

**Empowerment of Mothers of Students with Disabilities and their Allies**

March 9, 2019 at 1:15pm ET

>> [Debbie Fink, Series Project Director]: Hello mothers of students with disabilities! We are thrilled to have all of you here. This is the third of our six trainings that are part of our *Women's Disability Leadership, Inclusion and Advocacy Series,* and it means so much to us that you are here for this.

I want to get started with saying *it takes a village to educate a child.* We've all heard that phrase, right? And I want to start with participatory research. It is voluntary – you don't have to participate. But I would you to raise your hand if the question applies to you, and webinar folks, feel free to raise your hands as well.

My first question is, how many of you have a boy with a disability? Okay. Thank you.

How many of you have a girl with a disability? Okay. Thank you. How many of you have more than one child with a disability? Thank you.

Next question, how many of you have a preschooler with a disability? Okay.

How many of you have an elementary schooler with a disability?

How many of you have a middle schooler with a disability?

How many of you have a high schooler with a disability?

And how many of you have an adult child with a disability? Okay.

I would say, help me out here if you looked around at the answers, that the majority of you here today have a boy with a disability; and, in terms of age range, I think high school had the most hands up, no? Let's see for elementary school again. Okay. Hands up for high school. Okay. So just that we have a sense for who is in the room and where we are in the stage of development with our kids. Thank you for that.

I have to say that our goals for today are to help provide tools to further your empowerment. First, to take charge advocating for your child. Second, to take charge caring for yourself. Third, to take action in New York City's civic life, and fourth, to meet new mothers on a similar journey and cultivate new relationships.

And I am now pleased to hand the mic to one of RespectAbility's executive committee members, Vivian Bass. She is a woman who has been leading the way for people with disabilities for decades and working tirelessly to empower women and girls by ensuring and protecting their physical safety and economic security. It is a privilege to have Vivian here with us today.

>> Thank you, Debbie.

(Applause)

>> Good afternoon. Yesterday, March 8th, was International Women's Day. I can't think of a better way to honor this day to be gathered together today among women and mothers, doing what we do best, empowering one another to advocate and become better advocates for our nation's children. We are here with much thanks to so many in our village. Thanks to Guttman Community College and its Accessibility services for hosting us yet again. Thanks to the organizations listed. And thanks to the New York Women's foundation and the Coca Cola Foundation for generously supporting this effort.

Before we watch a powerful short film called *Ian,* I want to draw our attention to the disclaimer on screen. [Disclaimer reads: *Please note that any views expressed by today’s speakers are solely in a personal capacity and are not intended to represent the views of their companies, organizations or RespectAbility; or to be taken as*

*legal or medical counsel.*

>> We can turn the lights out. Now, a powerful, wordless, ten minute animated film, based on a true story created in Argentina by director Abel Goldfarb. It is a universal story of a child with a disability and his mother. Let's watch it together now. So now, without further ado, let's turn off our cell phones and give us what I have every sense will be a memorable afternoon. Thank you.

(Video played.)

>> Wow. Wow. Truly powerful, and so much to discuss.

(Applause)

>> I now want to turn today over to my fellow board member, Gabby Einstein-Sim who will moderate our most outstanding panel. Parent advocacy, victories from the past, navigating the present, and advancing the future. Gabby is pursuing her master's degree at Teachers College, Columbia University. Her field work included working with schools and educators in district 75 to bring nutrition education programs to their students.

>> Thank you, Vivian, and once again, welcome everyone. We're so happy to see you all. So you just experienced a powerful film am together and I'd like to turn to each of the panelists to get their responses to I okay a an. I want to approach this through the lens of our past, present and future.

>> Thank you for joining us today.

>> Sure.

>> You are a self-proclaimed historian and CEO of the National Association of Councils on Developmental Disabilities. I'd like to ask you to give us a synopsis of Ian filtered through the past. What disability advocacy had to be in place for this film to even be in existence today?

>> Well, thank you, Gabby. First of all, I think it's just a beautiful film. I don't know how you all felt about it. I've watched it several times now and of course I choke up every time. But I'm also a mom and any time I see something like that, it makes me want to cry. But this film makes me cry in a beautiful way because what I see is how far we've come. I don't want to go in to too much detail because otherwise I won't have a presentation to give in a few minutes. But you know, our history in disability in this country is actually very short, you know, we think of all the things that are all in place right now, but really, it's only been in about the last 50 so years that we have made great strides and great changes for how children are included in school, how we believe everybody should be included, fully included in our communities, people with disabilities in our workforce and valued at value players. It took a lot for us to get here.

So I think when I look at this film and I see this playground, I see this young child struggling, what I think is I'm so happy that it is different today. Once upon a time, that child would not have even been in that playground, he would have been in an institution or would have been at home but hidden behind doors. So I'm glad he's out on the playground.

>> Absolutely. Thank you, Donna. We look forward to hearing more about the past history. Next, moving on to Michelle, thank you for joining us today. As the Director of Social Work for Children for Gender Equity, I'd like to ask you to share your thoughts on Ian through the present tense. What universal attitudes exist amongst students and their educators today for their this situation to occur?

