According to the US Census Bureau, 54 million Americans have a disability, representing 18% of the population. Between 1990 and 2000, the number of Americans with disabilities increased 25 percent, outpacing any other subgroup of the U.S. population. With an aggregate income of $1 trillion and $220 billion of discretionary spending, people with disabilities are an often-ignored market.

Media, especially news organizations, has the ability to raise awareness, clarify information, and educate the public on issues as diverse as foreign policy and fashion. Although mass media has the potential to “socially construct images of people with disabilities” positively, in reality it often perpetuates stereotypes by depicting individuals with disabilities as dependent, helpless, burdens, threats, or heroes. According to the Special Olympics more than 80% of US adults surveyed felt that media portrayals were an obstacle to acceptance and inclusion of people with intellectual disabilities.

This symposium explored issues related to the representation of persons with disabilities in the media and how this representation influences the public’s attitudes and perpetuate stereotypes, which in turn influence decisions regarding school placement, employment opportunities, housing choices, use of public transportation, access to health care, and a host of other activities, programs, and supports that are available to all citizens.
Symposium Agenda

12:00  Welcome
Toby Long, Associate Dean, Disability Studies, Georgetown University, School of Continuing Studies
Associate Professor, Department of Pediatrics, Georgetown University Medical Center
Director of Training, Center for Child & Human Development

12:15  A Mother’s Perspective
Judy Woodruff, Senior Correspondent for the PBS Newshour

1:00  Panel Introductions

1:30  Discussion
Leon Dash, Swanlund Chair and Professor of Journalism, University of Illinois at Urbana-Champaign
Tawara Goode, Director, National Center for Cultural Competence, Georgetown University, Center for Child & Human Development
Beth Haller, Professor, Mass Communication & Communication Studies, Towson University
Deborah Perry, Associate Professor, Department of Pediatrics, Georgetown University, Center for Child & Human Development
Nolana Yip, Adjunct Professor, Department of English, Georgetown University
Jody Wildly, Diversity Program Manager at the Office of Diversity, Management and Equal Opportunity at the Department of Health and Human Services

3:00  Future Directions
Toby Long
A few years ago in 2004, the President of our University, Jack DeGioia, instituted a university-wide program, the Reflective Engagement Initiative. This Initiative promotes Georgetown as a forum to bring together “authentic dialogue, helpful methodologies, and multiple perspectives” to bear on socially significant issues. The Reflective Engagement Initiative hopes to engage public discourse on subjects that are important in improving society, not only in the District of Columbia, but throughout the nation and the world.

Together with my colleagues from the Journalism Department within the School of Continuing Studies, we were fortunate to receive funding from the President’s office to initiate this symposium to explore issues about the media’s representation of people with disabilities. We hope that this afternoon will be just the beginning of a stimulating, ongoing conversation about how we as disability advocates, disability service providers, individuals with disabilities, scholars, and journalists can work together to promote stories and highlight individuals with disabilities in the media that are positive, accurate, and honest.

Before we begin, I’d like to thank the special people who over the course of this year have supported me in bringing this afternoon’s activity to fruition. First, I want to thank my very special colleagues from the Center for Child and Human Development, who are always on the cutting edge of making a difference for people with disabilities and special health care needs in the District of Colombia, in our region, our nation, and around the world. I’d also like to thank my new friends, Barbara Feinman-Todd and Jackie Sanders from the Journalism Program, who were willing to try something very new, collaborate with a new group of colleagues and in the process develop some new cross-campus friendships.
“Today we want to engage you in asking us questions and in just talking about this issue and how we as advocates, providers, and journalists can work together building a network that promotes open, honest depiction of individuals with disabilities in the media.”

We are hoping that the agenda for this afternoon will stimulate a rich conversation leading to an on-going problem-solving relationship among us all. Following our guest speaker, Judy Woodruff, we are going to have a panel discussion that we really want it to be a discussion—today we want to engage you in asking us questions and in just talking about this issue and how we as advocates, providers, and journalists can work together building a network that promotes open, honest depiction of individuals with disabilities in the media.

Judy Woodruff, and for most of us in Washington, Judy needs no introduction, has been a voice of reason, objectivity and journalistic honesty for the past 30 years. Since 1977, when she served as NBC news White House correspondent, through her years at CNN with her weekday political program, Inside Politics, her anchoring of the award winning weekly documentary series, Frontline with Judy Woodruff for PBS, to now as senior correspondent for the News Hour with Jim Lehrer, Judy Woodruff has played a central role in covering our nation’s politics and major news stories. In addition to her day job, she also anchors a monthly program for Bloomberg television, Conversations with Judy Woodruff, and in 2007, she completed an extensive project on the views of young Americans called, Generation Next: Speak-Up, Be Heard. Through the fall of 2006, Judy was a visiting professor at her alma mater, Duke University, Terry Stanford Institute of Public Policy, teaching a weekly seminar course on media and politics. Prior to that in 2005, she was a visiting fellow at Harvard University’s Joan Shorenstein Center on the Press, Politics, and Public Policy, where she led a study group for students on contemporary issues in journalism. And finally, if that’s not enough to keep a mother of three busy, she is the founding co-chair of the International Women’s Media Foundation, an organization dedicated to promoting and encouraging women in communication industries worldwide. She serves on the Board of Trustees for the Freedom Forum, the Newseum, Global Rights, Partners for Justice, The Knight Foundation Commission on Intercollegiate Athletics, the Board of the National Museum of American History, and is a Trustee of Duke University.

It is my pleasure to welcome our guest speaker, Judy Woodruff.
Thank you Toby, I am so glad to be here with all of you on this gorgeous, almost summer day; and delighted to be at this wonderful university, Georgetown. No, I didn’t go to school here, but I live just a mile or two from here, and this is neighborhood for me, so I’m really thrilled to be here back on campus. I will tell you that as I look out on this audience. Some of you I don’t know, but I do know some of you and I want to recognize some good friends who are out there. Quinn Bradley, a very dear friend who has just written a book about his own challenge with his own disability and started a wonderful website (www.friendsofquinn.com), which I hope all of you will check out, and his mother who needs no introduction, most of you know Sally Quinn, who is of course a renowned and accomplished journalist in her own right. I’m so glad to see all of you, and I’m hoping and counting on Quinn and Sally and any other of you who have the kind of experiences that I know you have had to participate in this conversation that we’re going to be having.

I would like to tell you, there’s nothing going on in the world of news today, but of course we know that’s not the case. They’re counting the ballots, or maybe they’ve quit counting in Iran. The president at this hour is making a speech to the American Medical Association in Chicago where he’s beginning to roll out his healthcare reform plan. We’ll all know a little bit more by the end of the afternoon about what form that’s going to take. And healthcare of course is something that all of us, whether we cover it or not on a day to day basis pay very close attention to, it affects all of our lives, and especially those of us who have a particular interest in disabilities. I want to congratulate Georgetown and the Center for Child and Human Development for sponsoring this symposium and for addressing the issues that you are focusing on.
“For me it is two conflicting impulses: wanting to be as objective and fair as I can as a journalist, but on the other hand, living the life through my son, someone with profound disabilities.

I don’t have to tell you all that as somebody who has lived with this for 27 years, I do have strong feelings and there are two parts to this story, because there have really been two parts to Jeffrey’s life. He was born 27 years ago with a mild disability, the birth defect spina bifida. And then when he was 16 years old, there was a life altering event, ironically during surgery, that left Jeffrey profoundly disabled for the rest of his life. If it had only been the first set of circumstances, which was more than enough by itself, I think I would have been aware of the challenges that people with disabilities face and confront, but you add the second and it meant that we as a family live with those challenges day in and day out—that’s what’s pushed us to a level of awareness well beyond anything we knew before.

I’m going to share with you a brief version of Jeffrey’s story and try to answer a few questions with you. I don’t pretend to have answers to the important questions that you’re going to be asking here, later on this afternoon. I think these are the right questions to be asking, but perhaps we can get some of the conversation started. Twenty-seven years ago in 1981, I was 8 months pregnant when I went in for a routine sonogram. My husband, Al Hunt, was with me. Like the good journalists that we were, we wanted to know exactly when our first baby was due. We wanted to know was it the last week in August, the second week in September? Well, the concerned look on the face of the lab technician was the first sign that something wasn’t right. We had gone in, as I say, it was routine and he called in a colleague and then they proceeded to tell us something we didn’t understand. They were using words we had never heard before. Hydrocephalus, I had maybe heard a little bit about spina bifida—I had never heard the word spoken. For the next month, my husband and I essentially went every few days for an appointment with a doctor here at Georgetown, where we found a wonderful specialist who would guide us through the last part of my pregnancy and prepare us for what was likely going to happen. They couldn’t tell then if Jeffrey was going to have spina bifida, but they knew that there was a high probability of hydrocephalus, because they could see enlarged ventricles in the head of the fetus. But they warned us that spina bifida was a real possibility.

A month later, as I came out of the fog of the C-section Al told me that indeed Jeffrey did have an opening in his back, an opening of the spinal cord to the outside, meaning he did have spina bifida. And it meant, surgery at 15 hours old, to close the opening. The next afternoon, a doctor was there to do the surgery that would essentially give Jeffrey the kind of a chance that children up until just a decade or two before Jeffrey was born didn’t really have. They didn’t really perfect this surgery to the point where it could make a difference in people’s lives until the late 1960’s and early 70’s. So, I kept thinking if Jeffrey had been born a few decades earlier, it might
have been a very, very different story from what happened.

We spent a week in the hospital and came home to all sorts of dire predictions from doctors. Although the opening in Jeff’s back was low meaning minimal nerve damage there was still no guarantee of what damage did or did not occur. Over the years we made lots of doctor appointments; saw a lot of specialists; met with a lot of therapists. The good news is that because the opening in his back was as low as it was with minimal nerve damage, it meant that Jeffreay, at 13 months would go on to walk, pretty much on time, and would go on to do most of the things that kids can do. He did have to have, at 10 months, a shunt put in to drain off excessive cerebrospinal fluid, which is seen in 85% of individuals with spina bifida. Although we, as parents, were frightened, Jeffreay was up and bouncing the next morning. In his crib he was babbling and jumping up and down, with a big smile on his face. So we came through that scary episode feeling well, this is a strong kid.

And sure enough, Jeffreay went on to walk on-time, he went on to ride a bike, he learned to ski, learned to swim, he did all the things that kids his age did. He was in school, he was at grade level in school, he did well. But, the fact that there was some nerve damage meant that he couldn’t run as fast as some of the other kids in his class. He became quite aware of this as he got older, he got to the point where he stopped playing soccer in about 2nd grade, because he knew he couldn’t keep up with the other kids; with the other boys. I have a poignant memory of a foot race in second grade where all the kids were asked to run 3 or 4 times around the school yard and Jeffreay came in dead last, behind all the boys, and behind all the girls. But he had a big smile on his face, he was glad that he had gotten through it. And of course, inside my heart was breaking, but he betrayed no real discomfort over that.

Although Jeffreay’s motor difficulties were quite mild, his major concern, like most individuals with spina bifida was bladder and bowel incontinence. Jeffreay wore a diaper until he was 5 years old when he learned to catheterize himself to empty his own bladder. Although, at times, he was teased he never told us, he just handled it reinforcing what we, as parents knew, this is one tough kid!

Over the years we went to spina bifida conferences, we went to specialists, we went to Michigan, to California, to Massachusetts talking to specialists about whether or not there was something we could do about his incontinence. And there were little things, but nothing that would make a big difference short of some very risky surgery that would take him in a different direction.

