANCY REDER: It is my distinct honor to introduce these two distinguished panelists this morning. And I will start with my left, with Judy Heumann, who is an internationally recognized leader in the disability community and a lifelong civil rights advocate for disadvantaged people. She serves currently as the Director for the Department on Disabilities Services for the District of Columbia and is responsible for the Developmental Disability Administration and the Rehabilitation Services Administration. From 2002 to 2006, Judy served as the World Bank's first Advisor on Disability and Development, a position in which she expanded the bank's knowledge and capability to work with governments and civil society on including disability initiatives. Her work highlighted the importance of integrating disability priorities in bank discussions with client countries and providing policies and programs to allow people with disabilities around the world to live and work in the economic and social mainstream of their communities.

From 1993 to 2001, she served as the Assistant Secretary in the Office of Special Education and Rehabilitative Services for the United States Department of Education. She was responsible for the implementation of federal legislation for programs in special education, disability research, vocational rehabilitation, and independent living. And before that she co-founded the Center for Independent Living in Berkeley, California which is where I first met you Judy, and I was thinking about that last night, and I realized that that was almost 20 years ago when I worked on George Miller's staff. Yeah, it was a long time ago.

And to my right is Mary Jameson who has taught students with (pause) okay, I'm sorry we are skipping down, I apologize about that. Cheryl Jorgensen. (Should I be Mary Jameson?) I don't know. Who is the Project Director and Assistant Research Professor with the Institute on Disability at the University of New Hampshire. Since 1985 Dr. Jorgensen worked to increase the capacity of local schools to include students with the most significant disabilities in general education classrooms. She has directed state and federally funded projects in the areas of personnel preparation, professional development, model demonstration research, and educational systems transformation. Dr. Jorgensen is the author of numerous journal articles, books, and book chapters including The Inclusion Facilitators Guide and The Beyond Access Model promoting membership participation and learning for students with disabilities in the general education classrooms. She currently serves as the Director of the National Inclusive Education Initiative for students with autism and related disabilities, which is supported by the Fund for the Improvement of Education. And I will turn this now over to our distinguished panelists.

JUDITH A. HEUMANN: Thank you very much for asking me to come and present this morning.

When I had the opportunity to meet Dan, I guess it is more than a year ago now, I was very excited about the work that he was doing and particularly with the focus that he and his family were working on with his son and his capacity in the communications

arena. To be able to take some very personal information and share it with a larger audience to allow people both to see what their perspectives, mother and father, perspectives were for their son, for his future, and challenges that they were facing both personally and moving their son into the included environment in the United States. And then the fact that he also highlighted other disabled individuals who could share experiences with the audience about their personal stories.

I'm not going to dwell on my personal story except to say that I'm 61 years old and I've seen significant changes that have occurred in the United States and around the world. We've moved from having no policy that enabled children like myself who had disabilities to have a right to go to school. When I was five my mother took me to school and was informed I couldn't go to school and not to worry that a special ed teacher, this was in New York City, that a special ed teacher would come to my house, which turned out to be for 2½ hours a week. So, we can see that expectations have changed since both Section 504 and the passage of the Education of All Handicapped Children's Act and the IDEA. Children are now in school.

So the challenges that we are all facing, as I was discussing last week at a lecture at Cornell, is okay, we now have the policy for many years quite frankly, which says that disabled children have a right to go to school and to be educated in the least restrictive environment, but we are still struggling very much with what is effective pedagogy and how do we in fact ensure that principals, assistant principals, teachers, teacher support staff, etc, really understand effective ways of working with children in an educational system. Some people are doing it much better than others; some universities are doing better than others. But at the end of the day the accountability systems have also dramatically changed. We've really moved away from just saying that a child who has a disability, significant or not, has a right to be in a school building and there is much more pressure right now being placed on ensuring that disabled children like others are receiving an appropriate education which enables them to be successful in life.

As the Director of the Department on Disability Services in the District of Columbia, I see every day the adverse effect that poor education is having on poor and minority disabled children. It is my job to help people get jobs, but if I am having people come to my agency who have not been effectively taught and we are having to work on trying to help build both self esteem and helping youngsters, young adults and adults now obtain the education that they should have been able to obtain when they were in the public school system, it's really more than a daunting experience. It's one where you know in most cases you're not going to be able to help an individual achieve to the level they could have achieved if in fact they were able to receive an appropriate education.

Now we're looking at individuals who are 16 and older. Transition school to work, as you all know, for those of you at least that are in high school settings, is a requirement both under the IDEA and the Rehabilitation Act. And theoretically what that provision of the law is supposed to do, is to help prepare students to be able to think about the world of work. This includes all students, students with significant disabilities, and those without significant disabilities. But at the end of the day, if people have had a

positive educational experience, if they have learned to value themselves, if their teachers and administrators and families believe that they are capable and they can achieve, then the ability for these youngsters and their families to really think about the world of work and the possibility of people moving into the world of work, possibly moving into community colleges, other higher education settings, really will enable those individuals to be more successful. If you come into the world of work and you have limited experiences in the world of work, if the IDEA and other statutes have not effectively benefited you, if the environment that you've worked in really has not taught you that yes you can work and you have to have an expectation that you can work, and you can achieve and you can do meaningful work, then in fact that's not going to happen. And at the end of the day, that's really what education in my mind is about. It's helping people prepare themselves for adulthood, part of which is moving into the world of work.