>> First thing I want to say is Girls for Gender Equity, that's our organization.

>> I'm so sorry.

>> You're 100% fine.

>> What did I say?

>> And children. But it's okay, because we're talking about children. It's great. I think that in that question, you asked for what is the universal perspective, and I actually unfortunately think that part of the present is that we don't have a universal perspective on accessibility that is accessible to everyone. A lot of the schools I have worked in and have had the privilege to be able to partner with are in communities where the playground isn't even accessible for any student, when you talk about safety and community. So what I think is a general conversation around students needing to be able to have their basic needs met at school no matter who you are is what we're looking at in this moment in education and also thinking about the fact that we have come a long way in being a he is built and accessible playgrounds and that that still isn't available to a vast majority of students and young people in the country.

>> Thank you for that. We'll hear more from you later. And our first panelist Nelle. Thank you for joining us, Nelle. We're so happy to be seeing you today.

>> Hi.

>> Hi. As a self advocate, and you're a godmother of a child with a disability, can you address I okay a n through the future tense? As we envision a future of acceptance and inclusion for Ian and all of the other children with disabilities worldwide, what do you think is the most important action that we need to implement?

>> Well, thank you. Hi, again, everyone. (Speaking away from microphone) I'm looking at this in the future as the universe, but the (Speaking away from microphone) to entertain the students and accessibility, and disability, because in (Speaking away from microphone) nobody is actually going and empathy. And so if there's about disability. And I think it's another speaker perspective, not just a home or a family perspective but in a type perspective. And the solution for the inclusion for kids like Ian, where he could be included in, the barriers need to come down. The barriers need to come down so he can actually, you know, show that he has a ability and he wants to be inclusive and be able to the other kids but the barrier needs to come down, and that has to come from the perspective.

Another thing I would look at is more inclusion programs, that need to have inclusion where disability history, the students, the disability, only to be included, and so that is an environment where anyone can thrive, including the children with disabilities. And to be educated. To be educated. The children need to be educated. The parents need to be educated. The schools need to be educated and therefore they will send all of these application Educations and be inclusive. And have an inclusive environment and be involved and you know (speaking away from microphone). My goddaughter, she is here today, and you know, when we had children she was able to become, not speaking at all and so we were able to speak to her and encourage her, and sheer she is today, (Speaking away from microphone)

>> Excellent. Thank you to all of the panelists for your keen insight on Ian. Before we dive in to our panel some more, I wanted to everybody know there is paper on your tables, I believe, so we're going to have a question and answer portion at the end of the panel. So if you have any questions that occur to you, please write them down and hopefully they will be able to answer.

Now, before, I'll just say, looking around, the note cards didn't make it so you can write it in your little notepad and rip it out.

>> Okay. I warranted to let you know that Candace over here is our timekeeper, so keep out for her, so get an idea of how much time have you left to bring the bell when you're out. Kind of like the Oscars, you know.

(Laughter).

>> Okay. Let's start with our panel. Let's (Speaking away from microphone) on disability advocacy, sharing with us a narrative?

>> I would be happy to. Thank you. Are you running slides?

>> Yes.

>> How nice. Thank you. I'm used to doing my own. But I hope you all don't mind if I stand up because I'm more comfortable when I walk around a little bit because and I'm going to keep my eye on you and I'm going to go over and you're going do cut me off. Thank you all for being here, you've taken incredible steps in the right direction by being here today and coming together. So it is so powerful to be so many moms, and a few gentleman joining us as well, I think that's really great because this, it does take a family, it takes a village to support a child, a sibling, a family member. I am also a parent as well as a professional. I was a professional first. And so when my son started to present with some things, I was right on it and the funny part was I would have these people at school saying, you know, have you ever thought of being an advocate? I didn't tell them what I did in my real life until I really had to. And then that became, yes, we'll get on that right away. So I shared that with a few people. So that was kind of fun.

What I did want to talk about today, as Gabby said, is just a little bit of the history. Our country has a I'm going to say not so long history in terms of providing laws across our land that really make full inclusion possible, that really look at disability as a natural part of the human existence, and so what I do want to do is a little whirlwind tour, as Gabby said, a couple of pieces of legislation that I think are important for you all to know because I know when you leave this room today, you're going to go back to your life but you're going to be in the schools, you're going to be in your communities, maybe some of you will be going to the state house or even coming to Washington, D.C. and as you're thinking about your daily lives, you're going to need to know a little bit about some of these pieces of legislation that have shaped how we look at disability today. And as a parent, you need to know what some of those laws are, what are your rights but also what are your responsibilities? So that's really important so just as a little reminder, you know, our government works on three different branches. We have our executive branch, that is the White House, and our federal agencies. We have the legislative branch which is Congress, that is the House of Representatives and the Senate. And we have the judicial branch which is our court system. All three are really important when we're talking about disability policy and how we can shape things. So, for example, many programs will get their funding through the legislative branch, Congress appropriates money but it's the federal agencies that shape what that law is going to look like, like we take something like education, the individuals with disabilities education act, we get funding from progress and then through the executive branch we have the Department of Education, right, and they shape how that law is going to look and how it is going to play out in every state and territory of our country and in every district for education. So it is really important that all of these branches of our government are engaged. And when there's problem, guess where it all ends up? In the courts, right, and sometimes that's where we have to settle things.

