

**Empowerment Training for Jewish Women with Disabilities**

February 24, 2019

SHELLEY COHEN: Good afternoon. My name is Shelley Cohen

and it is my sincere pleasure to welcome you today on behalf of

RespectAbility and all the organizations listed on the screen behind me to

this groundbreaking conference on empowerments for Jewish women with

disabilities and their allies. The planners of this convening are a terrific

group of Jewish women with and without disabilities who are yearning to

see more Jewish women with disabilities play a greater role in both our

community and the civic world at large. As many of you know, according

to the U.S. census bureau, 18.6 percent f the general population has

some form of disability. Chances are that number is even higher for Jews

because we tend to marry within the fold and therefore, the genetic

propensity for a disability is increased. Take a moment to think about it.

That is almost 20 percent of our -- a fifth of our people. Can we honestly

say we see every fifth person that attends our synagogues, schools, and

Jewish organizations as having some form of disability? I suspect not.

And that in turn brings us to today.

This conference started by RespectAbility, a national organization

that fights stigma and advances opportunities for individuals with disabilities

realizes that the neurotypical, or able bodied population needs the voices of

those with disabilities to be more fully inclusive.

We have created this empowerment training where you will be

hearing from an amazing group of women with disabilities who have

learned to own their disability, and have found a voice to not only be

self-advocates, but have become voices of leadership within their

communities. We hope this afternoon proves to be time well spent, and

you leave inspired by these role models. We very much want to know

how you feel about this event. So please do not leave today without filling

out the feedback surveys that are located on your table. We will be

collecting them at the door. And just in case you have an ah-ha moment

during the course of the afternoon, there are some boards on the side there

with sticky notes. Please take that ah-ha moment idea and stick it on the

side so that we too can all learn from the insight that you just developed.

Lastly, let me introduce to you the two truly fabulous women who are

standing by my side. Vivian Bass, beautiful woman in purple, my

coChair of Jewish inclusion at RespectAbility, and Rabbi Julie Schonfeld,

the Chief Executive Officer of the rabbinical assembly, the international

organization of conservative Masorti Rabbis. You will be hearing from

both throughout the day. Now without further ado let's all turn our cell

phones off and begin what I'm sure will be a memorable afternoon.

Please enjoy.

(Applause).

RABBI JULIE SCHONFELD: Thank you, Shelley. I have the

privilege and pleasure, I was asked to give some continuity, a sort of golden

thread of Jewish tradition throughout the day's activity and to share a little

nugget of Jewish wisdom at several intervals, this is the first. I have to tell

you something I thought about a lot, one of the things about RespectAbility

and this event today is the recognition that the Jewish community needs a

lot more wisdom about inclusion of people with disabilities. And needs to

grow in this in many ways. And so I offer these nuggets with the hope that

we can bring all of this great wisdom to make our communities more

inclusive, more supportive, and also of a recognition of the work that we

have yet to do. And so in that spirit, the brachot quotes the mission as

follows. Rabbi, on entering and leaving the house of study, used to offer a

short prayer. What did he say? He said on entering, I pray that no

offense -- that no error should occur through me, and on leaving, I give

gratitude for my portion.

The explanation of this teaching said, what did he used to say

specifically on entering? He would say may it be your will, O Lord my God,

that no offense occur through me, that I don't stumble in the matters of the

best of our tradition, and that my colleagues have reason to rejoice

together with me in these teachings. That I not pronounce anything to be

good and okay, which is not, and that I don't fail to acknowledge that which

is good and okay which has not sufficiently been acknowledged before.

And that I too will rejoice in the teachings of my colleagues and friends.

VIVIAN BASS: Thank you, Rabbi. So let some music send a message for

why we're here we invite singer song writer Joanie Leeds to share how

good and how nice it is to see Jewish sisters sitting here together for a

greater good. Hinei ma tov.

(Applause).

(Music) (singing) Hinei ma tov u'ma'naim shevet achayot gam yachad.

Hinei ma tov u'ma'naim shevet achayot gam yachad Hinei ma tov shevet

achayot gam yachad. Hinei ma tov u'ma'naim shevet achayot gam

yachad. Hinei ma tov u'ma'naim shevet achayot gam yachad.

Hinei ma tov u'ma'naim shevet achayot gam yachad Hinei ma tov.

Hinei ma tov. Hinei ma tov. Hinei ma tov.

Hinei ma tov u'ma'naim shevet achayot gam yachad. Hinei ma tov

u'ma'naim shevet achayot gam yachad.

(Applause).

VIVIAN BASS: And as we sit together here is a new spin on an

older song, I am Woman. This iconic song empowered women and

feminists during the 1970s. I am woman has been adapted for our time

together today. Our voices matter. As Jewish women, hear us roar in

numbers too big to ignore. Feel free to join Joanie in singing this

empowering song. (Music).

(Singing).

I am woman hear me roar in numbers too big to ignore. And I know

too much to go back and pretend. 'Cause I've heard it all before and I've

been down there on the floor. No one's ever gonna keep me down again.

Oh yes, I am wise. But it's wisdom born of pain. Oh yes, I've paid the

price. But look how much I gained. If I have to, I can do many things. I

am strong. I am invincible. I am woman.