So, I reflect on stories and experiences that some of us have had. In the 1960s, children with Down Syndrome were typically being institutionalized. Today, children with Down Syndrome are not being institutionalized. More and more children with Down Syndrome are being integrated into regular school settings and are achieving at various levels. When I was the Assistant Secretary under the Clinton Administration, I visited hundreds and hundreds of schools around the United States where we were working on moving children into inclusive settings, working with universities, trying to get universities to be training general ed and special ed teachers more effectively so that teachers could work effectively together. Special ed teachers understood the curricula, would be able to work effectively with general ed teachers, general ed teachers should be getting more experience in working with diverse learners including children who have disabilities. Where that model worked, that was great.

When I visited these classrooms it was not unusual to meet children who had intellectual and developmental disabilities in the school, some in more inclusive settings. And it was always interesting for me to see teachers who were pleasantly surprised that a child who was placed in their classroom was in fact beginning to learn. And I remember teachers saying to me, "Oh, I really didn't know that so and so would be able to learn how to read, or would be able to learn how to do math, or would be able to learn how to do whatever was going on in the classroom." And I believe that we should be beyond that right now.

The discussions that we should be having right now in my view should be much more focused on good practices and promising practices that exist in your schools, in your districts, and in your states. Where there is a higher demand coming down for you to receive the information that you need in whatever capacity you're playing in school. And to help ensure that -- you know my presumption is, I don't know most of you, but my presumption is that you're here because you have an interest in helping move this agenda forward. So the ability to really take what you've learned, how you've changed the work that you're doing, how your work has helped make progress, not just for disabled children, but we also know that when you effectively work with kids who have disabilities, typically you're improving your teaching for other children. And I think that's also critically important.

We're not just as educators, concerned with any one group of kids. We're concerned that all children are becoming successful and because of laws like No Child Left Behind, and I'm on the No Child Left Behind Commission and have been since it was set up, we are really needing to look at how the information that we're gleaning will benefit all kids. And that's one of the real benefits that I've seen that's come out of effective teaching in classrooms. Where special ed and general ed are able to work more collaboratively together, use the expertise of both, of one profession that has different areas of expertise, which is the way I would like to look at it.

So I was told that I could speak for 10 minutes, I've now spoken for more than 10 minutes, but let me just say that your work as you know, is really critical. And I recognize that it's very challenging, but you know, maybe one way to kind of put this in a bigger picture is that each one of you needs to move into working in a job with adults who have disabilities, to see where we're being successful and where we're still failing. Cause that's at the end of the day, you know, what it's all about. So, thank you very much.

CHERYL JORGENSEN, PHD: If the goal of inclusive education is for all students to realize valued membership in a general education classroom, full participation, reciprocal social relationships, and learning to high standards, I believe that we really need to go well beyond tinkering with our current educational practices, including our instructional practices, and begin to question some of the assumptions that most of us have about kids with disabilities, about learning in general, and about our roles as teachers. And one of those assumptions that I'd like to focus my remarks on today, is this notion of how competent we view students with disabilities.

So I use the term assumption when I began talking, but really what I'm talking about is something bigger than an assumption. You know the word "paradigm." 40 years ago Thomas Kuhn defined a paradigm as a shared world view that is so strong and institutionalized that it takes a sudden and dramatic break in order to bring upon a positive revolution in thinking. And when I think about the paradigm that really shook up the world, I think the one that probably we all can identify with is in 1491, the paradigm was that the world was flat. In 1492, all of a sudden there was now such a radical shift based on several people's travels around the world, that maybe that was not so. I think that the shift in paradigm that we need to have about competence in students with disabilities is actually as radical as that one was 600 years ago.

So in order to sort of think about how the paradigm needs to be shifted, I think we need to assess what the current paradigm is. What is the way that most of us grew up believing about students with labels of disability and significant disability? What is the influence of that paradigm or that way of believing on our everyday educational practice? And if, as I'm going to suggest, many elements of that current paradigm are flawed, is there a more defensible paradigm? And what would that look like? So here's what I think the current paradigm is, and when I say, when I use the term "we," I'm certainly not suggesting that any of you as individuals believe in this current paradigm, but I pretty

strongly believe that it's the sort of person on the street, personal in the school way of thinking about many, many students with more significant disabilities. So the basis of the paradigm is number one, many people think that intelligence is a thing, it's like a glass of water, and you can measure it just like you can measure this bottle of water. On the flip side, people think that if you can measure this construct called intelligence, then you can also measure kind of variations in intelligence and specifically that we can identify children who have the lowest level of intelligence that we have labeled as this thing called mental retardation. Sort of the newest language is intellectual disability, but if we can say, "This is what is smart," then the corollary is also then we can say, "This is what is not smart." And I think we still believe that. Many students with significant disabilities, particularly those with this label of mental retardation or intellectual disabilities and the vast majority of students who are labeled as having autism are considered as mentally retarded and you can still read that in the literature that's being published in 2009.