So there are a couple of pieces of legislation that I want to briefly touch on today. And when I said a short history, what I really want to take you back to is thinking about that more of our disability policy has only emerged over the last 50 to 60 years. And when you think about it in terms of our nation's history of almost 300 years, not very far. It is within our lifetime that we know people with disabilities were either put in to institutions or were kept maybe at home but didn't really go out in to the community, certainly weren't educated. They didn't have the rights and the opportunities that our kids today have, and we're very grateful that those they have those today.

So I'm going to talk a little bit about what those pieces of legislation are. So if I could have the next slide. So going back to the 1960s, you might know that, in the early 60s, our president was John Kennedy, and president Kennedy had a senior, Rosemary, who had what was then called mental retardation, we don't use that terminology anymore, but we'll call that an intellectual disability, and so the Kennedy family had a very profound desire to really understand disability more and so to do something about it. And so a bill was developed, the original name was not

>> The

>> Oh

>> No, no, you're good.

>> That was me.

>> Okay.

>> So the original name of that bill that came about after President Kennedy was not the developmental disabilities assistance of bill of rights act, the name was changed a few years later, but it really started to look deeply in to disability, really it was about building research components, to understand where does disability come from, what are some of those causes, are their cures for particular disabilities, and for people who have disabilities, how do we give them the best life, what kind of medical care might they need, what else might they need from the community to make their lives successful? And so three different programs over the course of ten or so years came together in what is now known as the developmental disability acts. The program that I work for is one of those three. So the three components are, one, the university centers for excellence and developmental disabilities. There's three of those year in New York. One that is in Manhattan and two that are in other parts of the state. And they are really looking at research, they are training people who are going to work in the field, to go out to communities. And for many families, that UCEDD is the first place that after a child is born and presenting with a disability and parents don't know, do I need a diagnosis, what do I know, what do I need to learn, what might be the first place where they're getting this sort of wrap around and understanding of where to go.

The Developmental Disabilities Council such who I work for came in to being in 1970 when the movement was changing and we were moving away from a medical model and in to understanding that people with all kinds of developmental disabilities, all kinds much disabilities, really need to have a say in their own lives and how do they want to see their community's work. And so this system of 56 state and territorial counsel was put in to law. Every state and territory has this council. This council is made up of people who have developmental disabilities, they're family members, they respond to the state's governor and they tell the go of course nor this is what we want and this is what we need. And they get to shape policy, and then the third component are the protection and advocacy agencies. They're the people who help you know your rights and your responsibilities. Many of have maybe already had a connection with the protection advocacy agency if you had issues in your school.

Next slide, please.

Then came in 1972 and eventually 1975 with the individuals with Disability Education Act. That's probably what you guys know most about because you're parents and you're working in the school system, and we'll have some time later today in our tables to talk a little bit about like what does an IEP look like, do you have an IEP or does your child need a 504 plan, what's the difference, how do we have all of those things? But that really started with some parents who were really adamant that their children deserve this same level of education as any other child and therapy a series originally called the education for all handicapped children act, we now have the individuals with disabilities education act, with all pieces of legislation as a parent, this is the one you probably will want to know most about.

Next slide, please.

We also, in the 1970s, have the section 504 that was passed, that Rehabilitation Act of 1973 which states that no qualified individual with a disability in the United States, be excluded from, denied the benefits of, or be subjected to discrimination under any program or activity that either receives federal financial assistance or is conducted by any executive agency. This was really impactful. This was one of the first pieces of legislation where individuals with disabilities, this is a nice picture in front of the White House in Washington, D.C., the lady sitting with the big cart in front of her, Judy Human, Judy Human is a New Yorker, a woman with a disability, originally started her career wanting to be a deeper, she was shut out from the New York school system because she had a disability. She later became the assistant secretary of education for our country. She is a top disability advocate and somebody I'm glad to call a friend as well. We've often lobbied together. But your schools receive federal funding. Any entity in your state, in your community that receive federal funding, this is the commitment that it has to be accessible and open to all.

Next slide, please.

Last, I just want to share a little bit about the Americans with Disabilities Act which was passed in 1990, signed in to law by President Bush. I'm sure you guys know a little bit about this piece of legislation. It really is such an important piece of legislation. It is very deep it. Is very detailed. And it was a long time in coming. It is fascinating that for so many years we had civil rights laws but the disability population was not included.

