HAROLD HOLZER: Good evening. Welcome. I'm Harold Holzer and I have the honor of serving as the Jonathan Fanton Director of Roosevelt House. I know when the lights go up that's not a signal that the film is going to begin but that's how we do it here. Thank you for coming out in this frigid weather which happens to be happening in the first week of November. Those here for the first time I think I owe you a little bit of background about where we are. I think probably most of you know but this is the home that Franklin Delano Roosevelt's mother built for Franklin and Eleanor as a wedding present in 1908. So they moved here as newly weds and the house came with something of a condition. That is that elder Mrs. Roosevelt Sarah was to live on the other side of the house. It was one entrance from the street. I don't know if you noticed two entrances once you get into the vestibule. As soon as she came in, she declared that the dining rooms, which is where we had our sandwiches before this program, were a little too small for people of their exalted station so she immediately broke through the walls and as Eleanor later said her mother-in-law was in her side of the house at the most unexpected moments for the next 30 years. We call it the first New Deal. This was FDR's New York City headquarters. It was here he returned after winning the Governorship of New York in 1928. It was here he returned to after
winning the Presidency and it was here that he managed the transition from Election Day 1932 to inauguration day 1933. Then four months, not seven weeks. So we call it in our darker hours the Trump tower of 1932. Because this is where he conceived of the social safety net that became the foundations of the new deal. Social Security was conceived a few floors up in his private library, minimum wage, child labor laws and the first outlines of the recovery program that saved the United States.

Brief post war history, then I'll revert back. Post Presidential history. Sarah Roosevelt died in 1941 after which Franklin could not bear the thought of returning to this house and he put it up for sale. For $70,000. The house next door went a few years ago for 22 million dollars.

Eleanor, who had never quite felt completely at home here had been spending more and more time, and the Hunter library, meeting Hunter students, becoming a favorite there, bringing some home for grilled cheese sandwiches when she could. At the urging of the President of Hunter college she told her husband that this building should really go to Hunter. But it was too expensive so they reduced the price to $60,000. FDR kicked in the extra ten and hunter acquired it. It became a club house for the first Hunter clubs, and also a center for women of all nations and races and religions. People learned to speak English here as they arrived from Europe, and remember their first experiences of meeting girls from other backgrounds here.

Just to step back a little bit in time, what I think is so meaningful and inspiring today is the knowledge that after FDR came down with polio in 1921 in Canada, his mother wanted him to go back to Hyde park and sort
of rest there in perpetual illness. Eleanor said he should come here. It had an elevator which was unusual and not the one we all use but the little one you could look at on your way out. It gave him a sense of possibility. They designed a wheelchair that could fit into the elevator. And it was the same style of armless wheelchair that he used for the rest of his life. So it was from this place that he developed a sense of a future. So we're all very moved by that, and by the fact that it's sort of a continuum that that story represents we're here today for the screening of Hale.

I just want to acknowledge a few people who have made this possible. Wheeling Forward, Alex Elegudin. I hope I'm saying that right. For sponsoring CART which is so important for our access tonight. Lauren Schechter from TotalCaption for providing the realtime captioning, which I hope does not include me. Anyway, it will be the film. Isaac Smith, the producer of Hale and the Berkeley film foundation. The undergraduate student government which so generously provided support for the reception we had this evening. Brad Bailey, of course, who you'll hear from later who made this film, and made this connection, and was generous enough to have this important New York screening here at Roosevelt House. Special shout out to -- we have a few students in the audience today I'm happy to say so I can't pick favorites. But with a certain wink I will say that one of my favorite students is here. Edward Friedman. Class of '18. Macaulay Honors student who is not only a student but an advocate, and an activist committed to improving access for people with disabilities. And he's already had a slew of extraordinary internships, human rights watch, City Council, Mayor's Office for People with Disabilities, he's a member of the
college Senate, the junior board of INCLUDEnyc. I'm not surprised he plans to pursue a JD and an MPP later. I'm not surprised if he takes four or five post graduate degrees. He can do just about anything. Ed, thank you for all you did.

(Applause).

You'll see the fruits of his work afterwards. Now we can actually lower the lights and see Hale. Thank you.

(Screening of Hale)

(Applause).

BRAD BAILEY: Thank you for coming. My name is Brad Bailey. I'm the Director of Hale.

(Applause).

Before we get started with an excellent array of panelists I want to thank you for coming out tonight. I know it's cold and it's Friday night and people are busy but I think getting this important story out there is a crucial, crucial thing. I first met Hale when I was at the UC Berkeley journalism school and even before I knew who he was I knew he was extraordinary. It was a hot day. He was trying to communicate to us that he was thirsty. As you can see that took a second. So we finally gave him a drink of water and he zoomed away. I couldn't get him out of my head. I knew there was something about him. A few months pass by. When I found out who he was I was blown away because he was really living history, the embodiment of living history. Everything you see today from ramps to curb cuts to everything was started by this particular group of people in
Berkeley, California in the 1970s. He is still alive, still advocating for people with disabilities all around the world. I want to also thank the people here at Roosevelt House, Mr. Harold Holzer who did an extraordinary job in keeping this together. Also Rafael Munoz whose work here was extraordinary. In addition to a very special man named Edward Friedman. Can you please stand up and join us for a round of applause.

(Applause).