You can bend but never break us 'cause it will only serve to make us

more determined to achieve our final goal.

And we come back even stronger, not a novice any longer. 'Cause

you've deepened the conviction of my soul. Oh yes, we are wise. But it's

wisdom born of pain. Oh yes, we've paid the price but look how much we

gained. If we have to, we can do anything. We are strong. We are

invincible. We are women.

We are women, watch us grow. See us moving to-and-fro. As we

spread our loving arms across the land. But we're still an embryo, with a

long, long way to go. Until we make all ablists understand, oh yes, we are

wise. But its wisdom born of pain. Yes, we've paid the price but look

how much we've gained. If we have to, we can do anything. We are

strong. We are invincible. We are Jewish. We are women! We are

woman! We are women! [Cheers and applause].

VIVIAN BASS: Thanks so much to Joanie Leeds and to our

violinists, RespectAbility's own Debbie Fink.

(Applause).

Debbie Fink: We are now going to move into our

first panel to set up our discussions for the day. I'm going to ask our

panelists to take a minute and come join me here at the front table.

People need a moment to collect themselves at your tables, do. And we'll

be right back with you in just a minute.

Thank you all for coming back together. We hope throughout the

day, one of my goals I already derived a lot of joy and strength from,

meeting new people. Please take these moments to meet the people at

your table and I hope that we'll all walk away with some new friends today.

I'm sure we will.

Today's panel, our opening panel is about leadership and about

self-empowerment. I have been told since we have slides on each of our

very esteemed panelists I will not read their introductions. There is

however a disclaimer slide that all of us here, including me, are speaking

on our own behalf, not on behalf of RespectAbility. So we thank you for

the opportunities to share so freely. In terms of the subject of our

discussion, I want to just give one more Jewish thought and Jewish nugget.

As I indicated when I began, Judaism isn't only what we read in the books.

It's not only what was passed down to us. But every person sitting in this

room is a wise Jewish person who is bringing forth our traditions through

your lived experience. One woman who is a great inspiration to me, I can

remember meeting her in the Kosher butcher shop on Oxford avenue in the

Bronx when I was four turning five years old, Bella Abzug, known for her

hats. She wore them to make sure that no one forgot her. Bella was an

incredibly, incredibly brave woman. She served in Congress from 1971

through 1977. And she took a tremendous number of risks to stand for

what is right. And when I was a girl, in the early 1970s, it was very

clear -- it was made very clear to me that a lot of what Bella Abzug was

about was about being a woman in politics. That image is really etched on

my mind. I found this nugget.

She was not only a great trail blazer but she was a great student of

Judaism, love of Judaism, love of Israel. She said the following: The test

for whether you can hold a job should not be the arrangement of your

chromosomes. I think there's quite a lot to learn from that. The test of

what God puts in our heart is who we are and how we bring it forth into the

world. With that it's a great pleasure and privilege to turn this over to Ila

Eckhoff who as I told you, Ila, I'm very inspired to read your option B entry

on the web. I definitely recommend it to people. There's your bio. We

turn it over to you.

ILA ECKHOFF: Hi. I usually don't need one of these. We'll see if

it makes a difference. I am a managing Director at black rock, which is the

largest asset manager in the world. I lead an industry management effort.

I do a lot of advocacy for the firm, and participate -- I sit on boards, industry

committees, advisory panels. I also sit on a board of the cerebral palsy

foundation. By way of background, I have CP. I was born with CP. My

mother and I both hemorrhaged all the way to the hospital. I had about 12

surgeries between the ages of 2 and 14. I work

predominantly -- historically what was predominantly male dominated

financial services industry where the only time I saw somebody with one of

these is if they broke their leg skiing over the weekend. I come from a

place where thank God the world has changed and it's much more open

and flexible for people with disabilities today. And I actually am also the

sponsor for black rock's ability network because I'm sick and tired of the

word disability. It bores me. It's about what we can do. And I'm tired of

talking about what we can't do, and I'm very focused on talking about what

we can do. That's what we really should do. To somebody's earlier point

about the fact that 20 percent of the globe basically has some form of

physical or visible or invisible disability, that's 20 percent of the population

that's not being properly serviced. Either by the asset management

industry or any other business for that matter. So hiring people with

disabilities is not about doing something that's nice to do. It's about doing

that makes good economic sense. And there has been a tremendous

amount of research around inclusion and disability. People from different

backgrounds, different experiences, enable businesses to make better

decisions. So hence, thank God in this day and age there's a lot of

inclusion and disability programs around.

Self-advocacy is something you'll hear a lot about today. I think it's

a very personal experience and everybody has to figure out what that voice

is for them. But just like in Judaism where we can't let certain things be

forgotten, people with disabilities have to speak. That voice has to be

heard. Everybody has to find their own voice, and at different stages of

my life I've had a different kind of voice. I'm a little bit more comfortable

with it now in my current age than I was growing up. So I'll tell you two

quick little notes. One is I was about probably 8 and going

through -- about to go through another set of surgeries and feeling pretty

miserable and sorry for myself. We lived on Long Island at the time. My

dad dragged me to the cerebral palsy center on Long Island where it was

basically a workshop for people that couldn't work elsewhere because they

were just too disabled. Unable to speak, unable to move, unable to work.