Senator Harkin was one of the main champions in the Senate for this bill called the emancipation proclamation. It is really something that has changed our nation. And that's why I wanted to point out to you, it was only 1990, 1990, so very recent history, we have only had this law for us with 28 years and yet it made a huge difference. And it is based on four major pillars that all people deserve full participation in the community, that all people deserve independent living and the opportunity to live, where they want, with whom they want, and how they want. Your children are all going to be products of this law. Equality of opportunity, that meets no matter what our disability, we should have equal opportunity to pursue our dreams and live our lives, and economic self sufficiency. That means we should be able to work and earn money, be able to live the lives we choose.

I want to finish with this last thought for all of you. All of these laws have common language, and they were built upon one another. It is was by design. They all have interlocking language that supports and makes up different parts of what we do in the disability community. Each place a roll in our right and responsibilities and helps us know what we can do and what we can achieve. What I really want you to know is that while your life day in and day out probably feels very challenging on many days, I know that, I feel that, I've been there, too, but you're standing on the shoulders of giants. There are amazing people that really worked to get each of those laws in to place so that all of our kids today benefit from them. We are living in a better place. It doesn't make life easy it. Doesn't make our world perfect. We are living in a life where we have a lot of our great disability policies constantly challenged. But you are the advocates now. You're out there advocating for your kids and there is nothing more powerful than that. So be one of those giants. Be the best parent you can be. Hook up with other parents, your voices are very, very powerful. As an advocate and somebody who brings advocates together, I will tell you there are policy makers at all level, your local level, state level and I was going to say up in Washington, down in Washington, but they listen to you because you are people that they represent and that's the most important thing. So thank you for your attention to this today.

>> Thank you, Donna. That was a wonderful little history lesson and that was very helpful. So next, Michele. You clearly live in the present. Passionately working with girls with disabilities in the New York City school system. Can you please help us navigate the present as a patient advocate?

>> Happy to. Hi all. I am Michele Grier. I'm a born and raised Brooklynite, grown and raised in this city. And also a social worker who has been practicing in the city for, I don't know, I think ten years but has been doing social justice work for a long time. And so I was asked to speak on the panel, usually I am asked to speak about gender based violence and that impact of racism. However, because of my experience as a school social worker working with so many different people, was asked to speak a little bit about the present and what it looks like within our school system and my experience really partnering with parents. Parents are always advocates, right? You all know your and I mean parents in the largest form, so whether that's grandparents, whether that's aunties and uncles that have taken positions on raising people, the neighbor next door that's taken in multiple people, that's sort of what it looks like in my experience in New York City and who is helping raise our children. In addition, what really hit me in the film is that I think there's so much isolation that happens, when you are experiencing discrimination, no matter what that discrimination is and the impact of disability of discrimination, and so needing to have support and also made awareness at the same time is what really, really impacted about me that film what is that when we come together it's like the isolation. I think there's a lot of isolation happening in this country right now.

So that's me. The next one. We don't have to see me. I'm right here.

(Laughter)

>> Where we are today? So what I thought I would do is I am not a researcher, like I said, I'm a social worker, and what I have to do is probably what many of you do is go to other people for the research, for the information, and so have you all heard of the research alliance for New York City schools? Any of you all? They came out with a great article in 2018 around their research. They've done a whole study of the city and what's going on. So what I'm going to do is give you some information on what we're seeing right now in New York City schools in specifically IEPs. So understanding that New York Cities have 1.1, right, million students, we are the largest school district in the country. We are the most segregated school district in the country. We have 200,000 students with IEPs. That's not including 504 plans and that's including all of the students who haven't been identified, right, for support. And so I'm going to give you a little bit of information specifically on students who are have been identified as having those IEPs right now. So forgive me if this does not cover the private school spectrum, but this will also this will include charter school spectrum, public education as when in what we call DOE schools, magnet schools and any students potentially who went through that system and then transferred in to private schools.

I'll hit the highlight and then I'll go in to detail. So the percentages varies across the country, we have the most students with the percentage of IEPs varies throughout New York City and we have the highest number of students with IEPs in the country. And what I mean by that is that even though we have the highest number of IEPs, it is not consistent throughout our district, right? So one of the highest places and where are there are IEPs is in Harlem, in the city, and one of the lowest areas, where there are IEPs, is on the upper east side. And so when we're talking about who is getting identified and what is happening, we have to be thinking about where this is happening in terms of location. Right? The most prevalent disability classifications are learning disabilities and speech or language impairment. What we know pace based on that is that most students who are coming into this country as immigrants, so when we're talking about Latinx students and when we're talking about those identified as Asian and Asian American students that we see that they are having higher rates of IEPs within New York City and that's because they're coming in with ESL, right, so they're being diagnosed with needing to have language support but coming in with an IEP. And IEPs do protect students, right, we understand that saying that there is something that they need and also understanding that IEPs have been a part of tracking within IEP schools.