Edward is somebody who is very special. And his hard work, his dedication, not only his life and work here at Hunter but also helping this happen tonight is something I will never forget and Hale will never forget. I think it's extraordinary. He's an extraordinary man. I'm also looking very forward to his very bright future. Without further ado we're going to get started this evening with an excellent group of panelists. First I wanted to introduce Alex Elegudin. Please come up. Alex has spent almost a decade working as an advocate and mentor in the disability community. In 2003 when he was a college sophomore he was in a deer-related car accident and sustained a C6 level spinal cord injury. He faced an uphill battle to reclaim his independence through working at Hofstra University law school and became a successful patent attorney. He cofounded Wheeling Forward in 2011 to help others like himself to get the support and resources they need to lead active lives. Today he is the accessibility program manager at the New York City Taxi and Limousine Commission where he works on several accessibility initiatives including getting the yellow taxi fleet to 50 percent by 2020 and citywide accessible dispatch and FHV sector accessibility policies among others.
(Applause).

Excuse me, I tend to sweat a lot. I apologize for that.

Gennarose Pope. She worked at INCLUDEnyc for over three years bringing commitment to equity, access and inclusion of young people with disabilities to the organization. She is proud to have led the launch of INCLUDEnyc's Spanish language website, and is passionate about reaching the Spanish speaking disability community and depression and PTSD to New York's diverse community. Thank you for coming tonight.

(Applause).

Mr. Paras Shah. Can you please come up? Second year student at Harvard law school where he serves as the articles editor of the Harvard human rights journal. Legally blind since birth he understands and appreciates the importance of including people with disabilities in all aspects of society. Prior to law school he was the John gardner fellow to human rights watch where he advocated for the rights of refugees with disabilities. He received a BA in history in political science from U. C. Berkeley.

Last but very much not least, we have Katherine Bouton, editor of New York Times for 22 years and was deputy editor. She's the author of "Shouting Won’t Help", a memoir of adult onset hearing loss and living better with hearing loss. She writes the popular blog, and she has progressive bilateral hearing loss since 1978. In September 2009 she received a cochlear implant. She's the President of the New York City chapter of the Hearing Loss Association of America and a member of the Hearing Loss Association of America national board of trustees. Thank
Thank you guys for coming this evening. I wanted to let you know if you have any questions, especially about the film, because I would love to get your input and thoughts about the film making process, we're going to have all those questions at the end in addition to any other issues you think would be great to show up.

We'll get started. First, I want to talk to you -- I guess we'll start with the film. I want to sort of see what -- after watching the film, how far do you think society has come since the beginning of the modern disability rights movement? And what are some of the biggest current challenges to mainstreaming disability that you face in your life and work? Anyone.

ALEX ELEGUDIN: I'm the one all the way to the right. I've been disabled for about 15 years. And I still consider myself learning the ropes of being disabled and watching how society goes. I'd say -- I've had quite a journey working in the private sector and the public sector, nonprofits, advocating many times working on my own not just for disability rights but as an attorney for the world in general. I've seen all different parts of the world, and how they receive me. I think from going to school, from getting my education, I think that's come incredibly far. I was treated in college with all kinds of accommodations and help. When I got to law school it was a little weird. Because when you're an undergrad they have lots of accommodations, disability services office. The Dean called me on the first day of law school and said what help do you need? I don't know. Don't you have a services office? No, I'm it. Just tell me. You're the first student
who was a quadriplegic here for the last 12 years. You have to do a lot of advocating, and kind of even at that level. They did everything they had to do, everything I asked for. That part was great because they understand. When I got to the private sector, it's a little trickier because I had a desk, I worked for a judge in a courtroom. The desk -- I couldn't get under the desk with the height of my wheelchair. So while I was a fellow for a year and a half I worked sideways typing. It was a super kind of antiquish -- courts can be very nice looking. The new modern desks don't really fit in their style. I always felt uncomfortable asking but everybody understood I was working like this for a year. I got my work done, I had a great relationship with the judge. At that time I was a little bit more scared to bring something like that up. I didn't want to be the guy yelling in the office for accommodations and things. But nonetheless, I got through. When you get to a firm and you're working at a firm they're much more scared of these kinds of things. They got me desks and fancy computers and all kinds of things. In and of itself it brings progress. I work now where I'm an accessibility manager. There was a time those positions didn't exist, where the government didn't believe you needed people to work in positions that should help with accessibility. There was a guy working on IT that was assigned the accessibility role. Whoever was dealing with operations had accessibility on her platform. I think the world is changing in this way where people are being brought on to specialize in this. One from an operations standpoint, two from being the face of people with disabilities needing services. In that way I do give at least the New York City government and governments across the country credit for at least being
open to the fact that this needs to be worked on. We need to bring people in who specialize in this and do this and think about this all day, not just as some line on a task list for somebody else who has no interest in this. Do we still have a long way to go? Sure. There could be more people with disabilities working in government IT. Not everyone with a disability has to work on disability issues. I think that is still very much lacking. General integration of folks into the work force, into other areas. We've come some ways. And I've seen them all up and down but I think we've got some ways to go.

GENNAROSE POPE: Yes to all that. Clearly since the movement began, things have changed significantly. Specifically in that timeframe I think. Granted it takes a very long time to turn the tide of hundreds of years of discrimination and abuse, and lack of acknowledgement. Again, yes, I agree we have a long way to go.