Jeffreay was a trooper, he participated in as many sports that he could that didn’t involve running. He got interested in medicine. As he went into middle school, he said he wanted to be a doctor. At 14, he had an internship, at the Centers for Disease Control in Atlanta. At 15 he had an internship at the NIH (National Institutes of Health) here in Washington and then he was just about to start an internship at the Food and Drug Administration, when at the end of 10th grade, his physician said that the shunt that he had had for 16 years, which had given him no problems, needed to be replaced. It was not something that Jeffreay wanted to do. Two weeks later the new shunt, which they had had difficulty putting in, failed. Long story short, he went back into the hospital, they did a different procedure, and it was during that procedure that something went wrong, and Jeffreay basically came out of that a different person.

He came out of surgery in a coma, unable to walk, eat, talk. He stayed in the hospital for a month, went on to a neuro rehabilitation hospital in Baltimore, came home five and half months later using a wheelchair, unable to use his right arm, with dysarthric speech, vision problems, poor balance and motor control, and a significant loss of short-term memory. He could remember everything long-term, he knew what had happened to him, he remembered about his life, but if you asked him, what did you watch on television last night? That was what he couldn’t do. As we grew to learn, that became an enormously frustrating thing and to this day is still an enormously frustrating thing for him.

That was 11 years ago, it was 1998. Jeffreay went on—after missing 11th grade, to community college here in Montgomery County. Then he went to college, away to college, which I can tell you has been a really miraculous experience. Jeffreay is actually on track to graduate from college this December with a lot of help from tutors, and caregivers, and others. He’s been going to a school in
North Carolina, St. Andrew’s, and only has one more semester to go. It will be 8.5 years—its some kind of a record, but as we always knew, he is a trooper. He’s kept a sense of humor, amazingly, through the whole thing, they call him Mr. Personality at school, he wants to get to know everybody, whether they want to get to know him or not, he wants to talk to them. This summer (summer of 2009), Jeffrey is going to a program, a long way away from here in Bakersfield, California; a special program, specifically designed for adults with brain injury where they try to push them as much towards independence as possible. They provide intensive rehabilitation and therapy. He will be there until August when he heads back to school and then come December when he graduates we will need to make some very important decisions. This summer’s program is a really important step.

Jeffrey has shown my family and anybody who comes in contact with him what people with disabilities have to contend with every single day. Unless they are small children and really cute, people with disabilities are basically invisible to a lot of people in society. People just look through them. Often when Jeffrey says something to someone, if they don’t understand what he said the first time, and his speech, as I mentioned is dysarthric, they’ll nod their head and say, ‘oh well, that’s nice,’ and then, they’ll go on and change the subject, rather than saying, ‘I didn’t understand you.’ Or, people will just not look at him; to society it seems that there’s just something so unattractive about somebody whose different—who looks different, or sounds different, or seems different in some way that they’re just not taken into account. There are celebrated exceptions, the Christopher Reeves, and the Steven Hawkings, and people like Marlee Matlin, who are heroes in their own right for what they’ve done, and for what they continue to do. But for most individuals with disabilities, even though we live in a country that is arguably ahead of the rest of the world, when it comes to awareness and accommodations, individuals with disabilities still have to go through: repeating, ‘did you understand what I just said;’ doors that don’t open or are too narrow, homes you can’t visit because there are too many stairs, restaurants that do not accommodate adequately, streets in older neighborhoods that still don’t have curb cuts, the impatience of people when they can’t understand what you’re saying, and the fear that when there’s a fire on the top of a building, a hotel or an office building, that they won’t be able to get out safely. After 9/11 Jeffrey was very focused on the people who were carried out on the top floors of the towers. Those who didn’t make it and those who did make it because somebody was there to make sure they got out.

I guess the most basic thing that I’ve learned from living with Jeffrey is the fact that he doesn’t consider himself a disabled person, he considers himself a person with some disabilities. He will frequently correct someone if they get it the other way around.

Our journey with Jeffrey—and I want to say that it’s a journey that’s involved not just me, not just Al, but it also involved his younger brother and sister, Ben and Lauren as well. Our journey has been, it continues to be, a long and winding road with plenty of rocky, uphill climbs. A lot of twists and turns and profoundly frightening moments. Quick trips to the hospital because Jeffrey took a spill, fell out of a wheelchair. For example, the day after we left him at college he was talking to another student in a wheelchair, they were on their way to lunch, and Jeffrey just didn’t look and his wheelchair tipped over on a curb, because even at this school which had made accommodations, the sidewalks were so narrow that you really had to pay very, very close attention to where you were driving. Since then, from day one, the school has required that Jeffrey have a companion with him wherever he goes on campus, to be safe.

In addition to scary moments, we’ve had incredibly exciting and uplifting moments in our lives. Most always punctuated by the fear of the unknown, yes; but a knowledge that we’ve been given someone very, very special in our lives. And when I allow myself to think about, ‘gosh, I feel sorry for us, I feel sorry for our family,’ and I ask ‘Why Jeff?’—There’s no answer, there’s no answer to that; just like there’s no answer to the thousands of parents who ask, ‘Why my child.’ But, as I say, Jeffrey doesn’t dwell on this. We quickly figured out that it doesn’t do any good for anyone in our family to dwell on why, and what could have been. It doesn’t get us very far, and it doesn’t serve the needs of the children, the young people, and the adults who live with disabilities, whether its spina
“Jeffrey has shown my family and anybody who comes in contact with him what people with disabilities have to contend with every single day.”

bifida, or velocardiofacial syndrome, which Quinn Bradley could talk about, or any of the multiple disabilities that define the lives of so many Americans. It’s also why, not as a journalist, who doesn’t take side in these debates, but as a mother, I’m able to celebrate when I see that more money is being spent on medical research. I can be happy about that, because I know that it makes a difference. It’s also why I watch this healthcare reform debate with very, very close attention, because I know that if not for my own son’s life, but for the lives of others who have experienced or will experience something like what Jeffrey has gone through. All of us who’ve lived with someone with a disability can bring—we have been given a gift, and that’s the gift of greater awareness and understanding of what it’s like in their lives. But, its also an obligation that we speak out about what they live through, what they see, and why it is so important that their views, opinions, hopes, dreams and aspirations are taken into consideration as we have had these important discussions about how to talk about disability, how to cover disability. Individuals in the disability community absolutely need to be part of those conversations.

So, as I say, I come here today, not with answers, but to share our story, and to say, I’m so glad that you’re having this discussion. There haven’t been so many that I have been aware of as a journalist. So, I’m pleased that you’re doing this, and to say, that I’m happy to be here and answer questions for a few minutes, and I applaud you for what you’re doing. Thank you very much.
Panelist Presentations

Beth Haller, PhD

Dr. Haller is a Professor of Journalism and New Media at Towson University, conducts research in the area of media’s representation of individuals with disabilities as well as teaches in the Department of Mass Communication and Communication Studies at Towson. She began this line of inquiry while attending the University of Maryland in the late 1980s where she was fortunate to investigate the ‘The Deaf President Now’ movement that occurred at Gallaudet University in 1988. Dr. Haller received her PhD from Temple University. Currently her research focuses on media representation of disability. Dr. Haller analyzes the content of newspapers and news magazines, a little bit of television news as well. One major problem she has found is that journalists don’t talk to people with disabilities when they are doing a story about disabilities.

Prior to discussing issues related to the media representation of individuals with disabilities, Dr. Haller shared with the audience how honored she was that President Jordan* was in the audience. She explained that because of ‘The Deaf President Now’ movement she was introduced to this area of journalism, which has maintained her interest and scholarship for over 20 years.

We have already commented about the lack of coverage of disability issues in mainstream media. On a positive note, I think coverage is getting slightly better now with the internet. There’s a lot more people talking about disability issues through blogs and other on-line venues. For example, I have a blog that’s basically a database of disability news and stories from around the world that I collect from all news sources that I can find on the internet. So, although I’m seeing there is growing coverage about disability this issue of journalists not knowing where to find a person with a disability to cover the issue, to get the perspective of...
a person with a disability or finding a disability organization, if they can’t find a person with a disability, continues to be a problem. A lot of the stories don’t have a disability perspective reflected in the articles. To me, as a former journalist, it’s a big problem if you’re not including the group that you’re supposed to be writing about. So, that’s one big issue that a lot of my research has kind of discovered. I have also looked some at the disability media itself. This segment of media is vibrant; an area where a lot of people with disabilities have said, you know, if the mainstream media isn’t going to cover our issues, we’ll just cover it our own darn self! Now with the internet there are a lot more opportunities for people with disabilities to get their perspectives out. There are many really excellent blogs, where if somebody’s not covering the disability component of healthcare reform, people are writing about what it means to their life when home healthcare is not incorporated into the healthcare reform and what that will mean.

A lot of the local, smaller papers are doing a pretty good job, also. There was just an article in the Miami Herald a couple of days ago about a father saying, ‘I have a child with a fairly severe disability, and we have no money, and we need Medicaid to cover diapers. Our choice is food or diapers.’ So, he’s now suing the state of Florida to get Medicaid to cover diapers for his older teen daughter. So, these are really important issues that are gradually getting a little bit of coverage.
Tawara Goode, is an Assistant Professor at the University Center for Excellence in Developmental Disabilities, which is part of the Center for Child and Human Development at Georgetown University. She is also the Director of the National Center for Cultural Competence. The mission of the National Center for Cultural Competence is to increase the capacity of healthcare and mental healthcare programs to design, implement, and evaluate culturally and linguistically competent service delivery systems, to address the growing diversity that we have in the US, and to promote health equity and mental health equity. Ms. Goode’s work at Georgetown’s UCEDD, has centered on addressing the impact of culture within the context of disability, including the different perceptions and meaning of disability among different cultural groups.

There are differential experiences of diverse racial and ethnic groups within health and mental health, social service and educational systems because of their disability, and oftentimes because of their race. There are also racial and ethnic disparities among the population of people who experience disability, and clearly there are cultural beliefs and practices that are related to advocacy that may differ from group to group. I’ve had the privilege of spending a lot of time on the intersection of culture, language, health, mental health and disability with my work with the National Center for Cultural Competence. In this capacity, my colleagues and I work with broad constituency groups to advance and sustain cultural and linguistic competence on multiple levels and in diverse venues, including, but not limited to, policy makers, administrators, practitioners, consumers and families, and the communities in which they live. This includes institutions of higher education, such as Georgetown, and the network of University Centers for Excellence that Dawn* referenced earlier. This is a focus on really preparing our future workforce and also providing continued support to our present workforce so that they are able to address this broad array of issues.

I wanted to address just quickly a few definitions or ways for us to think about culture. There are multiple definitions of culture. I’d like to share one with you that’s based on the work of Wenger (1991):

Culture is a system of collectively held beliefs, and practices of a group, which guides decisions and actions and patterns in recurrent ways. It encompasses the organization of thinking, feeling, believing, valuing, and behaving collectively that differentiates one group from another.

*Dawn Rudolph, MSEd is Program Manager for the Association of University Centers on Disabilities (www.aucd.org) in Silver Spring, MD.
I’d like for us to continue to think about culture within this context. We know that culture is applicable to all people, is active and dynamic, that it changes over time; it changes to meet new challenges that may present to the group. It changes in relationship of a group to other groups and it changes based on our economic, social, and political climate. We know that culture is multi-layered, we think about it as an onion, as peeling away the layers of onion. And that we see different manifestations of culture in different settings, whether it’s at home, whether it’s in a community, whether it’s within a family, or whether it’s within a professional and work setting. We know that culture is malleable over time, and it always needs to be considered within a context. Lastly, we know that culture structures our perceptions, it shapes our behaviors, and it really tells group members how to behave.