For the next statistics. Boys are more likely to be classified with autism, emotional disturbance and other health impairment. Have you all heard that before? So what does that mean for girls? They're not seeing. One of the experiences I would have with going in to the classrooms with teachers is oh, you're student is noting to work. Oh, but she sits there and she's quiet and she listens to everything I say. And need to train teachers on how to be able to identify how girls present within the classroom. That's not a conversation that we're having. People automatically are identifying those who are disrupting the classroom. But if you're in compliance, that is not a conversation that is happening. So disability. And our girls are getting lost within the system. So that's also the lower number across the board, we're going to see all of these higher percentages of points. And I know we spoke about that in the beginning but really understanding what that looks like, even when teachers are in the classroom and they might be having this experience every single day with your child. Disability classifications also vary substantially by race and ethnicity which I think was clear when I said Harlem versus, right, the upper east side. However, we have to be really intentional about what that means, because it can also go to class if I case. I'm trained as a mental health clinician. So when I learned classification, it was under the DSM which is a diagnostic tool for mental health. When I came into the school system, I started reading IEPs and they would say, emotional disturbance. And I was like, this isn't a classification that carries over it into the mental health world, right? So a child who has maybe experienced multiple trauma or riff in an environment where they need more support or was just transferred to a shelter system or maybe doesn't know how to communicate their needs and is acting out is then given an emotional disturbance classification which coincides with poverty and race, with he where we have trauma that we need to be to dealt with and the school needs to have a trauma informed lens because we know there's more trauma happening within the school district. So these are some of the happenings that are occurring in New York City right now. Those are, I didn't want to spend too much time on my data points, but those are the ones.

And what I did, can we go to the next slide, please? I put the research up here. And I will say the research for New York City schools, they have great, great graphics. They have it all broken down in terms of really, if you wanted to look for your neighborhood or things like that, because they are the experts in this and I wanted to be share my experiences and be able to hear from you if you all have questions around what it looks like to be in schools, I know there are a mix of people here and would love to speak to the different experiences. Additionally, I put IncludeNYC. I know they're a partner with RespectAbility.

For me as a social worker coming into the school as well as when I was working in foster care, they were one of the major, major parts of being able to support me and my work with parents. And I think this is where we are in this present moment is that we have some really amazing organizations that have access to resources and who are really work within communities to build that out. I worked in east New York. There were not he are sources for families who had student with autism. If you wanted to go a place that recreational center you had to go to downtown Brooklyn which was 45 minutes away from that neighborhood. These centers are saying, we need to be making more spaces within communities in order to allow for students to have the accessibility and also they're working with parents to make sure that we have funding, right to make sure that people are going up to Albany.

The other thing I will say for those of you in the school community, you have to understand your social location when you are walking in the door of that school. And I'm really speaking to black and brown moms and dads right now. There is a history of calling the mom first in schools that teachers do. It's sort of the way that has always been taught. And also sometimes thinking that the father is the disciplinary which can lead to access issues where a school thinks that a child is having a certain issue that I've had experiences where students need more. Parents need help and resources and because it is seen that the parent is being neglectable, ACS is called. And a lot of that has to do with social locations, not understanding why a parent is doing more and understanding the parent is going through and so if you can find an ally in the school who can help to speak to those people for you and translate, because a lot of this is translation and being able to build relationships, I think that that is one of the biggest things that you can do in the school community because there's a lot of time misconception and thinking that people understand one another's experience when really we're not talking to each other because we've been in isolation so long as a country. So we're not talking about across barriers of a disability but also talking about race, class, sexism, and how that impacts your children and disability. So thank you.

(Applause)

>> Thank you Michelle. That was some really, really great information, and the resources, I'm sure you'll have lots of questions when we dot round tables.

Next, Nelle. You really focus on helping parents see and seek a brighter future in the midst of chaos. Can you please address how we can advance the future as parent advocates with children's with disabilities?

>> Nelle: Well, hello again, and I really appreciate all of the wonderful moms and the everyone and the males in the room, as we said before, I really appreciate everyone coming out today.

So I am also a parent and I have also an invisible disability and so I really want to touch this day on that issue of the godmother of a daughter with a disability. And so I know there are many mothers in this room, I don't do very well, I need to read my notes, but there's mothers in this room today, and I, most of you I have seen with your hands raised today because you have had a child or children with a disability, why he? And so I'm going to talk to you today and self care. I want to talk about the future of having a child with disability but also of you, each and every one of you, being an advocate for that child, and a parent of that child. And so self care, because self care, because we want to help people understand that if self care is not at the top of your list then it becomes a very, very challenging situation for the future, yes? Okay. So self care is a human function that everyone has a vested interest, must be intentional about. Self care has to be intentional. And I as a parent, as a advocate for children with disabilities at first it feels tough, if you don't make it intentional, then who you are advocating for? Because if you're not okay, can you help your child? I want you to just think for a minute that having a child with a disability if you're not around to help that child, in the future, you're not helping anyone. You're not. So it is really important that you put self care at the top of your list, yes? Because it is important you that have to take care of yourself first. And (Speaking away from microphone) of most individuals makes health makes I'm sorry, makes healthcare very, very translating. We have jobs, we have children with disabilities, we have other children in the home, we are wives, we are husbands, we have so much going on, and it is heck particular 24/7, I mean, yes? Can you relate to that? So how do we find for ourselves? How do we find time to take care of ourselves ifs we don't make it intentional to self care? It is the way to the future, and we have to both agree on that, yes?