Of course the seemingly fixable issue are things that people can put money into, which they generally don't put enough into to be honest. To fix things that are physical. Cut all the curbs, make those accessible. These are tangible things that we with can work on. I think personally having an invisible disability so to speak, there are deeper things. You can make a building accessible, an event accessible. You can get the ramps and the elevators and all the things you need. But do you necessarily want to go into that room if the room is full of people who don't acknowledge you as a human being? Don't acknowledge the things that you -- you can put a ramp into a room but do you want to go in there if people are hostile or don't understand your humanity? I think that's actually the hardest
challenges that we face. It's the aspects that are not necessarily tangible but they are the ones that need to change the most to continue to enable these physical fixes, and nothing is going to really progress beyond that if we don't attack that part.

PARAS SHAH: Thank you very much for having me here tonight. It's a real honor to be here with you. There are one billion people with disabilities around the world. People with disabilities are the world's largest minority which means that one in seven of us has some form of disability. The remarkable thing about disability is that it does not discriminate no matter the race, age, religion, creed. You can have a disability, acquire a disability any time. I think that's one of the reasons why disability has become a very salient issue in a lot of parts of society because it touches so many different aspects of our lives. Employment, transportation, education, and I think that looking back Judy Heumann, Ed Roberts, Hale, could not imagine what they have created so far with the ADA. I'm 24 years old, which means I have been alive the entire time ADA has been law. When I was born legally blind one of the things my parents insisted on as tremendous advocates is I could do anything in life. One thing my father always told me which really resonated was Paras, these are your rights. You have to claim your rights. That's a really important thing. When Congress passed the Americans with Disabilities Act, they created a preamble. In the preamble they talked about all the different forms of discrimination that are existing in society. So part of what the ADA did is to validate a lot of what people with disabilities feel. The types of stigma that we feel, the isolation that we experience, and the ADA put into law the
facts. That is true, and Congress also sought to create a remedy for that type of discrimination.

So one aspect where we still need to do a lot of work is on the international front. One of the remark things about the Americans with Disabilities Act is that it's actually inspired an entire regime of international law to address disability. In 2006 the UN passed a UN convention on the rights of persons with disabilities, and to date 170 countries have ratified it. The impact of Hale really goes across the entire globe.

KATHERINE BOUTON: Could you hear me? I'm not sure if this microphone is on. I'm very pleased to be here, first of all to see the wonderful movie. It's really powerful. But I feel that the movie, and Professor Holzer's introduction, both said something really important about my disability, which is hearing loss. Professor Holzer said that he hoped his introduction wasn't being recorded on the CART screen. If it wasn't recorded on the CART screen I wouldn't have known what you were saying nor would some of my colleagues here who have hearing loss. And in the film, there were so many incidents where I as a person with hearing loss would have been completely lost. In the BART station, with all those oral announcements going on. I only knew they were going on because Lauren told me so in the CART captions.

In the meeting of people with disabilities, I didn't see anybody providing any hearing assistance. There was one other very really remarkable absence of an acknowledgement that people with hearing loss, even with as I have a cochlear implant, the highest possible form of technology, and a really fancy incredibly expensive hearing aid, and I still
can't hear from sitting in the third row here somebody here. I can't hear announcements in the subway. I cannot go to a hearing at City Hall because City Hall does not have hearing access of a kind that benefits me and other people with the hearing loss I have. We're working on that. The disabilities Commissioner Victor Calise is very aware of hearing loss as a disability. But I think many, many, many people aren't. And it is -- it affects an enormous number of people. 48 million Americans have some form of hearing loss. Internationally, I believe the number is 250 million people worldwide have according to the world health association disabling hearing loss. They are not able to live their lives with their hearing loss, and they have for the most part no correction. I consider myself lucky. I can ask for CART and very often Lauren is available. On the other hand, this week for instance I spent a lot of time in the veterinary hospital because I had a pet who was sick and my dog had something contagious. Everybody was wearing masks. This happens in human hospitals too. I couldn't understand what people were saying to me. Finally one pulled down his mask and he was a sikh, and he had a big moustache and huge beard. I couldn't read his lips. Toni Iacolucci sitting here in the audience, and one of her colleagues is working on a way to provide access to medical care. My experience this week is so minor compared to somebody like me, or like Toni, going into an emergency room, having nobody realize that you can't hear. Especially if you're not conscious. Toni has an amazing story of having -- waking up from surgery and somebody was shaking her, and the only way she knew they were talking to her was because they shook her. They forgot she couldn't hear anything. It's really a tricky disability. I
don't look disabled. I don't talk disabled. I didn't really lose my hearing until about 20 years ago. But I have a really hard time in daily life.

BRAD BAILEY: That again is one of the reasons we wanted to do the film, to show again that there's a range of challenges that people face every single day. And it goes to almost my next question. What do you think the role is of stigmas and misconceptions, I guess the term is ablism, able bodied privilege with regard to people with disabilities and how do you work to mitigate or deal with these issues in your daily lives? I'm throwing it out there. I also want you guys to interact. If you see a question or want to pop in, pop in. You don't have to wait for me. Just go at it.

ALEX ELEGUDIN: Sure. Is there a time limit on our responses?
(Laughter).

BRAD BAILEY: We have a few more minutes. I'll rein you back in.