So, if we think about that very, very broad definition of culture we think of it within a context of disability. (Please see slide) This slide depicts a conceptualization of culture really looking at a convergence of cultural contexts. So, if we think about disability in particular, and its multiple manifestations, I’d like for us to focus on this graphic. This framework shows an individual with a disability in the center. I’d like for us to think about the multiple cultural contexts we heard just in the presentations from Ms. Woodruff, and also the individuals who shared with us. That there are multiple and complex perceptions and experiences of people with disabilities. There’s the cultural context of the family: how that family values the individual with disabilities—what their beliefs and practices are—all share influence. The cultural context of individuals who share the specific disability influences the person. There’s clearly advocacy groups, other shared experiences of those individuals with disabilities. There’s also the cultural context of the community and what the public perception of a particular disability may be, it’s the public understanding and the acceptance of that disability within those particular settings. There are also the cultural contexts of the associations and advocacy groups and the cadre of professionals concerned with specific disabilities. We heard this again earlier from Ms. Woodruff about the various groups that may be under a particular umbrella and very much concerned with a specific disability, not necessarily disability as a whole. Then we can look at the cultural context of various forms of media, and how they understand disability and how it’s portrayed.

I suggest to you that as we think about disability in the media and continue to guide our discussions, that this convergence of cultural contexts is really very important, because we’re looking at individual expressions; we’re looking at institutional understandings of this; we’re looking at how advocacy groups perform. I must say that this is a complex set of circumstances for anyone to understand, and in particular journalists. And so, I think we need to look at what will be our role, and continue to foster that level of understanding about the complexity and the depth of this issue.
Leon Dash is the Swanlund Chair and Professor of Journalism at the University of Illinois at Urbana-Champaign in the College of Media. Mr. Dash is currently developing a documentary film about the University of Illinois’ program to support students with disabilities as well as disability in American society. Prior to taking the position at the University of Illinois he was a Pulitzer Prize winning journalist for the Washington Post. Mr. Dash explained to the audience that he took the position at the University of Illinois over three other prestigious universities because of the supports that would be available for his daughter who has cerebral palsy and uses a wheelchair. The University of Illinois, has the oldest (established in 1948) and most expansive program for students with disabilities in the United States. His daughter graduated from the University of Illinois in May 2005 with a Bachelor of Science and theater degree. She also, while there, acquired her full independence. Currently she lives independently in downtown Silver Spring, Maryland, and is doing quite well in terms of her independence, but not in the employment market.

In terms of some of the things that have already been talked about, I’ve had a number of students with disabilities working for me as research assistants. One of them is from Iraq, a young woman, a person with polio. She’s doing a Masters degree in broadcast journalism at the University of Illinois. But, she has determined in the last 6 months that she’s not going back to Iraq. She uses a crutch to get around, she’s had 3 operations since she’s been here—she arrived in January of last year and she had 3 back operations that have straightened out her spine. The results of the operations have been productive for her and very good. But she knows 1) she will never be given full opportunities as a woman in Iraq; and 2) she will not be considered for any serious employment because of her disability. Thus she’s decided to stay in the US. So, that tells you that relative to many places overseas, including Western Europe, the United States is a much better place for people with disabilities, but it still has a considerable way to go.

I had a long list of things that I wanted to talk about today, but since people were sharing their personal stories, I wanted to share mine. But, one of the things that I got from Andrew Imparato*, he’s the head of the

“In 1990 when George Herbert Walker Bush signed the Americans with Disabilities Act, 70% of the people with disabilities in the United States were unemployed. Today, 70% of the people with disabilities are unemployed.”

*Andrew Imparato, a graduate of Stanford Law School, is the President and CEO of the American Association of People with Disabilities. Previously, he was the General Counsel and Director of Policy for the National Council on Disability. Mr. Imparato has earned honors from the U.S. Junior Chamber of Commerce, Secretaries of Transportation and Health and Human Services, and is a member of the Maryland Statewide Independent Living Council.
American Association of People with Disabilities, is that United States is still in the *Plessy v. Ferguson* period when it comes to people with disabilities. And I thought that was a good characterization. *Plessy*, for those of you who don’t know, was the Supreme Court decision made in 1896 that supported segregation. He (Andy Imparato) says that until the disability community itself comes together to re-activate itself in terms of the disability rights movement, this will probably go on for some time, and I sort of agree with him.

One of the things I wanted to point out is that since 2006 my daughter has worked as a house assistant at the Strathmore Music Center in Bethesda, MD. But, after a long time of looking for a job and getting rejected, specifically because she arrived for the job interview in a power wheelchair, and was told that ‘we don’t hire people with disabilities.’ I’m using ‘people with disabilities,’ those were not the terms used with her. And I was—her mother and I were very frightened, because I was afraid she would shut down with rejection after rejection, but she didn’t. Her mother says that’s her side of the family. I don’t get into those arguments, but at any rate, she’s been working there, and she’s begun working at the Stephen Knowles School as a volunteer in Montgomery County teaching autistic children. Now, that has brought her around to thinking about—first she was thinking about a career in theater arts, and all the doors shut in her face for that. Now she’s thinking about doing a Masters degree in special education, and then going into special education as a teacher. The debate right now is whether she goes to the University of Maryland, where her mother teaches, or comes back to the University of Illinois, which I think is better for her. <laughter>

One of the things that Judy Woodruff talked about was the high level of unemployment among people with disabilities. One of the things we’re going to emphasize in the film is that in 1990 when George Herbert Walker Bush signed the Americans with Disabilities Act, 70% of the people with disabilities in the United States were unemployed. Today, 70% of the people with disabilities are unemployed. So, it continues. Also, in terms of mobility, my daughter’s quite fortunate. Because she is carried on my health insurance, she doesn’t have to rely on Medicare. Medicare would not help her be independent. Medicare would help her be independent in her apartment, but not when she leaves. Medicare would not support her need to repair her power wheelchair that breaks down every three months, and that sort of thing. In terms of getting back and forth to work from Silver Spring to Bethesda and back and over to Stephen Knowles and back to her apartment, she has to rely on private transportation. Metro Access (the transportation service for individuals with disabilities) would never get her to work on time, and she would be unemployed again. Because when they hired her at Strathmore, they told her, ‘You must come to work on time,’ and they emphasized that with the assumption, I think—that’s my cynicism—that she wouldn’t do it and they would fire her. But she gets back and forth using cabs, taxis that are wheelchair adapted. She’s lucky that her parents are able to afford that. But, if she were someone who was relying on support from the US government, through Medicare, it would not happen.

One other thing that I just wanted to talk about is housing. My daughter just moved into a new apartment in Silver Spring. She needed to move from her previous apartment on East-West Highway because the intersection was too difficult to cross safely. I began talking to the Montgomery County government to try to change some of the traffic patterns at that highway, which were relatively dangerous for a person who was able-bodied and walks up straight and tall, for the drivers to see the person, but much more dangerous for anyone in a wheelchair, as other wheelchair users in that area told her. I talked with Isaiah Legget—this is all e-mail traffic, John Kelly, head of the county, Aging and Disability Council, and a number of other people and agencies. Because, the county said the state was responsible for that particular intersection, they referred me to the state of Maryland, and I said ‘I know where this is going now.’ The state of Maryland, told me, ‘We will study it.’ To make a long story short, there was no resolution of it, so the only resolution was to break the lease and move her to a new apartment, and that’s what we’ve done.

Even with these difficulties, I want to emphasize that my daughter is very fortunate in this area. Many other people with disabilities don’t have those kinds of options and supports.

Thank you.
Deborah Perry, PhD

Deborah Perry is an Associate Professor in the Department of Pediatrics, Center for Child and Human Development. Dr. Perry is also an adjunct professor at Johns Hopkins University, Bloomberg School of Public Health. Dr. Perry has expertise in the area of research and policy development for vulnerable populations of children and families, and is a nationally recognized figure in the area of children’s mental health consultation. She brings to the panel the perspective of federal and state policy affecting children with disabilities.

My first job after college was at the New York City Board of Education in the Special Education Budget and Policy Office. That was in 1985, I’ve now told you how old I am, I’m not supposed to do that anymore, right? <laughter> It was 10 years after the passage of the Education for All Handicapped Children’s Act (EHA)*, which is what IDEA was called at that time. Ten years out, NY City was already so far out of compliance with the federal law that there were 100,000, (one hundred thousand) children who were out of compliance with the federal requirements for identification and placement, and we were under a class action lawsuit, which is unfortunately how we implement public policy.

So, fast forward a little bit, I went and I got a Masters degree, and in 1989 I moved down to Washington, DC, three years after the passage of PL 99-457 (now: Part C of IDEA). 99-457 was a really important point in the expansion of the mandate of services under EHA. And the Education for all Handicapped Children’s Act really marked, I think, a turning point in the larger disability policy movement in framing services for children as a civil rights issue. EHA (now IDEA) guaranteed a free and appropriate public education for all children in this country regardless of their disability. What PL 99-457 did, now almost a decade later, was to expand those same rights to children birth-5. So, this new component, expanded the then optional program for infants and toddlers with disabilities, to a mandatory program serving children 3-5, preschool aged children.

*Education for All Handicapped Children’s Act (EHA) or 94-142 was the major federal initiative establishing the right for a free and appropriate public education (FAPE) for all children irrespective of their disability. Passed in 1976, the Act was reauthorized in 2004 and was renamed the Individuals with Disabilities Education Act (IDEA). In 1986, Part H (now called Part C) offered incentives to states to provide services to children from birth through age 5. Currently, IDEA has two major service provision components: Part C addresses the infants and toddlers program and Part B, including Section 619, addresses children from age 3 through 21.
Just a year later, 1990, the same year the Americans with Disabilities Act (ADA) was passed, another really important landmark in children’s disability policy occurred, the Zebley decision. This was when the Supreme Court decided that applying adult criteria for determining eligibility for disabilities was not appropriate for children. SSI, supplemental security income, was an important way for particular children who were poor and disabled to be able to access Medicaid, which offered a critical set of services. So Zebley really opened the door for more children to qualify for Medicaid. In fact, the number of children tripled from 1989-1995. This (the Zebley decision) is an example of the impact that public policy can have in terms of services. During welfare reform in 1996, I was at the National Governor’s Association, and we were grappling with the intersection among Medicaid policy, SSI, and Title V, which some of you may know is another really important pillar in the federal infrastructure for children with disabilities and children with special needs in general.

I found myself back at Georgetown University and at that time, a lot of the work that we were doing was focused on children with mental health problems, particularly around children who were very young, specifically birth to five. Not only thinking about treatment of children who already have disabilities, but trying to shift the conversation to trying to do some prevention. Prevention is a really important construct that the disability community has struggled with, trying to extend our services in a manner that may prevent the impact of disabilities and impairment.

Over time, my work has focused on how states can use federal programs to try to build a system of care. The federal government’s approach to serving individuals with disabilities is at best, fragmented, and certainly categorical. We have things like the Department of Education, SSA, the Social Security Administration, which is where Medicaid and Medicare are operated, SAMHSA, the Substance Abuse and Mental Health Services Administration, ACF, the Administration on Children, Youth and Families, the list goes on and on. We have this whole host of programs that are trying to help families live in communities independently and raise their children with disabilities to become healthy adults. Unfortunately for service providers, collaboration and linkages between and among the programs is difficult and cumbersome.

I think as we bring this back to how the media portrays this sprawling policy network, I think what we often see is tokenism. I think the anniversary of the passage of the ADA, let’s have a press conference, let’s talk about that, but let’s not talk about the fact that we haven’t made significant strides in any of the things that the ADA meant, and this is now 19 years later. What we sometimes see, but certainly not often enough, in-depth analysis when a federal law is being reauthorized. And often the reporting focuses on one or two specific issues. I remember during one re-authorization of IDEA, the big thing was children who were being expelled because of behavior problems. That was the only issue that the media focused on during a very complicated re-authorization that had a lot of important issues that were being discussed. Finally, what we almost always see is the media frenzy when systems breakdown. We hear about the lawsuit that sort of triggers people to say, ‘Wow! This doesn’t make any sense.’ The media could help make sense out of this. The media could be helping people navigate the system better.
After twenty years in the disability community I took a position as the diversity outreach manager within the Department of Health and Human Services. I have found that in this position I am able to affect change and influence the “system” greater than when I was focused on disability specifically. And the system certainly does need to be influenced!