So what mother of children with disabilities (Speaking away from microphone) to take care of that child. And I just want you to know today that we just want to bring the awareness that you as an individual have to take care of yourself first.

Every disability is different. Most of us, as I said, have one or two children that requires 24 hour care, 24 hour care, and so they tell us again you have to make it have you to really make it at the top of the list that you have to do everything you can to have that moment for yourself, to pick yourself that you will be able to be there for your child or for your children.

We have some disabilities, for example, we have several (speaking away from microphone) like my goddaughter had, you know, I know you probably heard that today, because I know children today, diagnosis (Speaking away from microphone) and neurological disorders. And those are just a few of the diagnosis that can take you as a caregiver and as child a parent of a child with a disability a form of care. I mean, if I asked to raise hands today of how much it takes care of one child with a disability, how many hands would go up today? Many hands would go up today. And how are you taking care of the child when you have so much going on? How many taking care of yourself? How about self care at the top of your list when there is so much going on because you want the best for your child. You're going 24/7. Because you want all of the best services for your child. But you have to understand that your health, your health has to be the priority. Because if you're not okay, then, as I said before, you can't be there for anyone else.

How many in the room has not just children with disabilities but you have other able bodied children in the home? And I want to talk about that today. You're having the right services for the child with a disability built. How many of you are also taking care of those children without disabilities? Because you they also need your love. They also need your attention. They also need your care. And so you have to also include them in the picture when you are doing everything else. Have you to include those children in the picture. We want to talk a little bit about making a conscious decision also to take care of them. So when he with looking also at the your health, I want to talk a ill will by the about your health, your own health, you picking the child when your health. How much do you take in a year to make the doctor's appointment, to make sure you follow up with your healthcare providers and to do you know, do everything you can to make sure you, as a parent, advocate, are physically and mentally loved? How much are you doing? Let's talk a little bit about illness prevention. Do you take that time to exercise? Because exercise helps you sleep. It is good for anxiety. So do you take that time? Do you take the time to exercise? Do you diet and eat well on a daily basis? Do you miss do that on a daily basis? Do you take your medicine as subscribed? Because you're running around 24/7, and half the time we forget to take our medicine and we don't take it as it is supposed to be taken, as prescribed by our doctor but it is really important for our diabetic blood pressure medication, the blood pressure medication, we have to take care of ourselves and put that priority also that we put on our child, yes? We're going to talk about the behavior and so, you know, things to avoid, things like alcohol, drugs, cigarettes, sugar. We use a lot of this, but it is important to reduce our sugar levels, the salt levels that elevate high blood pressure, for example. Beverages and lack of healthy foods, so much fried foods. It is important for us to take that conscious effort to make sure that we are taking care of ourselves as mothers, as wives, as, you know having children with disabilities and these advocates, because self care has to be at the top of our list.

So our time is gone but so we have one more minute, you know, and there was a so I just want to advance to one more point for the one minute we have left. I just want to let you know that self care is critical, that you, as a mother, especially, again, if you have a child with a disability, that you have to put self care at the top of the list. You have to put your health at the top of the list. You have to the same effort that you put in having the resources for your child, the same effort that you put in making sure your child is healthy and has the best possible, you have to put that same effort for yourself to make sure that you are loved and that you will have a good future and that your child will also have a good future, because without you, your child will not have the future that he or she deserves. I thank you.

>> Thank you, Nelle. Thank you so much for working so hard every day to make the future a better place and less chaotic for tower children. And most importantly, thanks for bringing up self care, it is important as women and men and caregivers, mothers and fathers. So thank you.

[Gabby]: Now we're moving on to our question and answer portion. If you've written down on paper a question, Debbie is going around collecting them. If you haven't had a chance and have you a question, go ahead and jot that down and hold up your hand and we'll get started in just a minute. Thank you.

Okay. Great. So and if you want to specify who the question is for, you can also do that.

This first question is: “How do you balance self care in a child with disabilities and another issues?”

>> (Speaking away from microphone)

>> Okay. Sorry. Child without one.

>> Nelle: So well I'm glad you asked. You know, as I said, I'm also a parent, I have two adult children without disabilities, and Katrina is also my goddaughter with a disability. And I have an invisible disability. So what I do on a daily basis, I make it intentional. That means that I wake up every day, at 5:00 a.m., and I use the time to relax, I use that time to pray. If you don't pray, use the time to meditate. And I just use that time to center in before I start my day, I use the time to center in before I settle myself before I start the day. Because when you have a child with disabilities and you have children without disabilities, you have to remember as a mother, as an advocate, that each of your children deserves the same time and effort and so you have to be able while you're also taking care of yourself, you know, because, again, you have to put yourself at the top of the list, health wise, you have to put yourself at the top of the list in every aspect, because if you're not okay and you're not well, you can't help anybody else, right? So you have to get that first. So I center in, as I said, in the day, I wake up, I exercise 20 minutes, and I pray, because I'm a religious person, so I do pray. And then I take that time, ten minutes, just to made day and to center in on my day before I start with the children.