ALEX ELEGUDIN: I can talk for a long time on a topic like this. Before I touch on stigmas, one thing I personally enjoyed about the movie, I can relate, with the opening scene all the help he needs. As a quadriplegic that really hits home for me. When I get to work and go about my business, in meetings all day, nobody thinks in the morning I have to go through something very similar to what Hale has to go through. In terms of the help, and the assistance. You could watch something like that as an able bodied person as a friend, as an employer, as a colleague, whatever, and be like holy cow how in two hours are you going to go out there and start working and producing and being a functional human being. Fortunately due to human technology, motivation, drive, there's a way. And human compassion. It's not that I can't always -- it's not that I don't ever
need help in work or in the work place but that is incredibly true. So many of the folks you see out there in chairs go through something similar, and sometimes even more so every morning and every night. Sometimes several times throughout the day. I want to bring it to light because I think for me it's the hardest part of my day. The morning is the toughest part. Once you throw me in my chair, literally throw me in my chair, I'm all right. I can make it. I can go about my stuff. But that moment before, and if my aide doesn't show up or something else doesn't happen I'll be in the bed for the day. You know what I mean? I had many days in my life. But I always know that tomorrow someone will show up and I can make it through. I don't know if it's a good way to go about it or just means I'm a really bad planner. But those days really give you perspective on how terrible this could be. And also on how fortunate you are to get up the next day.

Specifically on the topic of stigmas and being out in the world, I think in college is where I felt it the most. In every class pretty much. I would be the guy in the wheelchair sitting in the corner. I never took a class in 7 years of school where there was another wheelchair. I went to Brooklyn College, Carnegie Mellon, and other places. I was the only one. Before I spoke, nobody would talk to me. People would be like okay, there's a guy in the wheelchair. Whatever the first day that happened to be that I raised my hand to respond, at the end of class I had a line of ten people standing next to me, one at a time, oh my God, you're so smart! Wow, that was really fantastic what you said today. And I always knew that would happen after the first time I spoke because they don't expect you to articulate.

My most famous, or my favorite social experiment was when you
have group activities and if it was before I spoke, nobody would ever want me in their group. And then if they knew I would speak and articulate, everybody is like be in my group, please. Please. There's a lot of that.

BRAD BAILEY: I want you in my group.

(Laughter).

ALEX ELEGUDIN: Thank you. Would you have said that if I didn't speak? Just kidding.

It's something that for me I'm fortunate. I'm able to communicate, and I know that I do feel lucky, and very blessed to have that. But if I am with a friend, people still talk to the person next to me first. All those kinds of things still go on. I really believe that even people -- I never respond negatively or aggressively or angrily at all, period. I really don't believe anyone is evil towards disability, hates people with disabilities. I think some people aren't aware. At the organization wheeling forward we always say we wish we had a brother in a wheelchair. We mean that in a good way because those people who are around it, who are familiar with it, they get it. I can go into a restaurant, store, any public accommodation and know within two seconds if that person has a relative in a wheelchair. They know exactly how many inches I need to get by, where I need to go. That doesn't make those people better than the other ones. It just means we haven't seen them enough or been around them enough. I don't take it personally. I try to educate that person no matter how much of a transgression their action may or may not be. I try to roll through the world in that way. Obviously sometimes it's not easy. There are really some
nasty folks out there but I believe there are equal opportunity folks and they're nasty to everyone. That being said, that's kind of my take on the stigma question.

BRAD BAILEY: Very good.

KATHERINE BOUTON: You have a visible disability. And I think Gennarose might relate to this too. I think if you have an invisible disability, invisible disabilities include things like psychological disabilities, fear of small places, also includes --

GENNAROSE POPE: Fear of being on panels.

KATHERINE BOUTON: First of all, there's huge stigmas associated with almost all of the invisible disabilities so people don't want to talk about them. Often I don't get the accommodations they need just because they haven't talked about them. One thing we have to do is realize that the person next to you may be behaving really strangely, may be saying I'm sorry I can't help you move that 40 pound desk because I have a bad back. Well, maybe she actually has a really bad back and we should just believe that person instead of dismissing every excuse. Nobody ever believes me when I say I can't hear them. And then when they finally realize I can't hear them, they say oh, never mind, doesn't matter. I think invisible disabilities are something that we really need to keep in mind. They are much, much harder to accommodate, but they need to be.

Just one more. I think there's also a lot of confusion about at least my disability, hearing loss. I can't tell you how many times somebody has offered me an ASL interpreter. Or I have put on an airline reservation that I have a disability hearing loss and they meet me at the plane with a
wheelchair. People just don't understand.

ALEX ELEGUDIN: They never give me a wheelchair.

GENNAROSE POPE: I'll piggyback on that. I guess a really good -- like I said fear of panels. I'm not actually kidding. I'm trying hard to focus.

BRAD BAILEY: You can always look at me.

GENNAROSE POPE: Thank you, you're very calming. When I'm not losing my train of thought freaking out. This is also a safe space environment. And also Edward is amazing and I would do anything for him. Here I am. Also, the nature of my job is more accommodating than your average job though not as accommodating as you would think. There's still the you need to get over this. Just do it. You have to go out and do it, conquer your fear. It's not exactly like that. If I could just conquer my fear I wouldn't be 38 and sweating all over your desk, and unable to deal with public speaking in most instances. That's a very large underestimation of the things I deal with on a daily basis. But another illustration of the role of stigmas, misconception, ablism in my life is this is the first time publicly not in a therapeutic setting that I have really talked about the role of disability plays in my life. When I first started working in my organization three and a half years ago I didn't -- it didn't even occur to me the things that I dealt with were disability so to speak. It was just not the way that I was taught or how I viewed it. Pull yourself up from your boot straps, et cetera. Even though I'd gotten treatment finally at that point which is what I think started to help me come to terms with that. I worked with people with disabilities my whole life in various forms. And had no problem acknowledging that but not my own. Thankful serendipity happened to come about where this job came
into my life at the right time and here I am and I'm able to be here and talk about it. But the reason why it took 38 years to get to this point is because of ablism in a sense, and the stigmas and the misconceptions. Even for people with disabilities themselves, the misconception you have about yourself and how you present to the world, the way you view yourself is super complex.