It was to -- to say it was scary was an understatement. He dragged me

literally on my knees from this center, from one end to the other. When he

got outside he said I don't want you to ever feel sorry for yourself again

because the difference between you and them is probably another 30 to 60

seconds on the way to the hospital and not enough oxygen getting into the brain. It

can happen to anybody. Be grateful for what you have as opposed to

being miserable for what you don't. That's a lesson I learned pretty early.

I was very fortunate to have a father that was my biggest advocate. But

he also told me that I had to be better, smarter, and faster than anybody

else if I wanted to be looked at as an equal. He said you'll walk into a

room and people will make assumptions so you will need to teach them

that those assumptions are wrong. But understand that means you have

to work harder, be faster and be smarter. So look, we all need to accept who

we are. The gifts or not that God has given us. And make the best of

those tools. It's really important. And then later on, when it comes to

getting a job, I know Lori is going to talk later, she's from Ernst & Young. I

was at Arthur Anderson for a while. You had to carry big briefcases and

heavy files and I could tell the partner interviewing me was concerned

because he saw I walked in with a cane. I could see that look in many

interviews. I said just so we're clear, there's one thing I can't do. If you

need me to ride a bicycle, we'll have a problem. He laughed and I

laughed and he actually offered me the job on the spot which is unheard of

because it's a very formal process. But having a sense of humor, and

being realistic about who you are, so we'll talk about self-disclosure. I

work for a big firm. I walk in the door, you can't miss it, right? But when I

walked into my office four or five years ago, if I put my cane in a corner or

go to a conference or meeting, it went under the table. But if you didn't

see me, you didn't know. Now I sit on the board of the cerebral palsy

foundation and now I wear it proud like a flag. Things change, and again,

you're constantly going to evaluate what your voice is and how you do it but

it's really important that you use that voice. And find what's comfortable

for you. It's going to be different for everybody. Julie was kind enough to

mention my lovely little story. There are five principles that I live by, that I

sort of focus my head around. That is really about being yourself, and

seeing yourself as you want to be seen. So I have CP. I am not CP.

But I have cerebral palsy. But I don't see myself as somebody with a

disability when I'm out there and walking around.

Pick a path. If it turns out to be the wrong one, change it. Make a

different decision. You're not locked into every decision that you make.

The decision you make at one point in your life may be entirely different at

the other. Be realistic about what your strengths are, and also what your

limitations are so that you focus on the things that you're good at, like we

all do. Disability or not. And try to minimize the things you're not as good

at. Cause, why not?

Gratitude, and success to me -- might as well be one word. It's two

words but it's really one. Because at the end of the day I am truly grateful

for where I sit, the job I have. I worked at ten different firms before I got to

Black rock. I'm now managing Director at the biggest firm in the world. I

worked my ass off to get there, and I'm proud of that. So I'm happy to be

a mentor, an advocate, not only for people with disabilities, but for women

in general throughout. Be an advocate. If you're not comfortable doing it

for yourself, do it for somebody else. Trust me, you'll find your voice.

Last of all, be relentless. I never give up. I would much rather beg

for forgiveness than ask for permission. And one last thought, we talked

about the word empowerment. When I looked it up when we were on the

phone the other day, it says to give authority to. I take authority. I don't

give it. I own it. My daughter is sitting right there. Ask her.

(Laughter).

I'll stop there.

(Applause).

RABBI JULIE SCHONFELD: That is beautiful. I want to

remind people, I believe we have cards. There are cards on the table.

We will have 15 minutes at the end to take people's questions of our

panelists.

Thank you, Ila.

We now turn to Amy Rosenfeld who I really had the pleasure of

getting to know during this period of time preparing for this panel. And

hearing about Amy's really incredible work with some of our youngest folks

here at the JCC in our community. Amy, without further ado I'm going to

turn this over to you on the subject of self-empowerment, self-leadership.

(Applause).

AMY ROSENFELD: Thank you. I was thinking about this, and I

write letters to editors. A few years ago I wrote a letter to the editor about

the disability pride March here in the city. I wrote, the public needs to see

us for our abilities, not our disabilities. If we take the dis out of the word,

we have the word abilities and that is what we all need to be noticed for,

our abilities. Do not look down on us. It is more important to get the

word out that we are individuals and I prefer the term abilities to see us for

our strengths and what we're good for. You know, that really meant a lot

to me. Because I don't like the word disabilities. I like to be seen for who

I am, and my abilities. That really hit hard. I do work with the younger

ones here as a librarian. Some of that comes out when I do story times

with the kids. Because I make up stories about kind of be who you are, it's

okay to be that way. It's okay to be who you are and look at all the great

you do. I was thinking about also empowerment. I had some time. And

advocating for yourself. And giving yourself a voice. Not taking no for an

answer. I don't take no for an answer. I stick up for myself. I stick up

for my husband. I stick up for people. And it's okay to say who you are.

It's okay to be who you are. I find empowerment through my writing and

through my art and creativity, and also just finding a way to make it happen.

I just like to write. And my art is a form of empowerment. Just getting out

there, and seeing your strengths, and getting the word out, and just keep

on trying and pushing. I think that's all I have to say.

(Applause).