Disability is now a component of the wider sphere of diversity. It has been extremely interesting working for the Federal government because I’m not certain if you’re aware that only 0.6% of people who work in the federal government are persons with disabilities. We have been trying to work on that, but in governmental terms, beyond the bureaucratic rhetoric, you wonder how serious is the government who makes the laws about disabilities. We’ve probably been around 0.6%—actually we hired more persons with disabilities in the 80s than we have in the year 2000, and we often wonder why that is. We’re hoping that the president passes an executive order such as President Clinton did at the time that will mandate that certain agencies hire persons with disabilities and that there’s this rush on hiring. Also, one of the problems that we see now, with the Recovery Act, that all these agencies are doing massive hiring, but unfortunately, people with disabilities aren’t in that mix.

Recently, the diversity field has started to frame the issue of diversity as a business case. This is something that the disability community should also foster. I don’t think anybody has come up with a business case: “why should we hire people with disabilities, what’s in it for me?” In working with hiring managers, I have found that 1) hiring managers feel that its going to cost them a lot of money, because of assistive

"The diversity field has started to frame the issue of diversity as a business case.
This is something that the disability community should also foster... This shift in definition of diversity to include individuals with disabilities must be done at all levels, including the federal government."
technology and things that people with disabilities might need; and 2) there’s no real need to hire people with disabilities. Often times, hiring managers who are mindful of diversity don’t consider people with disabilities in the mix of diversity. They want to hire people from different cultures and different minority backgrounds. People need to be encouraged to be part of the arena of diversity. This shift in definition of diversity to include individuals with disabilities must be done at all levels, including the federal government. If you think about it, if the federal government isn’t going to do it, who is going to do it? But being a person with a disability, I am also a firm believer in the fact that it is my responsibility to make certain that happens. There are certain things that we should be responsible for doing to make certain that the government or any other entity realizes that people with disabilities are viable individuals with skills that the government can use. This is very timely because over the next 5 to 10 years, the baby boomers will be retiring creating a massive shortage of people within the government. Individuals with disabilities need to be positioned to be part of the succession planning.

Finally, I’d like to say, if no one has really thought about the business case, this is one that should be important to everyone. No one ever talks about the number of soldiers who are coming back with disabilities. People always talk about how many people were killed over there, but no one ever really talks about, on a serious level, the numbers that are coming back and the disabilities that they have acquired from being there. This is an opportunity for the media to portray people with disabilities positively.

Unfortunately, there is often a story about someone using a prosthetic limb or how someone is overcoming adversity. I would like to propose that the soldiers returning from war can be the solid business case we need. If you pay attention to the number of soldiers who are returning home with disabilities then you can’t help but pay attention to all the individuals with disabilities who want to work. I’d like you to keep in mind as we move forward that disability and diversity are inter-related and we have to build a case for people with disabilities to become employed.
Dr. Yip is a Lecturer in the Department of English here at Georgetown as well in the Liberal Studies Program, where she also serves as a faculty mentor to incoming students. In addition, she is on the faculty of the Corcoran College of Art and Design, where she teaches in Academic Studies—nothing as Nolana says, “exciting like sculpture or painting”. Dr. Yip received a PhD in literary studies, at George Washington University where her dissertation focused on issues related to disability and disability studies within the framework of ethnic studies literature.

Thank you Toby and Barbara for inviting me to participate in this discussion along with these esteemed panelists. My work within the academy is from a humanity, academic perspective. My work includes cultural studies, which examines text, broadly defined. I examine the totality of literature, film, broadcasts, journals, newspapers, as far and wide as Jane Eyre, Charlotte Bronte, The Mad Woman in the Attic—Rochester’s wife, who’s locked up in the attic because she’s mad—to something like Murder Ball, a very MTV-like production that actually students love when I show in class.

Within humanities, I introduce students to a field of disability studies that is likely they’ve never really considered or thought about. And, although scholars have been studying disability for such a long time, actually it was not considered a proper field until 2005, when the MLA—the Modern Language Association—which is sort of the governing body for humanities, considered it a proper field. That’s really not that long ago, actually. Shocking, isn’t it! So, although scholars have been interested in disability studies for awhile it was not until May, 2005 that it was consider a “real field”. I also take a very interdisciplinary approach to disability studies, for example incorporating disability and queer studies*. Also, along with disabilities studies post-colonial studies, like race studies, gender studies, all intersect to form a rich tapestry of the human experience. I also try to take a very local approach to disabilities, so it’s not just something I teach from the outside of ourselves, but we are looking at something, for example, our campus. A lot of you are from Georgetown University, I wonder how much we think of this university as accommodating as we’d like it to be. Or, even, sort of DC in general. You know, we talk a lot about what’s happening in Gallaudet, what the peers of the Georgetown students are advocating for through their

*I Robert McRuer, PhD, at George Washington University is a major scholar in the area of disability and queer studies. Dr. McRuer’s work focuses on queer and crip cultural studies and critical theory. His work includes considering locations of disability within contemporary political economies and the roles that disabled movements play in countering neoliberalism and hegemonic forms of globalization.
protests. Let’s find out, let’s get to what is happening here, locally, so the classroom discussions are connected to life.

I hope this doesn’t sound too much like a lecture, I did have class this morning. <laughter> But I just want to talk about a couple of theorists who really resonate with my students and maybe talk a little bit about some of the ideas that I thought we could expand on for journalism. One of the things that really resonates with students who are sort of new to disability, is really understanding that issue of language that a lot of you have talked about already. I’ll talk about something as simple as linguistics, semiotics, the sign system. I’ll have a cup, I’ll talk about, or a tree.

<holds up a cup> And this is a cup, and we call it a cup, C-U-P. And its been this way, this sign system for so long. We’ve used this term cup for this object that I’m holding here for such a long time. And it has a lot of power. But what happens when it comes to something like disability? When we think of disability the term, we think of something broken, something that needs to be fixed, something problematic, right? All of those connotations are negative. And so, when my students start to think about the sign system, or semiotics of disability, I think they start to think, ‘Oh, ok, I can see where that power of that term, disability, how do we work with that?’ I think that something just as simple as linguistics actually starts off a good conversation about disability and the power terms can have in establishing a representation of disability.

I also like to teach Lennard Davis who writes a great essay on constructing the norm. It’s really important to historicize disability. It’s almost as shocking to imagine that disability is socially constructed and it is culturally constructed. Tawara was talking about that with her really great presentation. It’s hard to imagine, but Lennard Davis points out that prior to the 18th century, there wasn’t a term ‘disabled’ or there wasn’t a term ‘normal.’ Everyone was even, because the only ones who could be perfect were the gods. Thus being disabled or being normal has been historically socially constructed.*

The other critique that students really resonate with is Rosemary Garland-Thompson. In her essay, The Politics of Staring: Visual Rhetorics with Disability in Popular Photography she explains that there are four major rhetorics in popular photography. There’s the wondrous, or the extraordinary, the kind of “super-crip” kind of thing. Where, there’s a photograph of a man in a wheelchair climbing up a mountain. This also includes the history of the freak show. So, there’s a picture of Charles Tripp, the armless wonder. The second rhetoric is ‘the sentimental,’ it’s sort of that pitiful, March of Dimes poster. She also talks about how the sentimental leads to a capitalist sensibility, where you get advertisements for a place like Benetton. You know, Benetton has got some great clothes, but let’s look at their advertising. The exotic is the third rhetoric, which is a very ethnographic kind of sensibility. But also, deals with capitalism. There’s sort of that high fashion, niche market of somebody whose trying to sell something. Finally there is the realistic, where she talks about portraits. Her example here is Judy Heumann, the former Department of Education official. Her portrait is wonderful because it shows her as a regular person. But in some ways, that’s not so good because it erases and minimizes the disability, and that’s also something that could be problematic.

So, I mention these two critics, because aside from the fact that they resonate with students very well, they actually have a call to action. They have three main points in their call to action. It seems simple, but it’s actually no easy task. The first is that we increase our awareness and consciousness around the issues of disability. That’s actually one of the reasons why I endeavor to teach disability studies. Either as an entire class, Introduction to Disability Studies, or I have disability studies somewhere in the classes that I teach. Because, Judy Woodruff has asked another young person who was teaching, what are those students going to do when they graduate. Well, they become engineers, doctors, teachers. They become the people you talk to on the phone. So, if in my class I’m able to really connect them to a concept of disability, or at least an awareness or consciousness of it, I feel like—it sounds like a romanticized of teaching, doesn’t it?—But, I feel like, that’s great, because maybe that engineer now

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*Lennard Davis* is professor of English in the College of Liberal Arts and Sciences and professor of disability studies and human development in the College of Health and Human Development Sciences, University of Illinois at Chicago. His works on disability include *Enforcing Normalcy: Disability, Deafness, and the Body*, which won the 1996 Gustavus Myers Center for the Study of Human Rights’ annual award for the best scholarship on the subject of intolerance in North America, and *The Disability Studies Reader*. His memoir, *My Sense of Silence*, was chosen Editor’s Choice Book for the Chicago Tribune and nominated for the National Book Award for 2000 and for the Book Critics Circle Award for 2000. He was co-founder of the Modern Language Association’s Committee on Disability Issues in the Profession.
is going to start something really great in assistive or adaptive technology, or that doctor is finally going to have an awareness of disability, or that teacher is going to be more aware of that. The second call to action they have is to review and revise our traditional notions of disability, and to note that those notions have social and political implications and ramifications. And, I think that a really key point for academics to realize is that everyone here is dealing with actual, hands on, people with disabilities and sometimes, you think in academia, you’re really separated from that. But, this point of realizing that our perceptions of disabilities have social and political ramifications really connects academia to the ‘real world.’ Because, that means, what you’re learning in school and what you’re learning—or what you’re even teaching—has implications outside of the classroom, it has real world ramifications. The third call to action that they have come up with is a new and alternative way to even consider disability.

So, my students always say, ‘ok, that’s great. So, I’ve read these essays, and this is what they say to do at the end.’ But, that’s not really an answer. How do I, you know how do we really change those concepts of disability? How do I revise our thinking? What are those alternative ways? Why don’t these scholars give us some answers? So I like to teach James Charlton’s Nothing About Us Without Us,* which is such a great title, I think: Nothing About Us Without Us. I like to end the semester on this, because he actually gives us five ways that can also work for the media to empower the disabilities rights movement. These five ways are global in nature, comprehensive and meaningful to a broad audience. The first is the establishment of histories, and I would say he’s talking about that broadly speaking. The establishment of histories of disabilities written from the perspective of the people with disabilities, including articles, books, newsletters, and journals. The second is the creation, distribution, and consumption of disability culture from music, dance, plays, literature, athletics. For example, there are dance troupes composed of individuals with disabilities or musicians or artists of all sort. The third point he says to empower the disability rights movement is to change the way people with disabilities are referred to. It’s an issue of semiotics, discourse, self-identification. And, for Charlton, self-identification becomes primary in the disability rights movement. That, you feel that you should participate in the discussion of what’s happening in and around disability issues. The fourth is an establishment of disability related and disability support organizations, NGOs, and networks. The fifth empowerment act is coalition-building within the disability community. So, those who have vastly different kinds of disabilities are working together towards a common goal.