**BRAD BAILEY:** It's an interesting point. With the film I've had people, especially in the editing process when I was showing them who Hale was, they're like is he a hundred percent there? Are you kidding? He's smarter than both of us. I had to sort of let that person know that just because he may look a certain way, it had nothing to do with his intelligence. Obviously when that same person ended up seeing the film later they apologized to me. You can't judge anyone -- no book can be judged by the cover, whether race, gender, anything.

**GENNAROSE POPE:** Just to jump in with no judgment also, sometimes somebody with a physical disability has an intellectual disability as well. And that's okay.

**PARAS SHAH:** This is a really interesting distinction that's come up between invisible disabilities and visible disabilities. I'd like to collapse that a little bit. In most situations for me I can pass as able bodied and you probably wouldn't be able to tell immediately that I had a visual impairment unless you tried to make eye contact or I had to look at my phone. A lot of time I can pass through the world as an able bodied person. About two years ago I was working in midtown and I was taking the chambers street metrouptown and I was getting very frustrated because it's sometimes very
hard to see the trains or signs and figure out where I'm going in a complex travel situation. I was wearing a suit going home from work and I took my cane out of my gym bag and as soon as I unfolded it, you could tell it was almost perceptible, you can tell the shift in people's attitudes. New Yorkers at 6 p.m. who have a lot of places to be. Usually I'm just some professional 20 something traveling around. And then as soon as I took my cane out, two very kind hearted elderly came up, grabbed me by the arm and directed me to the wrong train. With the best of intentions. But I really didn't need to go downtown. I was trying to go uptown. It's just one sort of example where this happens all the time. I had to very kindly and politely tell them I just needed to be pointed in the right direction. I think there's also a certain degree of destigmatization that we as people with disabilities have to do. There's a level of education that we have to do. I'm very fortunate that I have a lot of great friends who are great allies for me too and really just have it down as far as what I need and how to help. Part of my role is just educating people and telling them this is what I need and this is what I don't need. Another interesting experience was one time I was also guiding a colleague who was fully blind and I found it just as complicated and confusing and I thought wow, what can she see? Do I tell her what direction to go? How do I do this? I understand where people are coming from. As other panelists mentioned I think most people have good intentions and we have to educate people and create a more inclusive environment.

KATHERINE BOUTON: I think you said something really important about Hale. It's true of all visible disabilities. Also once people understand
your invisible disability, about that perception as well. Which is that until you prove that you can do it, everybody thinks your one handicap is resulted in your entire mental and bodily handicap. I think it's circular. It's really hard. People who have stigmas prefer not to talk about them if they don't have to because -- not stigmas, people who have disabilities prefer not to talk about them because they know they'll be perceived as something they aren't. In my case hearing loss is associated with being old, it's associated with dementia, cognitive impairment. You don't want people to think you're old or cognitively impaired before they have a chance to get to know you. That's why it's important to have events like this. For everybody to talk out. I think this whole audience is perfectly aware that people with disabilities are just as smart as everybody else. But that is a really hard misperception to overcome on a daily basis, probably for everybody. In a wheelchair, it doesn't affect your brain.

ALEX ELEGUDIN: Yeah. It seems clear. But you know, it comes with a package. And I don't mean that in the way of it actually comes with a package. It comes with the perception. I feel like people with physical and visible disabilities like myself, we're kind of working our way to try to gain the belief of those who are judging us. And again, I can't speak for folks with disabilities but I'll say it with invisible disabilities, sometimes they're trying to get that message across that we need the help. They're not working down what they're trying to say, just don't be shocked by the fact that I might need a little help or I'm a little different just because visually you weren't expecting it it's all about the perception. With us the perception is we got nothing, and with the other way folks aren't ready to understand
that some people are a little different, have different abilities. I don't think either way is pleasant to deal with. But it's part of our every day life.

BRAD BAILEY: This summer, especially with the discussion about repealing the Affordable Care Act, disability has always been front page news. But the protest aspect of disability became front page news. When I was looking at those headlines I was obviously remembering back to the 1977 protests and obviously protests over the years in a sense. But in a way we haven't gotten back there yet. I wanted to get your take on that protest spirit in a way, and whether or not you think it needs to come back the way it was before.