RABBI JULIE SCHONFELD: Thank you, Amy. I can see that we

are working towards what are going to be really an also very fascinating

question and answer period. One of the quotes that I read when I was

preparing for our day together is from the current political figure Diane

Feinstein. She said several years ago, women have begun to realize that

when they come through the doorway, they bring other people with them.

And I think that's such a powerful message of what we're talking about here.

That everybody is not only asserting their own abilities and strengths, but

also bringing so many people with them. And so with that I also turn now

to our third panelist, Dr. Danielle Sheypuk, who is a psychologist, a sexpert,

and to very much in her career brings what she learns and is to helping

other people.

DR. DANIELLE SHEYPUK: Hi. It's good to be here. That's true, I

do talk a lot about dating, sex, and disability. And I try and -- I feel like I

have a very big voice when it comes to that topic. I guess my interest in

dating, disability and sex began when I was in high school. I remember

this time when -- I have a younger sister who is just about two years

younger. We're pretty much kind of close. We were sitting at the kitchen

table and my family had some friends come over that we hadn't seen in a

while. I remember them going to my sister saying are you dating anyone?

My God, you're single? You're so pretty. We have someone for you.

Do you want to meet someone? I kind of just sat there, and felt really bad.

And felt that I was not a part of that at all. And I wasn't quite sure why.

Because I knew that I did like boys, like all my girlfriends did at the time. I

was interested romantically. Today we're going to talk about dating, sex

and disability in a way -- when the topic comes up, people sometimes skirt

around it or feel uncomfortable, or they don't want to get into the nuts and

bolts of it or the nitty-gritty. Today we're going to get -- we're going to do

that today. We're going to get down and dirty. That's what I was going to

say, which is appropriate.

(Laughter).

So I knew something wasn't right in high school but I wasn't quite

sure what it was. I thought maybe I am different. I don't know. I don't

feel different. I wound up going to grad school in New York City with the

hope of being in a big city, finding a lot of -- hoping people would be open

minded and not be so judgmental. Because you can be anybody in New

York City and people would not look at you or walk around you or step over

you. I'm like oh, that's perfect because I want to fit right in to the dating

scene. I did put up my first match.com profile encouraged by my

roommate. When I got my first response, I wanted to hide under the table.

I didn't know what to say. That was the start of my dating life which is

notable. It was grad school. I was in my early 20s. So that's also very

characteristic of people with disabilities, we start later when it comes to

dating. We have a lot less dating experience and opportunities. There's

a lot of students like that. Which I really won't get into because at that

time I was really into sex and the city.

(Laughter).

I was starting to date. But I knew there was a discrepancy between

myself and my girlfriends. I was getting some dates but they were getting

much more and I felt, well, we're so comparable on so many levels. The

only thing different is my disability. So I want to talk to someone about it, I

want to ask for advice. I looked around. Where is my Carrie Bradshaw

in a wheelchair? Who am I going to talk to? My parents aren't talking

about it and my friends didn't know what to say. I said okay, that's it. It

was like my calling right there. So I began writing a little bit. And then

there's three pivotal points in my career after that.

I'll talk briefly about the three of them. The first one was my friend

called me one night, and was like oh my gosh, I found something online

and it's perfect for you. It's a wheelchair pageant, they look at intellect,

academic achievement, but they also looked at glamorousness. I thought

that's the first time I ever heard disability paired with glamor, style, or cool,

or something, rather than intellect and inspiration. Those words.

I thought let me enroll in the pageant and let me try to win it and let

me use the title along with my Ph.D. to really open the window and start

talking loudly about this topic. That's what I did. And I hired a publicist,

and we hit the ground running because my campaign was a two part

campaign. There has to be media exposure because to me that's one of

the main issues. We do not see people with disabilities dating on

television. Or engaged in romantic relationships. So I feel like it could be

as simple as that. If you saw me on whatever, TLC, or ABC, dating

someone and kissing someone or making out with someone, then the

whole world would be like oh yeah, I saw that. Yeah. People with

disabilities date. No big deal. That's normal. It's just our lack of

exposure that's the main problem. So media is the first way that I get out

there.

The second way is through my private practice with my patients

which I'll talk about in a minute. So then after the Ms. Wheelchair I met a

designer named Carrie hammer, a fashion designer and she had a

show -- she was having a show during New York fashion week and she

wanted to use role models instead of run way models. Women in the

community who were doing great things. We were on the phone one night,

and talking, and she was like do you want to come to my show? I'm like

yeah, I want to come to your show. She was like -- at the same time we

were like wait, you should be in the show, or can I be in the show? And

we thought yeah, it's a great idea. Then we were thinking is the runway

accessible? She's like I don't care. We'll get wood and build a ramp.

We're going to make it happen. I'll do whatever it takes.

So I called this local news outlet, the only connection I had at the time.

Women in news. I said I'm going to be in the show, do you want to cover

it? They said yeah, we'll cover it. They did. The next day I woke up

and was excited to see the write up. What turned out was huff post picked

it up and it went viral. After that we were doing morning shows because it

was the first time someone in a wheelchair ever was on the runway in

fashion week. That was -- we're already in 2013 or 2014 at that point.

So the runway already had a lot of diversity except for us.