My final point that I’d like to make today is, actually twofold, that there is a hierarchy of disability, that we realize that mental illness is often left out of the conversation entirely, and this is particularly critical in the university setting, where issues of mental health are often prime, where a lot of time the professors are the first people to know things, where professors are often in the position to guide a student toward appropriate resources and supports. And, that there is a hierarchy also with congenital disabilities vs disabilities that are from accident or from war. As Jody was talking about earlier, there’s something more cool about having been an amputee from an accident than it is to say, have a congenital disability—I’m not saying that’s the case, but that’s what the perception is. That’s something that we have to keep in mind, about the hierarchy of disability. Then, my final point is that we are very well aware of the context of disability. I’ll give you an example—the mental illness in the context of say, Burmese refugees, in a novel such as Wendy Law’s ‘The Coffin Tree’ is vastly different than let’s say, the mental illness of a young college girl, let’s think of Sylvia Plath’s ‘The Bell Jar.’ To that end, we really need a high degree of cultural competence, not only in our healthcare system, by our healthcare providers, and I am thinking of Anne Fadiman’s ‘The Spirit Catches You and You Fall Down,’ or a great PBS documentary called ‘Hold Your Breath’ by Maren Grainger-Monsen and Julia Haslett about an Afghani immigrant dealing with stomach cancer. But, cultural competence is really important for us in a field representing disability either as scholars and teachers, but also as journalists.

*Nothing About Us Without Us: Written in 1998, this book quickly became a major read in the disability rights movement. It is the first book in the literature on disability to provide a theoretical overview of disability oppression that shows its similarities to, and differences from, racism, sexism, and colonialism.
A rich discussion occurred in the context of a question and answer session following presentations by Judy Woodruff and panelists. Event participants included a broad range of representatives from the news media, Disability Studies scholars, professionals who serve people with disabilities, family members, and people with disabilities. Throughout the discussion among participants and presenters, a number of issues emerged as being relevant to the media’s representation of people with disabilities.

Media Portrayals

Comments and responses were focused on both the quality of the coverage and underlying, sociocultural assumptions embedded in media coverage. Participants spoke of the need to feature issues and experiences of people with disabilities throughout the lifespan.

Dr. I. King Jordan, the former president of Gallaudet University made the following comments about the larger societal perceptions that frame media coverage, as well a fundamental need to change deeply seated attitudes and beliefs about disability and human variation:

*I think this whole discussion needs to be put on the table, and that’s the whole idea of attitudes about disability and perceptions of people with disabilities. I sometimes call it the great divide: it’s them and us. And it depends on who’s talking about it, who’s them and who’s us. And, most of the time, it’s the able-bodied people, or the not-yet disabled people, or the differently, mildly disabled people, or whatever you want to call the group that doesn’t include us. And, when they talk about accommodations for people with disabilities, they talk about how those accommodations are made to help ‘them,’ but we have to pay for them. And, so it’s not just that people with disabilities are broken, and need to be fixed, and it’s a negative thing to have a disability, and to be disabled, but it’s onerous... So, until we start talking about the attitudes and beliefs and what’s in people’s hearts instead of what’s in people’s minds, then we’re never going to make this. The only way what’s in people’s hearts is going to change is when the media and the public start to talk about differences as differences. And start to talk about disability as just one aspect of the human condition, and it’s in that diversity mix, disability is just one kind of difference.*

Panelist Beth Haller, a journalism professor and researcher from Towson University, followed up by addressing social and cultural beliefs in terms of the attitudes of journalists:

*I really think that some of what we’re seeing in the media coverage comes from the actual fears within*
the writers and journalists who are covering these stories. They think they’re being fair and objective and all that stuff that we teach them in journalism school—but they really can’t understand that their own fears for their own body are creeping into their stories and they can’t grasp that someone could have a full and enjoyable life as a person with a disability. I think no matter how many times you tell them that, they just can’t get over that kind of pitying part of human society that is just so pervasive. Journalists are people too and they have these same biases that are embedded in so much of what they do. I think that’s going to be the really, really difficult thing to try to get across to people, because, they don’t know that they have them, they don’t know they’re biased.

Tawara Goode, panelist and the Director of the National Center for Cultural Competence, highlighted a way of re-framing attitudes and perceptions about disabilities by offering expanded definitions of ability and disability, as well as thinking about how mental health issues are perceived of:

Disability arises at the interface between a person’s functional abilities and the environment’s accessibility (www.disabilityisnatural.com). Individuals who experience mental health issues are largely portrayed in sensational events. That may include homicides, suicides, or other violent acts. That’s what we see with mental illness frequently in the media. While the overwhelming majority of people with mental illness are not violent, if that is the sole media portrayal, it absolutely feeds stereotypes, it really fosters the stigma that people with mental illness indeed have, and also, to some extent, may foster discrimination.

Tina Campanella, Executive Director for Quality Trust for Individuals with Disabilities, and longtime advocate for people with disabilities of all ages, suggested that the ability to change larger sociocultural perceptions was mediated by another kind of diversity, socioeconomic level:

The central issue is societal, since disability is really defined or occurs within the context of society. As a society, what do we believe is the role of people with negatively valued differences? They are not just differences, they’re negatively valued. They’re not seen as desirable by other people. How do we expect, as a society, to respond to those? If you think about some of the things that have been said today, people with means figure these things out. It’s the people without means that really don’t figure these things out, and it touches a variety of things, like education, like opportunity to connect with lots of different experiences and people within the community, with accommodations.

These comments about media representations reflecting larger societal views certainly underscore a need for institutional and global change, which can in part be driven by individuals within the disabilities community. Many threads of the discussion were focused on pathways for change.

Participants spoke about the explosion of information available through new media—the many online newspapers and journals, personal web pages, and social networking sites that are increasingly available to some of us. This electronic content poses new challenges and responsibilities for the disability community to be mindful of.

Quinn Bradlee is a young adult with learning disabilities who has written extensively about his life, and also made available resources about learning disabilities and virtual communities of support through his website friendsofquinn.com. At the conference, Quinn spoke about how the virtual realities of cyberspace could specifically empower people with disabilities:

The media is a great place with people with learning disabilities and especially the Internet, because you can create communities, and you can create communities within communities. There’s now something called Second Life where you have your own avatar, and you can create him or her in any way…Your avatar is able to participate in a 3-dimensional instant messenger, in essence, to fly all over the world. I just think it will bring people of all sorts of needs together—that’s just one of the things that the Internet will be able to do.

Although Quinn highlighted the ways the Internet could provide a kind of virtual mobility for people with disabilities, other participants pointed out the limitations of new technologies. A woman with hearing impairments made the following comments:

The media’s very interesting to me, because with politics and everything that’s going on in the
world today, we all watch TV. But, we are also on the Internet. There’s no captioning on the Internet. CNN has video streaming, for example, on the Internet, there’s no captioning there, so how do I access that? My question slash comment is accessibility and how do I have full access to the Internet, and not just for media, TV, and theater...What do you do about that part of the accessibility issue for deaf folks and other people who may need it? What do you do about the accessibility issues with new media for other disability groups?

In referring to the experiences of a family member with disabilities, panelist and journalism professor from the University of Illinois at Urbana-Champaign, Leon Dash expanded on the participant’s comments about access:

Most of the Internet in terms of use of Twitter and hand texting and PDAs are unavailable to people in the disability community because the keys are too small. Particularly those, like my daughter whose cerebral palsy affects her hands, they just cannot do it. She manages a cell phone quite well, but she’s cut out from that sort of interaction. And most of the people, a lot of people in the disability community are affected in that manner.

In addition to the opportunities and challenges posed by new media for people with disabilities, other critical consumers of information available on the Internet also voiced concerns. Rachel Brady, faculty member at Georgetown University Center for Child and Human Development, articulated her concerns about the unregulated nature of what appears and is responded to on websites:

*What do you think the impact of new media consumption is on disability issues and discussion is? For example, somebody will put something on the Internet about their child with autism, or somebody will make themselves vulnerable in other ways— they have cerebral palsy and they want to tell their story on You Tube, but the response that you sometimes see is shocking! People will leave public comments to the effect, “I don’t believe autism exists;” “You should have all died.” It is horrific and I don’t see any monitoring of that or pushback. I actually responded to an article in a paper about somebody who had an intellectual disability. Two people had already commented that the person should have died. I contacted the list-serve person, or the webmaster, where they say you can report abuse, and I reported it. Now that we have this impact of media that is so immediate and unfiltered, how does it influence our discussion?*

Several panelists spoke to this participant’s call for all of us taking responsibility for the way information is handled on the Internet, an admittedly unregulated forum. Panelist Deborah Perry, faculty member at both Georgetown University Center for Child and Human Development and Bloomberg School of Public Health at Johns Hopkins, expanded on the notion of becoming actively involved in shaping the dialogue that unfolds online:

*The new media opens up opportunities, but it also opens up responsibilities. I try to take the time to actually register, or create an account on websites where I see something and would like to intervene. If there are times when you encounter that, I think it’s an opportunity for education that reaches another sector of folks you may not normally come into contact with. Those of us who are university professors, we get to*
inform and educate. Those of us who do training out in the community as well. But, this is one more sphere where we can influence the dialogue.

Beth Haller ultimately concluded that the unfiltered nature of information on the Internet by people who experience disabilities, tempered by comments from a supportive community, could help shape perceptions in real time:

Before the Internet really took hold, the way people could respond was letters to the editor, and editors decided whether this information was going to get published. Now, it seems like the ultimate freedom of speech for everybody, no matter what hateful thing they have to say, can say it. But I think, that on the flip side, the fact that somebody is able to get their message out there is amazing. There’s a really great series of videos on You Tube by Amanda Baggs, who is a person with autism, and she does a brilliant job of discussing what her life is like, and how she communicates, why she does some of the things she does, and how they help her—just what her life is like. Some of the people enter negative comments on her videos, but it is highly educational for people who do not know to be able to obtain some specific information about disabilities. So, I think you have to take the bad with the good.

The Tangle of Terminology: Towards Person-Centered Language

Societal views by journalists and laypeople about disabilities are inescapably encoded in the terminology we use to describe people with disabilities. Beth Haller and her collaborators have contributed substantially to our understanding of the relationship between disability language use in the media, the self-perceptions of people with disabilities, and the larger ways people with disabilities are perceived of by others. In 2006, Beth Haller and her colleagues Bruce Dorries and Jessica Rahn suggested “that something as mundane as the words used to refer to a group are important because they have ramifications for both the self-perception of people with disabilities and what the general public believes about disability.” At the symposium, panelists and participants discussed the inadequacy of the terminology that we use to describe people with disabilities and deconstructed some of the more problematic language issues, touching on many of the themes in the literature on the changing cultural language of disabilities.

In response to a clarifying question by National Public Radio’s Lisa Shepherd, journalist Judy Woodruff noted the following in reflecting on her son’s experience with disempowering language:

For me, it’s very straightforward, I mean when you say the term, the words ‘disabled person,’ that says that person has no ability, is not able, they’re disabled, and so, I have a problem with it. I mean, I know people use that in shorthand, but what it basically does is that it confines that person to sort of a heap of humanity that isn’t capable of doing anything. And so, that’s not what we’re talking about, we’re talking about individuals who have abilities, who can do things, who can get things done, but who happen to have some differences and in some cases, some profound differences in the way they can do things, but they have abilities as well. They are not simply to be defined by their ‘disability.’ They are, you know, they have something to offer. As I hear my son Jeffrey, and I’ve heard other
people with disabilities say, 'I want to be considered a whole human being, just like everybody else. I have all the dreams, hopes, aspirations, both personally and professionally in terms of a career, in terms of a life, as everybody else. But I have to go about it in a different way.' So, to me, it's not a small difference.

Ms. Woodruff's comments certainly highlight the way identities of people with disabilities can be deeply affected by terminology used in the media and elsewhere.

Quinn Bradlee responded to the question of terminology from his perspective of a person with a learning difference:

The other thing I'm trying to do is transfer learning disabilities to differences, because learning disability literally means that you're disabled at learning something. If you think about it, that could be about anything. If that's the case, then we all have learning disabilities. Learning differences is that we just have a different way of learning, and again, we all have a different way of learning. In a way, it's kind of like the word, 'normal'—there's really no such thing as normality. Normality is an idea and a concept of something. There's no one actual definition of normality.