ALEX ELEGUDIN: I think a hundred percent. That protest spirit is what's needed in every battle, civil rights battle. Specifically with people with disabilities. There are so many of us, as mentioned. We're the largest minority. But we as a community for whatever reason -- I'm just going to speak as an advocate, struggle with coming together, being a force of numbers, getting critical mass. Some of that is just good old physical barriers in terms of you can take a bus of 80 people down to DC and it's pretty straightforward that's a bus. If you needed 80 people in wheelchairs to get down to DC you probably need 20 buses. And it depends on where you're going and what you're doing. There are barriers. But honestly that's not the biggest one. I think we don't -- there is segregation in the disability community, even amongst people with disabilities. The folks at MS have foundations. Paralyzed like myself, we have foundations. The hearing impaired folks do what they do. Candidly, there's nothing that binds us together. Although reductions in health care affect us all in a similar way.
At my organization Wheeling forward we have a belief. Part of our mission statement is regardless of your disability there is more that binds us than separates us. Especially in the physical world. MD, ALS, SCI, post polio, the list goes on. Amputees. We're all very similar and we run our programs in a way where it doesn't make a difference. Doesn't make a difference for people with developmental disabilities, DD, and things of that nature. But we need that spirit. I believe specifically in local government, I work in it, if there was a group of 20 people in wheelchairs outside the agency I work for, you better believe the commissioner will call everybody into the office and try to accommodate. Nobody likes having a group of folks in wheelchairs standing outside saying they're not getting served. Culturally the folks who work in high management and executive positions now understand even culturally, and they feel it. That we're doing something wrong. It really works. And we don't -- I don't believe we do it enough. It's incredibly powerful. I could work at my agency for two years but 20 people outside of the agency protesting or saying something will achieve more in that one day than I could probably do in two years.

BRAD BAILEY: Katherine, what do you think?

KATHERINE BOUTON: I think one thing you're starting to get at is that each disability has different requirements for accommodations. Even within hearing loss, my disability requirements are nothing like what a Deaf person's are. A Deaf person needs ASL. I need captioning. A lot of people would also like to have auditory help in the form of loops. Even within my little bit of a community, we aren't cohesive. But I think that one of the things that you see in this movie is the spirit of -- what led to the
ADA, is this spirit of people with all different disabilities managing to get together. We can't lobby for accommodations for our own specific things, and be really inclusive. But what we can do is raise people's consciousness, make sure people know how many different kinds of disabilities there are. And also all be supportive of each other. HLAA always has people at the disability pride parade. It's really great for us to be there because most people don't think of us as being part of them. I think that's a really good thing for us to try to do. If I could just say one more thing.

BRAD BAILEY: Sure.

KATHERINE BOUTON: We shouldn't have to get together and ask and demand. How many years is it since the ADA was passed? It's ridiculous that -- we're very involved with city government, and the city has passed a couple of pretty good laws in the past few years that affect people with hearing loss and also people with disabilities in general making sure there's a disability advocate in every city agency. But why is that only being done now? And why is it that you still have to get 20 people outside a building in wheelchairs to make a point? And why is it that we have to ask every single time for hearing accommodations? It's very frustrating.

BRAD BAILEY: Right. Gennarose?

GENNAROSE POPE: I absolutely think we need the level of protest and forcefulness. Listening to Judith, when she was younger -- her tone. I don't think you understand what I'm saying even though you're nodding at me. With every movement sort of comes a whole politically correct adjustment, and then people don't think it's a problem anymore because
there aren't visible -- it's not as visible anymore so people think that it's solved. There's no sexism, there's no racism. Intersectionality. But as soon as that dialogue and that straightforwardness goes away, then people think that it's no longer a problem. I think that with all this pussyfooting around the actual language and the discussion that things get lost in the shuffle. There's so much more work to do. And I think that unfortunately one of the if not the only beneficial side effects of the current political climate, you can guess my politics --

(Laughter).

Is this kind of resurgence of people feeling the need to protest and speak plainly like this again. I'm hoping to all possible deities that this is going to be a trend, and that we all unite. Again, intersectionality has never been so relevant and that's why there's a term for it now I suppose. Like they said in the documentary, if you fight for the rights of one group of people, you fight for the rights of all people. That's really where we need to go right now.

BRAD BAILEY: Last but definitely not least.

PARAS SHAH: Piggybacking off the last comment, I agree that we need to have a higher level of protest but what I really think needs to happen is the disability movement needs to be folded into and integrated among other existing social movements. With Black Lives Matter there's been a lot of attention on race. But what people aren't talking about the fact that -- and the ways in which disabilities intersect. So people with disabilities are far disproportionately higher to be in jail. People with mental health conditions are far more likely to be arrested, shot, experience
violence from the police. There's a complete lack of accommodations in that process. No one is talking about how that is impacting these types of situations. So what the movement is needing to do I think is have a hard look and figure out how to integrate these issues, how to talk about the issues, how to find commonality between what we're experiencing.

BRAD BAILEY: The last question. The unfortunate things about these questions are because they're so short. There's so much to cover. I want to ask the last question. What do you want the audience to sort of take away from this evening? If there was one quick thing in a nutshell to take away from the film or the discussion, another point, what is it? Who is first?

ALEX ELEGUDIN: Sure. I guess I'm going first all night. Might as well keep going.

That's a really tough question. The movie itself covers so many different topics on disability, humanity, life, advocacy. I would just say -- I want everybody to really understand the human element of what we go through. Yes, it takes us a little bit longer to get ready in the morning, a little longer to do this. Yes, I have to eat with a special fork. Or do things very much differently than what you do. But in reality, even comparing to myself before my disability I was hurt at 19 years old, I enjoyed many of the same things I enjoyed before. The kinds of places like to go, the music I like. Trips, the world, vacation, food. It's all very similar. Obviously it took me many, many years to adapt. But there is a human element, and we are very much like you. In understanding our struggle, and I look at able bodied privilege to me is not an able bodied privilege. One of the things
that drives me crazy is when a friend or my mother is scared to tell me she has a headache because she knows my pain is worse. Mom, it's fine. I can take it. It makes me feel more disabled when you don't tell me. You know what I mean? We're human. We're just like everyone else. We do things differently. Please be compassionate. Please be patient. In New York patience toward disability is one of the biggest problems when you get on a bus, subway, anywhere else. Definitely ask for patience. Just ask. There are many people in wheelchairs or with disabilities who don't want help. If you want to grab my chair and push me two blocks, by all means. But you will never figure it out by looking at someone. People in wheelchairs can be angry. If you grab their chair they'll tell you not to so. Just save yourself and ask. We're human. Compassion. We're all the same.