Finally, the third point was I did a TED Talk after that. A TEDx talk

on disability and sexuality and that was really a way for me to talk about the

topic. When you prepare for a TED Talk it's supposed to be solution

focused. So you can't go up there and complain about a problem, and not

offer a way to see it another way. So I thought okay, how can I get people

in the audience to entertain dating people with disabilities and not out of the

goodness of their heart? Because I'm tired of that crap. I'm tired of being

looked at in that way. I thought well, for my studies, I know that humans

can be inherently selfish. So let me talk about how they could improve

their own dating lives, or why their dating lives may be lacking

because -- my point was because they're ignoring a whole group of

possible dating partners. That's people with disabilities.

So the divorce rate is so high, people are often unhappy in their

relationships. Maybe you should open your eyes and look around for

other partners. After that -- with media I also do my private practice which

is my main gig, if you will. I set it up where I see my clients or patients

online. I wanted to make it easier for people with disabilities to come to

therapy. So I have clients who maybe have home attendants or nurses

who don't give them privacy. I had someone email me one time saying

can we do sessions over the phone because I literally have no privacy. I

have nurses with me all the time with my family. I said you can't really do

therapy over the phone. I said let's try one thing. Let's try it one time.

Tell them you're going on Facebook. Go in your room. Let's try a

session. If it works, it works. If it doesn't, it doesn't. I've been seeing

her almost four years every week. It gives people a chance for privacy. I

have clients who are not verbal, who use a Toby dynavox system who type

with their eyes. I see it on the screen. I have clients who don't have

disabilities. But I guess I will conclude with the topics my clients come to

me with. I can talk about it at the table today. Where do I find a romantic

partner if I have a disability, or what happens if I need to bring a home

attendant with me? I have one client who brought her home attendant on

the date and the home attendant sat in the back and they have a signal if

she needed help with something so it wouldn't disrupt the date. Or how to

have sex if you have a disability. When to reveal you have a disability, or

how much to reveal, or what sex toys are available to use if you can't use

your hands, or if you need help with someone placing them. Or how do

you have privacy to do that if you live at home? Or even to the topic of

sex surrogacy. I don't know if anybody saw the sessions -- that's really

the iconic movie. But do you hire someone to engage in therapy with you

in an intimate way so you could learn about your body when it's hard to do

that with someone you might meet on the Internet or just organically. We

can talk a lot about this in our round tables. There's really so much to say.

It's hard to break it down in ten minutes. I was hoping to take up some of

Amy's time but that's okay. I won't.

(Laughter).

That's it. I look forward to seeing you guys in the group.

(Applause).

RABBI JULIE SCHONFELD: If we have cards with questions, if our

table hostesses are sending up any cards with questions for our speakers.

I'll give that a minute. And in the meantime, I'm going to ask my first

question.

My first question to all of you is you've each been on a

journey -- everyone is on a journey. If you could look back ten years, 20

years, with what you know now, and say I would coach my younger self to

do this, I would coach myself of ten years ago -- and by the way, I know

speaking for myself, not the early, early days of my life, and I still need

coaching and there are still years ahead of me that I might spend better or

less well. It's not just about people who are just starting on their journey,

but what is the one piece of advice that each of you would give to your

earlier self? Start with -- anybody want to start? Anybody willing to start?

DR. DANIELLE SHEYPUK: I would tell my younger self that -- I

spent -- I have great parents. And they told me -- they wanted me to fit in.

A lot of it is I was the only one in grade school, the only one in high school

in a wheelchair. Kind of like fit in the best you can. You have a disability,

but you could do what everybody else can. Not minimize it, but just do

your thing in school. Don't make a big deal out of it. I see this a lot in the

disability population and with my clients. It kind of breeds this

environment of trying to hide your disability, or down play it so you can kind

of fit in, or pass as, quote unquote, normal. And that's very detrimental.

It's very ablist. Because you're feeling ashamed or embarrassed about

something that's a significant part of who you are. And it's something that

shouldn't be shameful or embarrassing. I would tell my younger self to

embrace it, the fact that it's different but everybody is different. So don't

try and down play it. Maybe I would have had more confidence back then

in high school when it came to dating and I could have approached all the

boys differently. Maybe I would have had more dates or a date to prom.

That's what I would have told myself.

RABBI JULIE SCHONFELD: Thank you.

AMY ROSENFELD: I would say look for your strengths, and -- look

for your inner strengths. And take that and go with that. And never say

never and don't take no for an answer. That's what I say.

RABBI JULIE SCHONFELD: Thank you.

ILA ECKHOFF: I think for me, I had a lot of anger and frustration

that I ended up having to find outlets for. I think I probably would tell my

younger self now, I wish I could have taken a breath. I wish I could have

learned meditation earlier. I use that now to kind of bring my stress level

down. I create a one minute meditation. Because I don't think I ever

gave myself a break. I drove myself pretty hard and I'm better at it now.

Take a breath.

RABBI JULIE SCHONFELD: Thank you. There are a number of

really excellent questions that came. Some of them I'm going to flag them

for the small groups. I'll mention those, and flag them specifically. But

here is one that I'd like to start with. Can you name and talk about a time

where you faced ableism and/or discrimination from people who were

supposed to help you? I'll add maybe even from people who you think

wanted to help you, who just weren't really educated enough to be able to

do it.

>> Can you give a definition of ablism?