Quinn poignantly highlights the idea of multiple kinds of differences, as well as the potential of language to restrict the way we imagine difference. The comments of other panelists were also instructive in this area. For example, in discussing the experience of a family member with a disability, panelist Deborah Perry added:

My husband became disabled a year after our marriage. He had a very serious motorcycle accident, broke his neck at C3 and C4. As a result, was not in a wheelchair, but lost the use of one of his arms and significant hearing loss. When I, as someone who does disability policy have talked to him about this people first language, you know that part's the easy part; the disabled part is the hard part. And as I said in my opening, as we've shifted from using the word 'handicapped' to 'disabled,' from his point of view, he prefers 'handicapped,' because there's nothing that he can't do, it's just harder for him to do it. He just has to figure out a creative way to do it, whether it's using a button hook on his top button, because he wants to button that top button when he's putting on a tie himself. He doesn't want to ask me every morning, 'help me honey'... So, I just think that we have to be aware that even within this language issue that it may be that the word 'disabled' is not something that is preferred, even if from the perspective of a person with a disability. Again, and I resonate with Quinn saying, you know that there are differences, and we have differences across multiple domains, and I appreciated the comment.

Clearly, the preferences of an individual with disabilities must always be taken into account when determining what term to use, and as panelist Tawara Goode points out, there is sometimes a tension between what an individual or family prefers and overarching changes in terminology:

As I think about the issue of how do you refer to people with disabilities, I think it is really very important to respect the language that an individual with a disability and/or their family use to describe themselves. Even if you choose not to use that terminology, you have to be respectful of the family's wishes. From a media perspective, you may explain that there may be a disagreement within the broad disability community overall of what is the most appropriate or acceptable term. Then, you should be able to acknowledge the term that the individual and/or family wants to use, and be able to justify in a publication or broadcast, why that term is being used.

The preferences of individuals or families around language could also be culturally bound, as Beth Haller indicates:

One other point about language is that it is also very culturally specific, because I know from having several friends in England doing research with people in the UK that they hate people first language over there. Their preferred term is 'disabled people,' and I forget their explanation about why they hate 'people with disabilities' as a term, but they love the term 'disabled people,' that is why maybe you can explain to us why the difference is there. So, you have to also be very careful, and I think the problem that a lot of people have with the terminology is when people what I call 'nounify' it, when you say 'the disabled,' you're taking all the humanity out of the terminology, whereas 'disabled people' vs. 'people with disabilities,' at least they're still people in the terms, whatever you may think of them.
Katherine Guernsey, Education and Outreach Director of the United States International Council on Disabilities (USICD) offered her insight on the connection of language to larger sociocultural contexts by commenting on how people first language has been handled in the UK:

I really appreciate all of the comments about the need for people to self-identify with whatever speaks to them. And, that there are differences of opinion both within the US disability community and certainly abroad. With respect to the UK, my understanding from colleagues there is that ‘disabled people’ for them is more consistent with the social model of disability. In other words, when one says ‘people with disabilities,’ it implies that disability is somehow an inherent characteristic, whereas it’s different functional abilities that are the inherent characteristics. It is society and society’s barriers that are disabling. So, for them, ‘disabled people’ implies people disabled by societal exclusion and societal barriers.

These comments by conference participants suggest that language choices by individuals, families, or organizations often reflect the way disabilities are framed—whether issues of access and ability rest with the individual or society. Considering the way larger views can be encoded in language, it came as no surprise that in the context of this conference, there was much discussion about disability language that appears in the media. Paula Terry, Director of the National Endowment for the Arts Office of AccessAbility, registered her frustration with how reporters seem to have disregarded guidelines for use of people first language about disabilities:

I work with many artists around the country who have disabilities themselves. The language is very important. We have on our website a language paper (http://www.arts.gov/resources/Accessibility/index.html), that not only artists themselves have spoken about, but older people as well. When I do interviews with the press, I always give them a copy of this paper and invariably, it will not come out correctly. It will be ‘the disabled,’ ‘the wheelchair-bound,’ ‘the elderly.’ And I’ll call the writer and say, ‘What happened?’ And they’ll say, ‘You know, our editors, it’s our editors.’

Judy Woodruff was sympathetic and equally perplexed about the persistence of disempowering language in the media, even in the face of resources that provide guidance about the use of more inclusive terminology:

Yes, to write ‘person with a disability’ or ‘persons with disability’ takes up what, another 1/2 inch, or inch of one line beyond what it would take to write ‘disabled person.’ In television, it takes another half of a second to say that. I know space is tight and heaven knows the media are going through a tough time right now, but these are some things I think we shouldn’t have to give in on.

Beth Haller followed up by providing information about the resources on language and disability that have been readily available to journalists:

The Associated Press Stylebook, which is used by most newspapers as the way they’re supposed to refer to people and it is a 300 page book that has from how you refer to the FBI to disability. Disability activists back in the late 80s worked with The Associated Press Stylebook editors to change the language. So it says not to use the term ‘wheelchair-bound,’ it says use ‘person with a disability.’ It says don’t use the word disability if it’s not part of the story. Again, this goes back to my point about human beings are human beings. They are so entrenched in their own biases that they don’t even

“From a media perspective, you may explain that there may be a disagreement within the broad disability community overall of what is the most appropriate or acceptable term. Then, you should be able to acknowledge the term that the individual and/or family wants to use, and be able to justify in a publication or broadcast, why that term is being used.” — TAWARA GOODE
think to pick up the *Stylebook* to look at how to refer to a person with a disability, which is what they’re supposed to be doing if they’re a reporter. So, there are those resources, and they’ve been approved by the disability community and they’re a great default for the media to just use the language there.

Journalists and other media representatives are certainly in the position to influence the way laypersons think about disabilities though the amount of coverage, the tone of this coverage, and the language used to describe people with disabilities. Yet, by purposefully selecting people-centered language, we all have the capacity to make inclusive terminology more salient.

Transforming Beliefs about Disabilities through Formal and Informal Education

Augmenting what Dr. Yip presented about the Disability Studies courses she has developed, several participants discussed university-based course offerings (or the lack thereof). Disability Studies is an interdisciplinary field that is focused on the contributions, experiences, history, and culture of people with disabilities. Although, as Dr. Yip pointed out, Disability Studies is a relatively new discipline, courses and concentrations of study are increasingly being offered in this area. In fall of 2010, a Masters of Professional Studies in Disabilities Studies Program will begin enrolling students at Georgetown University’s School of Continuing Studies.

In addition to formal coursework, conference participants discussed the ways views about disabilities were transformed through familial relationships and long-term friendships with people with disabilities.

Jody Wildly, Program Director for Diversity Management at the Department of Health and Human Services and panelist, wondered the following about university-based training about people with disabilities:

Oftentimes disability isn’t included in the whole scheme of diversity. Do you believe that if it was a requirement in the university arena to add a diversity course but inclusive of people with disabilities that that would open up—particularly in journalism, that would open up people’s minds that people with disabilities are just as efficient and effective and can do as many things as people who are non-disabled?

In response to Ms. Wildly’s question, several participants discussed their experiences with disabilities-focused classes—both as students and instructors. Judy Woodruff suggested that disabilities in different educational settings could result in raising consciousness on a larger, societal level:

*I don’t know what’s involved and what it takes to expand the kind of educational offerings that are available, but we need to begin to think as a society regularly and typically about individuals with disabilities. There are several different ways I’ve heard it expressed, but individuals with disabilities have been described as the next great civil rights frontier. I don’t know if that’s necessarily the case, but I do think that there’s no question that people with disabilities have needs that are not being met, they are not thought of, either in a jobs picture, education, the many, many issues of accommodation, it just isn’t there. Except perhaps when they’re celebrating the anniversary of the Americans with Disabilities Act, the ADA, and congress is debating a few amendments here or there—you’ll get a little bit of media attention. Otherwise, it isn’t done. I know there are some of you here that do work in higher education obviously, and you can address the feasibility of adding that to the curriculum. I think, absolutely, what would be wrong with adding*
a few classes per semester on, what are the laws when it comes to disability, what do we owe these individuals, and how potentially could those laws and should those laws be changed.

An instructor and graduate student from the University of Maryland shared the following about her teaching experiences having an effect on a broader demographic of undergraduate students:

I’m currently teaching an American Studies introductory course where we talk about popular culture and identity construction. So, I have added in Disability Studies readings and those types of things to my coursework for my students, as well as having experienced that in other courses—in women’s studies, in American studies, across the campus. I’m not sure how much everybody is aware here, that there are Disability Studies programs that are now growing across the country. Temple University has a really amazing program that is just growing by leaps and bounds, as does the University of Illinois in Chicago. There are a lot of professors taking up Disability Studies in their own work. These classes are popping up as well as the programs, and it’s really a growing community, so everybody is aware of that...In terms of who is taking these classes—A number of the students that I have in my own class are American Studies students, or there are a lot of humanities and social sciences students, they’re looking at careers either in Anthropology, or Sociology. Some in political science. I had a number of criminology students in the winter session, who were really taken aback by a lot of the things they read in terms of Disability Studies and were able to develop a new awareness of people and how people want to be treated. And I can only hope that the readings that make them aware of things will have an effect on the way that they deal with other people in their own careers.

With respect to reaching even students beyond those completing Disability Studies concentrations, Sandra Strachan-Vieira, mother of a child with disabilities and co-chair of a local Special Education Advisory Committee, suggested that teachers who serve students with disabilities are often woefully underprepared:

Georgetown doesn’t have a school of education, but many other universities in the area do. Many general education teachers when they complete their programs, Masters programs, included, do so without any background in behavior management skills nor any skills to implement accommodations and modifications for children within general education classes. We did a brief survey and looked at some of the coursework offered, and there really is no coursework offered for these general education teachers. Even some of the special education degrees, if you look back and go over some of their coursework, many times even that falls short. I think recently one of the universities in the area, I believe its George Mason, I believe it’s only in the last years that they instituted courses on behavioral and classroom management. So, going forward, from the university perspective, I think that the educational establishment needs to put more emphasis in that particular arena because of the coursework that they offer to general education and special education teachers to make sure they’re thoroughly prepared going forward.

In order to make changes in higher education curricula, colleges and universities are certainly in need of institutional support. Dawn Rudolph, who works at the Association of University Centers on Disabilities (AUCD), highlighted some of the support available to universities through a national network:

I just want to offer a resource as a follow-up to the conversation about disability courses in higher education. Our agency is a national membership organization for university centers that focus on disabilities, we support a network of university centers on disabilities, University Centers for Excellence in Disabilities, such as the one here at Georgetown. We also support the Leadership in Neurodevelopmental Disabilities (LEND) programs, and also the IDDRCs, which are Intellectual and Developmental Disabilities Research Centers. We also work with CDC health and disability grantees. These university centers are a tremendous resource, not just for intellectual and developmental disabilities, but all disabilities. There is a directory on our website (aucd.org), or you can search for the particular center in a particular state that you are looking for. Or, if you need an expert in a particular arena, this is a great resource as well. I just wanted to point that out.
Panelists certainly highlighted the need for disability-focused content for pre-service practitioners and educational professionals who will work directly with children and adults with disabilities, for professionals who will represent people with disabilities in the media, as well as for a more general audience of undergraduate and graduate students.

Beyond formal educational settings, conference participants also discussed the advantages of cultivating a deep understanding of the issues affecting people with disabilities through personal experiences.

Catherine Polanksy, Director of Professional Development at Georgetown University’s School of Nursing and Health Sciences, noted poignantly that in terms of changing attitudes and beliefs about disabilities, “all of us are in the media.”