GENNAROSE POPE: Similarly, our needs are not special. They're the same needs that everyone else. We need love, we need education, we need access, we need community. We need all those things. Just personally -- stop saying special needs. It's disability. They're not special needs.

When one group of people can't have their needs met, everyone suffers.

PARAS SHAH: I'll sum up in one word. Engage. Engage with us. Have dialogue. Conversation. We'll question your biases, you'll question our biases. We'll get closer.

KATHERINE BOUTON: There's so much to say. I guess I think the most important thing, and I think the thing that is so important about your
film, is don't judge people by their conditions. Hale is an incredibly powerful, intelligent, successful advocate. When the film first started, I had probably the same response that everybody else has. How can he go through lifelike that? And then the film makes you see that he goes through lifelike that because that's his life. I have a feeling everybody here is pretty sympathetic to people with disabilities. I don't think anybody needs a lot of reminders about being open minded, not prejudging people. And also I think doing the most you can to help with access. That doesn't mean pushing Alex's wheelchair. It means making sure the curb cuts are there.

BRAD BAILEY: Great. We have a few more minutes for Q & A. If any of you have any questions, not just about the film but also about some of the issues that sort of came up this evening, we'd love to hear them. A few more minutes we have. And we have a microphone back here. If anybody has a quick question, I would love to hear it. Could you also say who you are, and where you're from.

FROM THE AUDIENCE: I'm Lizzie Reese. I'm teaching a class on the politics of disability. Edward is in my class and he's a fabulous student. I'll add that. Thank you so much for organizing this.

My question is two questions. One is about the film's availability. Because I would actually love to show this in my class if I could maybe arrange that. And also, I'm wondering what Hale thinks about how the film turned out.

BRAD BAILEY: On that second one, I learned a long time ago I don't talk for Hale. I will get in a lot of trouble for that. I'm going to see him next
week. We'll hopefully have him potentially say something publicly about his thoughts on the film and his impact. One thing, he's had a lot of people interrupt him as he's going about his daily life. The film ended up getting -- to tell you, we won a student academy award for it. The gold medal for that.

(Applause).

And I was surprised because there were a lot of films submitted this year. I think one of the important aspects is it raised awareness not just for the issue of disability but also for Hale. He's somebody who I believe has been overlooked all these years. To have somebody just ride in your streets who affects the way we interact with the world, he has big knowledge. There was a sense of urgency I had when I did the film. Now he's probably going to tell me off but he's getting interrupted all the time from people who see him on his daily route. They stop to thank him. I'm waiting for the email soon from him. In terms of availability, we'll see. We're chatting with people it. Right now it's on the film festival circuit. We just played in Savannah, and St. Louis last weekend. I'm heading to St. Louis tomorrow for tend of the festival and the awards section. I want to be able to when this is done give this out essentially. This is not a money making process for me. It's to give it out to advocacy groups around the world. And for them to use as they see fit for educators, for people who need to show that this man -- two reasons. This man exists, and he's living history. And B, people are capable of anything. To show that if Hale could do it, I could do it. Anybody could get up and just live their lives because we only have one. That was the goal with that. Thank you.
FROM THE AUDIENCE: My name is Linda. I'm a graduate student at the school of professional studies for disability services in higher education. My question was a little bit technical. What was the last word Hale said at the end of the documentary? Because I'm used to whenever -- I'm very used to seeing subtitles. I'm very used to looking at both things at the same time. So I was kind of hoping that the last word would have been spelled out. And then said at the very end. I was having a hard time comprehending the last word. What was the last words?

BRAD BAILEY: The last words were cramped. I didn't want my style cramped. We had so many conversations. This filming process took about six months. My thesis at UC Berkeley. I met Hale that previous April. I'm going to be full disclosure here. My grandfather was in the process of passing away. I lived in California and he was in Georgia. I was literally commuting doing that. My mind was in craziness. I had no time for anything. When I first met Hale I didn't have the patience. Like what is he trying to say? What is this all about? It didn't resonate with me until much later. Until that summer when I sat in the nursing home with my grandfather. I didn't learn patience but something transformed. My grandfather passed away that September I think I was a very different person. When I met back up with Hale we understood each other in a very different way than we had when I met him that April. We were able to talk. We sat for hours and hours and just talked. I probably shot over 40 or 50 hours of footage. It came up with a 20 minute film. That's okay. For me it was our time together to get to know each other. He's brilliant. He understood that process and he knew something changed in me. My goal
was to show the process of transformation I had in six months in 20 minutes to other people. That was my goal in the film.

KATHERINE BOUTON: I can answer her question. Because I had the benefit of Lauren Schechter's captions. The last words were thin line. I didn't really understand.

It was cramped. But I didn't really understand what the last line meant. Something about one thing I learned is we're on either side of the thin line. What did he mean by that?