RABBI JULIE SCHONFELD: Thank you. First, to give a definition

of ablism, Debbie, is there a definition that RespectAbility uses?

Remember in my disclaimer I speak only for myself.

DEBBIE FINK: Don't hold me to it. Ableism is I would say a context

for people who are ablists who make assumptions about people with

disabilities that they -- the official definition is discrimination or prejudice

against individuals with disabilities. There you go. Very simple. Thank

you.

RABBI JULIE SCHONFELD: Going back to the question, can you

name and talk about a time when you faced ableism or discrimination from

people who were supposed to help you? I'll also offer a second spin on

the question. You can take either one. Can you give us some advice on

how to work with people who want to be our allies? Can you think of

some time when you were able to help people be better allies for you?

Either way you would like to take the question.

ILA ECKHOFF: When I was a kid growing up in the '60s I took a lot

of bumps and bruises for a lot of different things. Kids would steal my

crutches, trip me in the hallway, or going down a flight of stairs. Just

cause me all kinds of pain and suffering. Some of them would happen in

school and my dad would talk to people in school and it didn't really change.

So then my dad went out and bought me a punching bag and boxing

gloves and taught me how to fight. You go into school the next day, the

next kid who picked on me, don't go after him. Pick the biggest one in the

crowd and deck him.

(Laughter).

If you deck the biggest kid in the crowd that's making fun of you, then

everyone will understand. My father who was my advocate, who was

fabulous, obviously everybody in school and camp and other places where

I was, when they were supposed to protect me, they weren't particularly

good at it. I learned to deal with it myself. I had to pick the fight, in

elementary school there used to be double doors. I couldn't move much.

At the time I had metal crutches that go around the wrist. I had my

physical therapist teach me how to use them to get somebody in a head

lock, bring him down to his knees so now we're the same size and literally

punch the crap out of him until somebody in school pulled me off. I never

had to do that again. Once I did that other people started sticking up for

me because they realized I would stick up for myself. Kind of a weird

story. But I think it makes the point.

(Laughter).

RABBI JULIE SCHONFELD: Thank you.

DR. DANIELLE SHEYPUK: An example that I could think of was

when I was on a date and I talk about this in my TED Talk. It was our third

date. Whatever it was that was happening but I met him online and I

thought things were going really well. I thought once you get past the

second date, it means a lot. In current times. I was feeling good, relaxed,

competent. I remember he -- the conversation got a little awkward or he

seemed awkward or there was some sort of tension. Finally he mentioned

that he was concerned that he wanted to have a family, and he wasn't sure

how I would manage that, or how I would be a mother, or how I would help

raise children, or clean the house or clean his dirty underwear or whatever.

I was like well, that's easy. I can manage that the way I manage my life

now. I just have people who help me. I have assistance. That was kind

of ablistic thinking because he just assumed that I wouldn't be able -- I

wouldn't make a good wife or mother. And that's all stereotypes. There's

no truth to that at all. So I guess to help -- I think that sometimes people

just don't know. They because of lack of exposure, they don't know how

to go on a date or take someone out with a disability because online some

questions -- my patients get this all the time. The number one is can you

have sex? Of course. Why not? I don't mean to be graphic, I'm

speaking for myself now, but people have sex with anything in any way, in

different types of positions. Of course it's possible. And then also how to

take out someone on a date, or maybe they're not sure if -- my last point is

their friendship circle. Again, I'll use a guy in reference. But maybe he'll

be comfortable dating me, and okay with it. But from his friends and

family he'll get why? Why did you pick someone who has so many

issues? Why not make it easier for yourself? When they face that sort of

pressure from their peer groups it's another obstacle for us promoting

ablistic thoughts. Thank you.

AMY ROSENFELD: As the youngster, I had a learning disability.

And my family said no, you can't go to college. You can't go to graduate

school. You can't do this, you can't do that. I wasn't good at math and I

got through it. I turned the can't into I can do it and I did it. I went to

college, I went to graduate school. I tied the knot exactly 8 months ago.

Not a shoelace. But I got married 8 months ago.

(Applause).

I've overcome a lot. My family supported me through all of that and

they still do. But like I said, I don't take no for an answer. And at the

dating and sexuality table if you come to that you'll learn how I met my

lovely husband.

RABBI JULIE SCHONFELD: Thank you. I'm going to put two

questions together. By the way, also before we close, I'm going to just

read every question that was asked. Some of them I think will work better

in the small group but I want everybody to hear what people's questions

are. I think that's helpful. These are two questions I'm going to read

together. This is addressed to Amy or Ila in regard to terminology. Both

of you said that you don't like to use the word disability. But if we

advocate for the disability community as a community, and if we

own -- that's emphasized -- if we own our disability, don't we need to use

the word? And then a related question is there was some talk about being

better and faster but I believe that accessibility should not be based on

merit. How do we demand accessibility even if we're not better or smarter

than average?

ILA ECKHOFF: That's a loaded bunch of questions.

(Laughter).

I'll start with my friend Stacy I don't think is here but she and I had a

big debate when we launched or disability network at black rock which we

called ability network. I was obsessed with the word. She has a son with

Down Syndrome. It's a word just like any other word. The point of the

question, it would be great if we could talk about it like it's just a word.