>> Thank you.

>> Thank you, Nelle.

>>Gabby: And if we don't get a chance to answer your questions, all of the panelists will be joining you in informal group discussions later on. Our next question is for Michelle. This question is about district 75.

>>Michelle: Sure. Does everybody know here about district 75 schools here in New York City? So just a brief, district 75 schools are separate school spaces that look different based on the district and look different based on really the goal of schools, and sometimes those spaces are focused on children who have been classified with emotional disturbances and sometimes they're spaces where students with intellectual days dis is a bits and emotional disabilities there. And what's happened over the last decade is really with the desegregation of programs and bringing more programs into the community schools that district 75 schools have shifted and so what we see are a lot of students being shipped I should say not shipped. Being sent to these schools. And there are people who are doing their best within these spaces and also its not enough, and that's what we know. And so unfortunately, they're just, from my perspective, there isn't enough. And so these are spaces that you can either be getting a lot of resources or be getting little resources and you might have a classroom where there are multiple different varying abilities in the space, and really the teaching staff or the resources aren't there to actually support what's needed.

And what I can say is that in my experience, I've had students who have come in to my space coming from district 75 schools because they were relegated there because of having intellectual disabilities, because of having invisible disabilities and no one has not no one but not having those connections to have someone really identify what was going on and then access, right, because access is a huge issue. And then also to families. It's a huge cultural difference if you don't come from a country where people don't speak about disabilities. And we have a lot of different people coming from different spaces, and sometimes as a school social worker it would get four years to get a family to say my child is living with ASD, my child is living with this. It is other things first. So I think that's why our relationships are such a huge part of the work.

>> Gabby: Thank you. Michelle.

>> Next. We are going, there's so many choices, so many great questions. This is actually a follow up for Nelle. *How do I manage self care and care giving with very limited healthy food availability.* I think you could probably both touch on this.

>> Nelle: So you know, I work also with my local community churches and so what that does, some of the the one that I actually work with specifically had (Speaking away from microphone) and we have challenged to have healthy food to the community. And so a lot of the times when you're looking at self care, as I said, you have to make it intentional. So when you go to the grocery home and sometimes you might be challenged to buy all sorts of different foods, right, because foods, as a matter of fact, is expensive. So when you go to the store, you might be challenged to buy the chips and the drinks that are not the healthy ones, you know, a cheaper version as opposed to buying carrots and beans and a lot of people, in my experience, in my space, don't like to cook. And so I think what I have challenged my church to have groups and we have taught mothers how to cook, we have taught teenagers how to cook, so when you go to the grocery store, instead of buying foods that is not healthy for your body, learn how to cook the healthy foods and bring it in to your home. And that has helped our mothers, that has helped our teenagers to, you know, I don't know the right words, but to really help the situation of self care when you don't have a whole lot of money coming into the house.

And one more thing, we taught communities how to grow healthy vegetables during the summer so in the backyard we have taught people how to plant healthy vegetables and that has also helped a lot.

>> Michelle: Okay. Be the community organizer is what I'm hearing you saying. So food, housing, those are all issues here in New York City. And in different communities there are community gardens and there are some places, there are used to be Georgia's Place, does anybody know about that, and that was a space where people were living with different mental diagnosis and on their rooftop they had a garden and they did it as a way of actually engaging people in healing processes but then they would sell all the food to restaurants. And so I think we can. There are so many different things in New York City that you can access by I doing a little bit of research, and also CSAs because that's what I do in order to get access. And there are a bunch of slow food and urban growing space that is are doing that work. I saw hands raised. Do you all have suggestions? Just yell them all, if you can.

>> Participant: That was my question, actually.

>> Michelle: Oh, okay.

>> Participant: The issue is not the issue before me is not community and I am from northern Manhattan which is from, I (Speaking away from microphone) too.

>> Michelle: Oh, that's where my people are from, Colonial project. That is where my family is from. So the issue is we have access to two major stores, three now, and it is healthy food displayed at that is not edible and so because I (Speaking away from microphone). I've been working extra hard to try to even get the healthy foods to prepare. So the issue is I don't know what to do. Because I could change things in a home but I don't know. And I'm more concerned too with people in my community, the kids, my kids, one of my kids has ADHD, there is a correlation with ADHD and diet and all of those things, and so I'm working hard to try to try to find a way for us to eat healthy.

>> Michelle: Can we add that to one of the things we talk about in our sessions?

>> Gabby: That's a great idea, yeah. There's actually a lot of great questions that can hopefully be answered during that time and at the end of this, there's so many questions Goode questions that we are going to pick up the Q&A then.

There's a (Speaking away from microphone) for Donna.

>> I feel like we should just connect.