We keep coming up and saying, ‘You need to do …’ when there are things we personally need to do. And, I invite you to develop close relationships with people with disabilities. I had the opportunity to work with a number of people on a curriculum that we developed for children where we hired people with disabilities, and I was working closely with them, and I became friends with them, and they became part of my extended family, and they were always at my house. I had my dogs running around when we were having meetings, I had people who were deaf, people who were blind, people who were in wheelchairs. The amazing thing to me as I stand before you today is to tell you that my son, my 26-year old son is dating a woman with cerebral palsy and thinks nothing, absolutely nothing of that. They met on eHarmony, and they are like so matched. And he said to me, ‘Mom, its easy for me, we were always around people with disabilities, I don’t think anything of it.’ And, I think about all the people that I know who have said to me, ‘Aren’t you upset that your son is dating this woman with this severe disability,’ they will say this to me; young people will say this to me. I say to them, ‘I am so honored that my son loves her, she’s wonderful, I love her, this is a fabulous thing.’ And they don’t get that; they think that it’s a burden on everyone that this happened. The depth of that is huge. And so, what can each of us do?

In response to how impactful personal relationships can be in changing views about disabilities, Jody Wildly offered the following insights:

One of the things that I love, and that I think is vitally important is that children, young people, see more positive role models as it pertains to people with disabilities. One of the things that you notice is that when children are exposed to people or youth with disabilities, that disability goes away so quickly. My nieces and nephews, they don’t even recognize that I have a disability now. They’re more interested in using my wheelchair than seeing that their aunt needs it. <laughter> But, my point is, that it doesn’t register to them, and then when they do see someone else that has a disability, it’s not even an issue. It’s us as adults that make it an issue. If we are going to do any advocating, then we need to start advocating at a very young age as it relates to media, and not just the shows or the news that we watch, but even in the youth newspapers that they have at school. That’s a small thing that we can advocate for in their newsletters or their newspapers that they demonstrate more youth with disabilities with those, then they’ll start getting accustomed to people with disabilities, so they don’t have to wait. I know that a lot of people, a lot of times, spend a lot of energy trying to advocate for the students that need things but I think that if we advocate for more exposure at a younger age, then we’ll see a difference as they get older.

“One of the things that you notice is that when children are exposed to people or youth with disabilities, that disability goes away so quickly. My nieces and nephews, they don’t even recognize that I have a disability now”

— JODY WILDLY
The Personal Experiences of People with Disabilities: Transforming Information about Disabilities from Within

Larger framings of people with disabilities from the media and in other realms are certainly problematic. Much symposium time was devoted to discussing how people from within the disabilities community can reframe the messages about themselves by mobilizing their personal experiences, in order to—as Beth Haller noted—maintain control of our own stories. The experiences presented varied from what occurs in K-12 educational settings to university-based and workplace experiences after children with disabilities transition to adulthood, and recurrent themes included the need for change generated from within the disabilities community.

The Need to Transform K-12 Experiences

The mother of a 16-year old adolescent with autism made the following comments about creating teachable moments in K-12 settings through full inclusion of children with disabilities:

I’ve been dealing with public schools for many years. And, it seems to me there’s a divergence, and I would love to see the press cover this more. Laws are made, and put into place to protect people with disabilities and give them accommodations, but then they’re never fully funded. And, this becomes an issue in the schools with people accepting disabilities going back to K-12. We don’t really have full inclusion in a lot of school systems right now. Many years ago the Center for Exceptional Children put out a video from Fairfax County School system, and they were explaining that if you funded and included these students among other students and gave them the supports and services that they needed in the regular classrooms, that not only would students with disabilities benefit, but all students would benefit. The other point I would like to make is that when you have students with disabilities among students who don’t have disabilities, there becomes great opportunity for students to help one another, and they get to know each other. We’re seeing it now, as this generation, and its taken years and years. It’s certainly not perfect, but people with disabilities have something to teach people without disabilities, so.

Judy Woodruff responded by sharing some of her frustrations about the difficulties her son had navigating school settings as a child and adolescent:

I will tell you just from personal experience as Jeffrey was moving through school and—this was when he was younger and had some learning differences connected with the spina bifida that not so much so that he couldn’t be at grade level but he had to work especially hard at certain things that had to do with math, and creative writing, and executive functions and so forth. I found that every single year I had to sit down with his teachers and go over his entire program, that there was no mechanism that passed it along from one grade to the next, it was as if I was starting from scratch every year to say, ‘Ok this is Jeffrey Hunt, here’s his profile, here are his challenges, please keep these things in mind as you teach him this year,’ and then check back in with them. As a full-time, working mom and having two younger siblings—or even if I hadn’t been working outside the home—I found that it was something that you had to constantly advocate for your child and perhaps that’s going to be the case no matter what. But there was not, and I would say, surprisingly
so, there was not an awareness and even an openness in some instances to making any—not even an accommodation, just an awareness, just know that this child has those issues as you work with him or her in the classroom. It wasn’t there—I mean, it was there occasionally, but not nearly often enough, so I think that as you say, it carries a lot of importance.

**Problematic Experiences in University Settings**

If the situation for school age students with disabilities requires a great deal of support from family members and school professionals, conference participants pointed out that in many ways, college age students and adults in the workplace are left with even less protection. **Mike Jernigan, a self-advocate, and Iraqi war veteran who is blind** is currently completing his bachelor’s degree. Mr. Jernigan spoke extensively about his experiences negotiating a college campus that he did not feel was offering adequate accommodations, as well as his frustrations about the way his situation was covered by the media:

Hello, I’m an undergraduate student who can’t see, at a prestigious, local university. On campus, I’m the only blind student, I’m known as the blind guy. A few years ago, I was known as Corporal Michael Jernigan who led Marines in combat operations in Iraq. I’m not getting a fair shake, I’m having to leave the university I’m at because they’re not accessible, and they’re not willing to be. I’m having to transfer to another university, a state school that is not as prestigious...

The media itself can change this. We all know, when Paris Hilton gets a DUI, but we don’t know when some local kid can’t go to the school he wants because that school’s not willing to change. If the media is willing to concentrate on this, different organizations, TV, print, the Internet, you know, it would change. You put a university on the radar as we like to say, you put them on the grid, and start hitting them on national news, changes are going to be made. You put them on the news, they can’t see people with learning differences. You know, I’ll be the first one to tell you I’m not a hero. I did my job in Iraq, I’m not disabled, I just can’t see. I do better than 90% of my classmates in school. We need help, we need advocates. Everyone says that they want to be an advocate, but we need advocates, we need people in the media willing to go to bat for us, willing to put our story out there. We need people that work at these universities, these institutions of higher learning, whether it be state or private, to say something to their presidents of their universities, to their boards of trustees, to where the money is...

My face has been splashed on documentaries, newspaper articles, hell, I got 10 billboards up with my face on it, you know. And its all because I’m a veteran. That’s great, but I’m not a hero. Everyone says I’m a hero, but I’m not, you know. I’m no different than some other 30 year old blind guy who’s trying to get through school, and where’s our help?

In response to Mike’s palpable frustrations, panelists offered suggestions for involving the media and controlling the subsequent message. **Beth Haller** had the following advice:

I completely agree. And one thing I would say is that sometimes, working in a university, I’ve also seen how universities are not stepping up like they should—but they do need to step up. I think sometimes just the threat of media coverage, if you can just get a journalist to call and ask about doing a story, half the time, the story doesn’t even have to be done, but things start changing. Just because, I’ve had that experience several times with advising people to just find a journalist that you know to call and start looking into the story. Whether they get it done doesn’t matter as much as somebody—some people will fix the problems if they think they’re going to be in the media. But, what’s concerning me now with the economic downturn—I’ve seen this just in the last couple of weeks—some universities are first cutting their disabled student services and other things that benefit people with disabilities on their campuses. So, you know, things that are already bad are getting worse. This is very unacceptable. This would be another great story the media should be covering. In the economic downturn, they have been doing some stories about the economic downturn’s impact on disability services, but I’ve not seen anything about what’s gone on at college campuses. And we see these positive stories about, yes, there’s this program for returning vets to go to school, but do they follow up and find out what’s going on with the potential problems with those programs. So, you keep hammering away is what I’d say.
Nolana Yip also spoke to experiences within a university setting, as well as how to address issues within universities locally: 

Certainly not in defense of any institution, but in the 1980s that term sort of ‘reasonable accommodations’ was popularized, and that can be a problematic term. What’s reasonable? And I think it’s unfortunate that a lot of institutions can hide behind the idea of something being reasonable…The other thing is, I think in terms of local journalists, there’s nothing more local than the school newspaper, which might be a good place to start. I think that university papers could use more disability coverage.

Similarly, Leon Dash offered some history of how accommodations have historically been offered at universities, and discussed the need for advocacy on how media issues are covered from within the disabilities community:

When the program for students with disabilities started at the University of Illinois it wasn’t that universally welcomed, and there were a number of efforts to undermine it, and even destroy it by people on the faculty and people within the administration. And their question was, what does a person with a disability want? They didn’t put it in these terms, remember this was 1948. But, what does a person with a disability want with an education? What are they going to do with it? And that question has since been answered. I’ve seen students with disabilities at the University of Illinois have to leave the university. A student of mine, who is a student in a wheelchair with a disability is also a marathon athlete, was writing a story about a student who is blind having to leave the university and go to another school because the language department — she was a Spanish major — was unwilling to invest in the software that would run her computer, and get her access to the Spanish language website at the university. So, the student was covering this, and he was hoping to publish it, and he did publish it in the student newspaper. And he came to me and he said, ‘what do I do in these circumstances? There is one person who is holding this up and causing the student to transfer, and he’s granted me an interview.’ And I said, ‘well, hold his feet to the fire. And make it very evident to him that this is a selfish and inconsiderate decision, particularly when he had the budget capability.’ And the student did that…

Media institutions are not different from any other institution, and they respond to pressure and confrontation. That may be the painful process of learning. Generally, I think everyone in this room wants an expansion of the coverage of issues of disabilities. This has to be an organized, ongoing effort, and it has to be constant.

Jody Wildly presented other ways she would like to see people with disabilities re-framing media images about themselves in ways that shatter common misconceptions about disabilities:

This is my media challenge: I would love to see the media follow several different people with disabilities throughout their days. You know, there are all of these reality shows, let’s talk about this reality. It is when you focus on, the super hero perspective, that these people are extraordinary. First of all, most people with disabilities don’t feel that they’re extraordinary, they’re just trying to get through the day. Second of all, is that when you do focus on people who are extraordinary, you give a false impression that this is easy, and it is not easy, but if in my media challenge, people would follow people with different disabilities throughout their day, they would recognize that we make it look easy, but it is definitely not easy. And, I do that with the people that I work with on the faculty, and oftentimes, if we just walk to a coffee shop, you have to ask, ‘Is there a curb cut?’ We get up on one, then, ‘Is there a curb cut at the end of the walkway?’ Well, someone would think that, ‘Well, you know, duh!’ Does it make sense that if you have one to come up, you have one to come down? That is not always the case. And people are horrified, people who don’t even think about disability are horrified when they just spend, not a day with me, if they just spend an hour with me, just trying to go from my building to Starbucks. It’s just one example. They have a Starbucks next to the metro station, but for a person in a wheelchair, you have to go down one block to come up a ramp to get to the Starbucks. So again, my media challenge is to spend a day with various disabilities, and I’m certain that there would be a lot of stories to come out of that.

Beth Haller offered some parting advice about ways to keep media representatives on message about people with disabilities, and shared a vignette that demonstrates how this can be done:
I have a handout here for some people, maybe with disability organizations, or with activist groups that I put together a few years ago. Basically, what I go through in the handout is some issues that you need to think about when you’re approaching the media, how to get them interested in your story, decisions you need to make when the media do call you for a story, because it may be that sometimes you don’t want to be affiliated with a specific topic. There’s a lot of thought that needs to go into when you are being interviewed by the media, and kind of how you need to stay on message.