And I hope some day we get to that point. But sometimes I think you need

to go sort of to the other extreme, to end up in the middle. Growing up,

look, I had the pleasure of meeting Tim Shriver a while back, the CEO of

Special Olympics. He brought all pictures of people in the '40s, '50s, et

cetera, people being put in institutions and locked away somewhere

because people don't know what to do with it and deal with it. I think the

reason why I push on ability so hard is I want the language to change.

Sometimes I think at least for me personally, because mine is visible, and

I've gone through my stuff, that's kind of my approach to doing it. But to

the point of the question, I think everybody has to take their own voice in

their own way. This is very much an individualistic community. We need

to work together to facilitate change and have an impact on a wider scale.

But every individual with a disability or somebody who advocates for

somebody or lives with somebody with a disability, you have to find that

voice and what works for you.

RABBI JULIE SCHONFELD: Thank you. Before I transition, I

wanted to reflect something Jewish on these questions, which is there is a

drash I like very much that says when a king or a Queen makes a coin for

their kingdom, every coin looks the same. It has the picture of the king or

the Queen. But when God makes God's coin for the world, we are God's

coin. And every one is completely unique and different. We got a long

way to go to really realize people internalizing that and understanding that.

But that's the vision and that's what these questions reminded me of.

Does anybody else want to address this particular set of questions on the

language of ability/disability, and also whether people need to feel that we

needed any way to deserve to be able to demand accessibility, by being

better or different in some way, or we not -- just making everybody

recognize God's difference and God's coinage.

>> Could you repeat the second question one more time?

RABBI JULIE SCHONFELD: I put them down. I was being so

organized. Thank you. Amy or Ila, about the terminology? That one?

The second part. You both said you don't like to use the word disability

but if we advocate for the disability community as a community and if we

own our disability don't we need to use the word? There was some talk

about being better and faster but I believe accessibility should not be based

on merit. How do we demand accessibility even if we're not better or

smarter than average?

DR. DANIELLE SHEYPUK: That's a really, really great question.

That's a big one. I encounter a lot -- I had that brought up in my practice a

lot with my clients. Because I think that is what a notion that is instilled in

us when we're younger, be better, be faster, achieve more. You have a

disability so be above the rest. Or achieve and succeed. Which is a

good message but sometimes the second part of that is try not to ask for

too much. Do it the best you can. And try and find ways to do it but don't

draw attention to it. Don't put a spotlight on it. That could be very tiring

and very exhausting. I've had clients who just -- you try so hard and you

get run down because you're running this marathon and not asking for the

help you need, which is written in law through the ADA what you're allowed

to ask for, for employers, and you don't have to worry about getting fired if

you need an hour for lunch as opposed to half an hour, or if you need

shorter work days as opposed to longer ones. That doesn't mean you're a

bad psychologist or you're a bad teacher or you're performing below

standards from the rest. That's just what you need to do your job as a

teacher, for example. Because you're qualified and a brilliant teacher.

Asking for that, knowing what to ask for, and asking for it assertively will

help you be more of a brilliant teacher rather than being like oh my gosh,

I'm asking for too much. They're going to fire me. It's a big one that

comes up a lot.

RABBI JULIE SCHONFELD: Thank you. I believe that we're

coming to the end of our time for the panel. What I'd like to do very

quickly is I just want to read out, there are a few other questions, because I

want people to know what folks in the room are thinking about, and also I'm

doing this hopefully so when you go through the day and prepare to go to

small groups, people will come to small groups feeling free to bring the

questions in your heart even if they are personal questions. We really

hope people can feel comfortable here and feel this is a safe and private

space so that we can really be with one another in a constructive way.

This question would have been for Ila. It says you talked about

knowing your limitations with regards to disability. Can you give an

example of when you turned it into an ability? And how is this important to

you? Also to Ila, could you speak about negotiating salary and how to

advocate for your worth in New York workplaces? This is not addressed

to any single one of our panelists. When is it appropriate to disclose your

disability when you start to see or date someone? That probably was

towards Danielle, or towards Amy. Or it works towards Ila. And when

you mention having intimate feelings for an able bodied member of the

opposite sex, how do you deal with able bodied friends who change the

subject or even laugh? I think that would have been written in the

opposite way. How do you deal with able bodied friends who change the

subject when you discuss -- when you open up and discuss a romantic

interest you have.

Finally, what protection outside of the ADA do you have when you

first seek employment in the first interview? I will also add to that, since

this is a Jewish group, remembering that to a certain extent some of our

Jewish institutions actually are not bound by the ADA or the IDEA, not as

other institutions and that is a very, very significant challenge that we all

face.

With that, I'm going to bring what was a really phenomenal panel to a

close. I learned so much. I want to say, tending to close with my nugget.

I had a different nugget and Debbie and I had this long discussion about

can you prepare a nugget? I said I can't relate Jewishly to things that

haven't happened yet. So I had a different nugget. But now it's not right

for the end of this panel and I want to close really with for me, and maybe

other people can feel this too, Ila mentioned having some kind of

visualization, meditation to draw aside with, and really remembering how

each of us, however you define God in your life or don't define God -- we

are all sacred, holy people, however we relate to our sacredness and

holiness, but to remember that each of us is that coin of the highest value

that we can imagine. Each of us is really minted perfectly as a coin of all

that is most sacred in the world. And to hold that vision in our hearts.