>> Okay. Great. Donna, what are the best resources to find out about a student's right as a college student and also how that relates to medical needs?

>> Is it on?

>> So I want to make sure did can the person who asked.

>> It's actually two persons.

>> So I wanted to make sure I'm answer thing this correct.

>> Donna: So the one is finding out the rights of a student as a college student, and someone else asked about medical we'll just stick with that one and we can pick up the other one later how about that. So we're talking about students with disabilities who are going to college.

>>Gabby: Correct.

>> Donna: So depending on the disability, I think certainly something that I put in to place for my own child was making sure that earlier on, before college, we had an IEP in place. Most colleges these days have an office that is all about accessibility. Before your student even applies to the school, I would recommend looking on line for the variety of colleges or institution that is your child was looking at to see what they do offer and have a conversation. Give that office a call. And talk to them about what kind of services do they have available that helps students with disabilities to be successful in a college setting. You know, a number of years ago, there were very few and now maybe, many schools from community colleges, to major universities, have opportunities.

There are also a lot of schools that have specific programs for kids with more intellectual disabilities, some of them are shorter time semesters or where your students really have, like, somebody who works specifically with them. One really good site to look at is through the institution of community inclusion in Boston, it is a program called [Think College](https://thinkcollege.net/), and you can find [Think College](https://thinkcollege.net/) on line and it will give you a lot of resources and a lot of information. But I think as parents, first of all, you know, congratulations if you're already thinking about your student going to college. That just makes me so happy. Because today most students with disabilities, no matter what the disability, should be thinking about higher education. We have laws in our country that do make that available and accessible and as I said, most students now are thinking about that.

If you've got good documentation, you've got an IEP in place, you will send it, you will have recommendations coming from your child's secondary school that will go forward and then you would go in and meet with them. The biggest thing that you need to know, though, is that you can set up all of the best systems in world but once your student goes off to college, they're like,

*Oh mom, I'm an adult now, I don't want to get help on that or I don't want to walk in to that door, I don't want to tell the professor that I need extra time for my exam or whatnot.*

Well, sometimes they learn the hard way and it means they're going to start failing their classes and then they get -- did you want to add to that?

>> (Speaking away from microphone)

>> Donna: You know, he's like that and there's nothing you can about it and just you know, accept it. Don't ever accept anything. There is a divide what used to be called in my son's university the office of the and the (Speaking away from microphone)

>> Mm hmm.

>> Participant: So the professor accept or embraces that culture. Particularly when you're dealing with the specifics of the sciences and the attention and all of that. So this is where that communication with your child, not own the helicopter parent but sort of be the helicopter parent.

>>Donna: You sort of have to be the helicopter. So that you support your child.

>> Right.

>>Donna: The relationship, like, with those allies that we all need in every part of our life. So it is tricky. It can be done. But you think, oh, 18, 17, I can breathe a little bit down.

>> No, you're never done. You're never done.

>> That's okay.

(Laughter)

>> Donna: There are things to think early on is preparing your child to be the best self advocate that they can be.

>> Gabby: Self advocacy, we're actually having a training here for girls who are college students disabilities next month. So if you have, if you know anyone or your own child, please let us know that we're offering training and check it out on the accessibility website.

>> Debbie: Okay. Thank you. How awesome it is to spend the whole afternoon here and with Donna, Michelle, and Nelle. Thank you so much, so much, and we'll pick up on some of this. But I want to give a shout out relative to Donna's response, Guttman Community College, and its accessibility program, I mean, this is a great place to look at if you have a student transitioning into the college and maybe you want to keep him or her closer to home, this is a great place and space for that. So we're going to hold on the questions because we really need to sort of keep the trains on track. And so with round of applause for our fabulous panel.

(Applause)

>> [Gabby]: We're going to take about a 15 minute break; so please stand up, stretch, maybe meet someone new. You can talk about what being a parent advocate means to you, walk around a little bit, and then sit back down and we'll get going again with the smaller group discussions.

>> We actually have ten minutes.

>> Really introduce yourselves to one another. This is the time to mix and mingle. Then we will be doing what we're calling the *Tip Talks,* where we're going to go around the room to do neat work and we can pick up on some of the more questions. Yes, a ten minute break. Thank you.

One more thing for everybody that we would like to (Multiple people speaking)

>>[Dr. Jordana Mendelson]: The higher education program and those range from, they have programs that are located in the colleges, so if, if they have situation, or if they have what is something in the college and (Multiple people speaking) also a program where federal assistants is normally available, that's one of the things I know of, when the federal funding which isn't usually what our kids have access to. So if you can't go, just look on line, they archive and there's just great resource there is in terms of the content and and (Speaking away from microphone) and I've learned a lot from that.

>> It's on Monday. It is on Eventbrite. I think we do it every year.

Debbie: This concludes officially the webinar component, and we want to say fair well to our webinar participants. Thank you for joining us. There's a survey on line that you will fill out. So thank you very much. And make it a great day!

>> Thanks for awesome interpreters!