Another dimension or another characteristic of this current prevailing paradigm is that if you're one of these kids who's labeled as being mentally retarded, you're thought less able to learn really the academic content of the general curriculum and probably can't benefit all that much from being in a general ed classroom, being taught that academic curriculum by a general ed teacher. Now, yes, you know, we think you can get some social benefits by being in general ed classes, but there's still, and you can look at the state data on placement to know that teams are deciding on a regular basis everyday, that if a student has a label of mental retardation, they belong in a special ed classroom.

I also think that a characteristic of this prevailing paradigm is that even when we don't know for sure what students know, what they might be able to learn, what they are or can communicate; the tendency is to presume that they cannot. So this paradigm has strong influences on everything that those of us in higher education, in research, do on a daily basis has implications for what teachers do Monday morning in their classrooms, has implications for what parents ask for, for their children's education, and it certainly has an implication on policy. One of the biggest influences of this paradigm is that far too many students lack any formal means of communication. Or their communication systems or devices often have no academic or age appropriate vocabulary on them. We let kids say things like "I have to go to the bathroom" and "I need a break" but we don't provide them with a way to say "Pythagorean Theorem," or " $6.02 \times 10$  to the  $23^{\text{rd}}$  power."

Again, most students in most states with a label of mental retardation are still educated for the majority of their school day outside the general education classroom and their educational program is still focused primarily on life skills. And even those who are in general education may not have general education goals on their IEPs. And really, it, quite in concert with what Judy was saying is kind of the end outcome of all of these prevailing assumptions and practices is that our vision for students' futures, students' with disabilities futures are much narrower than our visions for students who do not have disabilities, characterized by lack of access to post secondary education, sheltered work, segregated housing, and a lack of choice and control over their futures.

So, here's my proposition, and it's a "duh," I would hope to many of you in the room today. The first element of this proposition is that as long as we believe that mental retardation is a thing that's a scientific, observable fact, I think that in itself is going to continue to perpetuate low expectations for students. That those low expectations then lead to creating and placing students in segregated educational programs and those programs do not, as much as general ed classrooms, focus on content area learning, literacy, and those programs again, tend to narrow students' visions for the future, so that changing our beliefs about disability is necessary, it's necessary but it's not totally sufficient but it's necessary for promoting students' learning, inclusion, achievement, and quality of life before and after school.

So I would suggest that you don't necessarily trust my proposition for this new paradigm just based on the fact that I'm, somebody thought that I was a good person to talk with you today, but that there is an underlying principle called the principle of the least dangerous assumption that might help you decide that your least dangerous assumption is to presume that all students are competent. And a colleague of mine named Anne Donnellan actually developed this, or articulated this principle more than 20 years ago; and here's what she said. "The criterion of the least dangerous assumption says that in the absence of conclusive data, educational decisions ought to be based on assumptions which if those assumptions are incorrect, will have the least dangerous effect on the likelihood that students will be able to function independently as adults and that furthermore we should assume that poor performance on the part of students is due to instructional inadequacy rather than something inherent in the student him or herself."

So, I suggest that the least dangerous assumption is to presume that all students are competent to learn age appropriate general ed curriculum content in the general education classroom and I'm going to give you an end with the five reasons why, for me and maybe for you, this particular least dangerous assumption makes sense.

So why should the least dangerous assumption be to presume competence? The first is stated by James Rhem when he wrote his paper on the Pygmalion effect: simply put when teachers expect students to do well and show intellectual growth, they do. When teachers do not have such expectations, performance and growth are not so encouraged and may in fact be discouraged in a variety of ways.

Second reason to presume competence. Norm-referenced assessments of students' intelligence or adaptive behavior usually measure what kids can't do rather than give us some clue about what students might be able to do if they had the right supports.

Another reason to presume competence is that this thing called competence is a very complex idea, concept. Great example, Ross Blackburn, a woman who has a label of autism, describes how she literally cannot make a sandwich for herself, she cannot bathe herself, she cannot cross the street independently, yet, she makes her living going around the world giving presentations like this because she is such a talented speaker.

She is very intuitive; she can get into peoples' hearts and minds. So, is Ross competent or is she incompetent? What is competence?

The fourth reason why I think it's the least dangerous assumption to presume students' competence is that we do have 30 years of research studies that show that a significant proportion of people, students, who are labeled retarded show themselves to be more competent than we ever thought before when they have a means to communicate. Certainly only when Helen Keller had a means to communicate did she escape the pronouncement of being retarded.

Next to the last reason for presuming competence, and this ties back into this least dangerous assumption notion, is to presume incompetence could result in harm to our students if we're wrong. And finally, even if we're wrong about students' capabilities to learn the general ed curriculum content, the consequences of being wrong about that presumption are not as dangerous as the alternative. Thank you.