I have a former student from a number of years ago whose fiancée became severely disabled after falling off a roof, and he became a quadriplegic. She lived in the Philadelphia area, and the Philadelphia Inquirer got wind of she and her fiancée, and because of Medicare/Medicaid insurance reasons, they could never get married, because he would lose some of his benefits if they got married, but she stood by him, and they had a commitment ceremony. She was so upset that he never got to live at home ever again, he had to live in this nursing home as a 38 year old man. She sent me this story that had been done about the two of them. It was obvious from the story that the reporter wanted to do a story about ‘angel fiancée sticks with guy whose quadriplegic.’ That was what was in his mind when he came to do the interview, and she was a journalism student in college and she knew that wasn’t the story she wanted to tell. And so, no matter what question he’d ask her about, she answered with, ‘What’s wrong with our society when a 38 year old has to live in a nursing home and can’t live with on his own with proper supports?’ It was just so funny to read the story, because he still tried to go for the angel fiancée angle, but so many of the quotes that she had said were all about this issue of, there needs to be more in-home care, and proper supports, and personal assistants, and things like that.

So, it’s really tough sometimes to stay on message when you are being interviewed, but that’s one thing, when I do discussions with groups about how to work with the media. And also, you have to make the decision, you may not want to be in that story, you may get the sense that they’re going on this angle that you don’t want to be a part of, so you may just say no. But, staying on message, because, if you don’t say it, its not going to be changed in the story, so if you just stick with what you want to say over and over, that’s the best thing you can do.
Throughout the symposium, ways of re-framing sociocultural images of disabilities that are reflected in and disseminated through the media and other sources were presented and debated. The need for institutional and global transformation in the way people with disabilities are treated and represented was highlighted most poignantly through the personal and familial experiences of people within the disabilities community. Several practical strategies for these necessary transformations from within were presented by symposium participants in the rich and engaging conversations that took place between panelists and audience members, and most of us left the symposium with new ways of thinking about the experiences, history, and culture of people with disabilities, how these elements have been portrayed, and how each of us as stakeholders can influence small and large scale portrayals of people with disabilities.

“Media institutions are not different from any other institution, and they respond to pressure and confrontation. That may be the painful process of learning. Generally I think everyone in this room wants an expansion of the coverage of issues of disabilities. This has to be an organized, ongoing effort, and it has to be constant.”

— LEON DASH
Resources

Disability Studies


Georgetown University Offers Disability Studies Program

Georgetown University, School of Continuing Education in collaboration with the Center for Child and Human Development offers a Masters degree and Advanced Certificate Program in Disability Studies. The program which has three tracks (*Developmental Disabilities, Early Intervention, and Mental Health System of Care for Children and Youth*) begins in September, 2010.

The Disability Studies program offers you the resources and knowledge you need to build a career collaborating with individuals with disabilities and special health care needs and their families helping them meet their goals and become active participants in the community. The program will prepare you to be a leader advocating for individuals with disability, providing community based services, developing policy, and participating in scholarship in the area of disability.

These three tracks build on the strengths of the existing work being done at GUCCHD and the Georgetown University community at-large. The GUCCHD was established over four decades ago to improve the quality of life for all individuals with disabilities and special health care needs and their families. The Center is founded on an interdisciplinary approach to service, training, research, community outreach, technical assistance, and public policy. The Center brings to bear its unique capacity on critical social issues most notably disability, poverty, homelessness, and social injustice by influencing local, national, and international programs and policy.

Unique to the Disability Studies program will be an on-line and classroom based program of study. All students will be required to meet as cohort groups at Georgetown University for specified amounts of time during each course. Ongoing instruction, however, will be delivered through an on-line platform. This model offers greater flexibility building a vibrant, diverse community of learners.

The Center for Child and Human Development is excited to be collaborating with the School of Continuing Studies, providing a rich program of study.

For more information on the Disability Studies Program please go to http://www12.georgetown.edu/scs/departments/32/master-of-professional-studies-in-disability-studies

**Toby Long, PhD, PT, FAPTA**
Associate Dean, Disability Studies, School of Continuing Studies
Associate Professor, Department of Pediatrics
Center for Child and Human Development
Georgetown University
3300 Whitehaven Street, NW, Suite 3300
Washington, DC 20007
Who Are People with Disabilities?

People with disabilities are -- first and foremost, people -- people who have individual abilities, interests and needs. For the most part, they are ordinary individuals seeking to live ordinary lives. People with disabilities are moms, dads, sons, daughters, sisters, brothers, friends, neighbors, coworkers, students and teachers. About 54 million Americans -- one out of every five individuals -- have a disability. Their contributions enrich our communities and society as they live, and share their lives.

Changing Images Presented

Historically, people with disabilities have been regarded as individuals to be pitied, feared or ignored. They have been portrayed as helpless victims, repulsive adversaries, heroic individuals overcoming tragedy, and charity cases who must depend on others for their well being and care. Media coverage frequently focused on heartwarming features and inspirational stories that reinforced stereotypes, patronized and underestimated individuals' capabilities. Much has changed lately. New laws, disability activism and expanded coverage of disability issues have altered public awareness and knowledge, eliminating the worst stereotypes and misrepresentations. Still, old attitudes, experiences and stereotypes die hard. People with disabilities continue to seek accurate portrayals that present a respectful, positive view of individuals as active participants of society, in regular social, work and home environments. Additionally, people with disabilities are focusing attention on tough issues that affect quality of life, such as accessible transportation, housing, affordable health care, employment opportunities and discrimination.

Eliminating Stereotypes -- Words Matter!

Every individual regardless of sex, age, race or ability deserves to be treated with dignity and respect. As part of the effort to end discrimination and segregation -- in employment, education and our communities at large -- it's important to eliminate prejudicial language. Like other minorities, the disability community has developed preferred terminology -- People First Language. More than a fad or political correctness, People First Language is an objective way of acknowledging, communicating and reporting on disabilities. It eliminates generalizations, assumptions and stereotypes by focusing on the person rather than the disability. As the term implies, People First Language refers to the individual first and the disability second. It's the difference in saying the autistic and a child with autism. (See the other side.) While some people may not use preferred terminology, it's important you don't repeat negative terms that stereotype, devalue or discriminate, just as you would avoid racial slurs and say women instead of gals.

Equally important, ask yourself if the disability is even relevant and needs to be mentioned when referring to individuals, in the same way racial identification is being eliminated from news stories when it is not significant.

What Should You Say?

Be sensitive when choosing the words you use. Here are a few guidelines on appropriate language.

- Recognize that people with disabilities are ordinary people with common goals for a home, a job and a family. Talk about people in ordinary terms.
- Never equate a person with a disability -- such as referring to someone as retarded, an epileptic or quadriplegic. These labels are simply medical diagnosis. Use People First Language to tell what a person HAS, not what a person IS.
- Emphasize abilities not limitations. For example, say a man walks with crutches, not he is crippled.
- Avoid negative words that imply tragedy, such as afflicted with, suffers, victim, prisoner and unfortunate.
- Recognize that a disability is not a challenge to be overcome, and don't say people succeed in spite of a disability. Ordinary things and accomplishments do not become extraordinary just because they are done by a person with a disability. What is extraordinary are the lengths people with disabilities have to go through and the barriers they have to overcome to do the most ordinary things.
- Use handicap to refer to a barrier created by people or the environment. Use disability to indicate a functional limitation that interferes with a person's mental, physical or sensory abilities, such as walking, talking, hearing and learning. For example, people with disabilities who use wheelchairs are handicapped by stairs.
- Do not refer to a person as bound to or confined to a wheelchair. Wheelchairs are liberating to people with disabilities because they provide mobility.
- Do not use special to mean segregated, such as separate schools or buses for people with disabilities, or to suggest a disability itself makes someone special.
- Avoid cute euphemisms such as physically challenged, inconvenienced and differently abled.
- Promote understanding, respect, dignity and positive outlooks.
Legislation Passed or Pending
Addressing Language Use

**Alabama:** pending respectful language bill (HB246) in 2007 legislative session

**Alaska:** state law (HB357) effective May 12, 2006 revising existing state statute to remove outdated terms and replace with respectful language

**Arkansas:** passed People First Language bill in 2007 legislative session

**Connecticut:** passed respectful language bill (SB63) requiring the use of respectful language in Connecticut General Statutes when referring to persons with disabilities, October 1, 2007

**Indiana:** pending bill (SB94) Governor Mitch Daniels signed Senate Bill 94 into law May 2

**Louisiana:** policy in Department of Hospitals and Health to use respectful language; seeking an executive order to expand this to other departments

**Massachusetts:** legislators considering House Bill 1876 to change the name of the Department of Mental Retardation to the Department of Developmental Services

**Minnesota:** people first language law effective August 1, 2005

**Mississippi:** state law effective July 1, 2005 directing state agencies and drafting offices to prepare legislation and rules using respectful language

**Missouri:** legislators considered a bill to remove "mental retardation" from the state DD agency's name but didn't pass it

**New York:** Governor Spitzer signed the Person First Bill in August 2007 to institute people first language for new and revised state laws, documents, etc.

**New Hampshire:** Governor John Lynch signed Senate Bill 153 into law to establish a commission to study changing statutory references to "mental retardation"

**Oregon:** state law effective January 1, 2006

**Pennsylvania:** Executive Order signed July 22, 1992

**South Dakota:** lawmakers considered a bill early in 2007 to establish the use of People First language in state laws but didn't pass it

**Vermont:** the DD Act of 1996 required a state department name change from Division of Developmental Services to Division of Disability Aging Services

**Washington:** state law effective June 10, 2004

**Washington, DC:** passed 2 bills in 2006, the 1st to make sure past language changes and the 2nd to make sure present and future language will be People First Language

**Utah:** joint resolution made during 2006 General Session urging state agencies to update references to archaic language (mental retardation)

FROM: PEOPLE FIRST LANGUAGE BY SELF ADVOCATES BECOMING EMPOWERED (SABE)
Websites

Disability and Society
American Association of People with Disabilities: http://www.aapd-dc.org
Center for Human Policy, Law, and Disability Studies, Syracuse University: http://thechp.syr.edu
Center for Universal Design. What is universal design? http://www.design.ncsu.edu/cud/univ_design/ud.htm
Definitions of Disability: http://www.accessiblesociety.org/topics/demopgraphics-identity/dkaplanpaper.htm
Disability History museum: http://www.disabilitymuseum.org
Disability Rights Promotion International: http://www.yorku.ca.drpi
Disabled Word, magazine for people with disabilities form Canada: http://www.disablled-world.com
Disability Social History Project: http://www.disabilityhistory.org
International Center for Disability Resources on the Internet (ICDRI): http://www.icdri.org
Mind Freedom International: http://www.mindfreedom.org
Mobility International: http://www.miuusa.org
Models of Disability: http://www.copower.org/leader/models.htm
National Arts and Disability Center: http://nadc.ucla.edu
National Institute on Disability and Rehabilitation Research (NIDRR): http://www.ed.gov/about/offices/list/osers/nidrr/index.html
National Organization on Disability: http://www.nod.org
Research and Training Center on Independent Living: http://www.rtcil.org
Society for Disability Studies: http://www.disstudies.org
World Institute on Disability: http://www.wid.org

Media and Disability
BBC Ouch! http://bbc.co.uk/ouch
Center for Accessible Society: www.accessibliesociety.org
Database of films with disability content: http://www.disabilityfilms.co.uk
Disability blogroll: http://disstud.blogspot.com
Disability Nation online community: http://www.disabilitynation.net
Disaboom social networking site: http://www.disaboom.com
DREDF Media and Disability Initiative: http://www.dredf.org/Media_and_Disability/index.shtml
e-bility disability news from Australia: http://www.e-bility.com
Inclusion Daily Express, a disability news wire: http://inclusiondaily.com
National Center on Disability and Journalism Style Guide: http://ncdj.org/styleguide.php
New Mobility magazine: http://www.newmobility.com
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