BRAD BAILEY: Thank you. It was actually shot almost a year ago -- over winter break that was shot. I asked Hale about suicide. Suicide is a human condition, period. I asked him about it because I felt I'd known him long enough to do so. He was very forthright. He didn't hesitate giving me a very honest answer. He told me he's on the other side of that thin line. But guess what, Hale just isn't on the other side of the thin line. We all are. We all are one step away from another possibility. I think Hale brought that out and shows his brilliance in the sense that he's able to articulate. He's very existential. We're all on the thin line. His hope and his optimism is why he never went through with it and why he kept living and kept waking up every morning to do what he does, 40 years for disability. He's 74 years old. That was what I -- you're right, in the beginning I didn't get it. But it took me a beat later to get it and then it stuck with me for a while. Any other questions? You have a question, young man.

FROM THE AUDIENCE: Did you try to invite to this panel a representative from the Mayor's Office for People with Disabilities? I'm trying to get not an appointment, but for the last 25 years, about a month
ago I called and I'm still waiting for an answer.

BRAD BAILEY: Edward, we did try to chat with some folks from the Mayor's office. Maybe after the panel, we can --

ALEX ELEGUDIN: If you have questions or need the Mayor's office, I'm happy to relay the message.

FROM THE AUDIENCE: I left a message. They don't answer.

ALEX ELEGUDIN: We can talk after the panel.

FROM THE AUDIENCE: Hi. My name is Dan. I work at Hunter College's office of accessibility which is the disability services office. I wanted to say I really enjoyed the film. My question is actually more for the panel. All of you have alluded to separate and different disabilities. As most of us know, I'm really surprised when other people don't know, disabilities is not a monolithic block. Not one organization for all disabilities. But you guys have alluded to the fact that things might be better if there was an over-arching organization. I'm kind of curious is that even possible considering the disparate nature of disabilities and if it is possible how you build it.

GENNAROSE POPE: Clarifying question, by organization what do you mean?

FROM THE AUDIENCE: Separate organizations you guys -- the nonprofit disability services, the organizations. But they're all disparate.

I was referring to your individual organizations, and there are so many more. At times I always felt like some organizations were at that crossroads. Different disabilities, different needs. The resource pie is always the same so everyone gets a small sliver. But we talk about
working together and sometimes I find that's a little more difficult than the lip service we should all work together. Is it possible to build a more cohesive over arching disability organization.

BRAD BAILEY: It's a long question.

GENNAROSE POPE: Quickly, age wise we're specific, 0 to 26 but INCLUDEnyc is an organization that serves all disabilities across the board. Advocacy, resources, include NYC.org you can learn more about us.

ALEX ELEGUDIN: My thought as somebody who runs an organization and has been involved in many, I think there's some uniqueness in disability. If you look at the LGBT movement they're super unified. The model movement in terms of how they've been able to come up. I think they're very closely related, their interests. The civil rights movements of black Americans, and the black movement. Also very unified. Somebody like myself, and you can hear it on this panel between somebody who is visually impaired, somebody who is hearing impaired. We do have different needs. I need wheelchair access. I need an elevator, and a ramp. Nobody in here other than me and the wheelchair folks don't care. Not that you don't care but you don't need it. I don't need CART but somebody else does. Those unique -- everything I just named costs a lot of money in different ways and makes our interests kind of divergent. We all care about each other. But there is a very significant difference that has led to us fundraising, gaining money, a bill that helps someone that's hearing impaired unless you're talking about the ADA generally doesn't help somebody like myself. It's the nature of it. I wish there was a big monolithic organization that had a committee on hearing loss and
committee on visually impaired and we could all funnel our money. But it's a little bit tougher out there when you're competing and working with groups. That's on the very real human level, very different. But legally at the Washington federal government very similar.

KATHERINE BOUTON: I think there are a number of places where we actually do come together. Right now, for instance, the New York State judiciary has just formed a panel to discuss accessibility in the judicial system. That panel is made up of every disability they can think of. There's 18 so I'm sure they left a lot of disabilities out. They're working -- that is a completely disparate group of people with different interests. I'm sure when they actually get this commission going everybody is going to be battling for their own need.

ALEX ELEGUDIN: Height adjustable desks.
(Laughter).

KATHERINE BOUTON: But to answer I forgot who asked the question, I don't really think there is a way for us all to come together. Except for things like parades.

ALEX ELEGUDIN: Panels.

KATHERINE BOUTON: The resources are very limited. We're all trying to get the one that we --

BRAD BAILEY: I'm optimistic. If they can do it I think it can be done. I really do. We have time for one last question.

FROM THE AUDIENCE: My name is Margaret. I work for the Brooklyn center of the independent for the disabled. I want to piggyback on
what Alex said. I think part of the problem that keeps us separate not only because of our different needs but because of attitudinal barriers and we're so busy fighting over the same funding of money. That's what separates us. If we can find a common goal such as housing, what everyone needs, and fight together as a group instead of just thinking about hearing loss, people in chairs, if we can just come together on that, we would have a better chance. But we're so busy trying to stay alive in our own group that we forget the power of cohesiveness.

(Applause).

BRAD BAILEY: Thank you very much. On that wonderful and very important last note, thank you. That's it. I want to thank you guys for coming out this evening. Can we please give our panelists a wonderful round of applause please.

(Applause).
I want to wish you all a wonderful evening. If you have any questions by all means, I will give out my information. Have a safe trip home. Thank you.