And we are the currency. And we are the currency. And together we

make great investment that we should put under asset management.

(Laughter).

To go back to my script here, we are going to take a short break.

We invite people again to make some friends, get to know each other, and

we will then prepare for the next wonderful section of our program. And I

will stop here. Debbie, is there anything you want me to adhere that I

have not yet added.

DEBBIE FINK: Round of applause.

(Applause).

And we really hope and encourage -- not hope, but we encourage

really to turn to people you don't know. You can even move tables,

musical tables today. Ask somebody what does empowerment mean to

you? You can ask them to talk about the qualities of Jewish woman that

they admire. We hope there's a lot of mixing and mingling today. We

invite you to take advantage of that.

VIVIAN BASS: Please be seated. We're about to continue with the

program. We now welcome Rachel Kunstadt, a mental health advocate

who is all things theater. While working right here at the JCC. We have

the opportunity to experience her use of the arts for mental health

advocacy. Her piece today is called life day. Choosing life. Thank you,

Rachel, for joining us along with vocalist Marissa Davis, pianist Anessa

Marie. (Applause).

RACHEL KUNSTADT: When I was asked to speak this afternoon I

had a moment of panic. I thought I can't speak in public. That moment

of panic was just that, a moment. But years ago the thought of leaving my

comfort zone ruled my life. I had panic disorder with a history of

agoraphobia. I had my first panic attack when I was 10 years old. I was

diagnosed with panic disorder at 13, and when I was 16 years old I became

agoraphobic. I became completely house bound for six months during my

first semester in junior year of high school. There's a lot more to me. For

instance, I love theater. From a young age I went to Broadway and off

Broadway shows and experienced the magic of live theater. I performed

in school and camp musicals as a kid. And when I was in high school I

discovered writing. I wrote short plays, monologues, and lyrics. I didn't

know what I wanted to be when I grew up, but I knew it involved theater.

I grew up in Westchester County about an hour north of New York

City. In 10th grade every weekend I went into the city to see Broadway

shows. I would babysit on Saturday nights and then spend the money I

earned on theater tickets on Sunday. I loved being in Manhattan. It was

so alive, full of passionate, driven people. I loved my theater adventures

in the city but high school is not without hardships. Adolescence is difficult

for everyone, even those without a mental illness. Growing up into an

autonomous adult is terrifying.

As 10th grade continued the world became too overwhelming.

Class mates were caddy, school was demanding, and on top of it all I

discovered my sexual orientation. My panic attacks got more severe and

frequent. I began avoiding situations in fear of having a panic attack. I

stopped taking weekly trips to New York City. My world which had been

as big as Manhattan sky scrapers got smaller and smaller until I confined

myself to my house. My agoraphobia threatened my friendships, my

education, my theater, and my life. This is before social media and texting

were readily accessible and since I wasn't present in school I wasn't

present in my classmates' lives. I was home schooled and tutored for a

few hours a day, and I spent the rest of the day watching daytime

television. I attended a private high school because they had a performing

arts program. In late September I was officially expelled from that school

because I was unable to get back to school to attend classes. One day an

envelope arrived in the mail, tuition refund papers. It was real, I wasn't

going back to school. I would stay in my house forever. I locked myself

in the bathroom. I was anxious, depressed, sad, scared. I didn't know

what to do.

I opened up AOL instant messenger, which was as far as social

media got back then, and I reached out to the friends I had for support.

You're a lion who thinks she's a kitten, one responded. If you can create,

you can do anything. If you can create, you can live. I paused, took this

in, and breathed. Then I created. I wrote a song, my first, about the

intense emotions I was feeling. One song turned into two, and two turned

to four, and on and on.

I could have given up on life and myself but I walked out of the

bathroom and started to see the inner lioness within. In addition to my

writing therapy I had phone sessions with my therapist twice a week where

I talked about the underlying issues beneath my panic. I had been very

fortunate to have access to mental health care and a relentless supportive

mother who would not give up until I had my life back.

On January 9, 2007 I left my house for the first time after six months.

I call it life day, and every year I celebrate the anniversary of choosing life.

This year I celebrated 12 years. I made strides in my life. Attending

school every day and making new friends but I still couldn't get back to New

York City. It was too crowded, too hectic and too far from my comfort

zone. After finding the right combination of medications and having many

therapy sessions with my wonderful analyst, a year later in the spring of my

senior year of high school, I was ready to go to New York City. A friend of

mine recommended a new musical that was playing off Broadway, Next to

Normal. Not knowing anything about the show, my mom and I bought

front row tickets to one of the final performances before it closed. We took

the Metronorth train to grand central, walked across town, and for the first

time in my life I saw mental illness depicted on stage a foot in front of me.

The musical about a woman with bipolar disorder closed off Broadway but

transferred to Broadway the following year and won the Pulitzer prize for

drama. I graduated from high school that spring. I enrolled in a small local

college in Westchester four blocks from my therapist's office. I lived in the

dorms away from home. I continued to push myself out of my comfort

zone. My love of theater and my world grew and grew. I got an

internship at an off Broadway theater company in Manhattan, and I decided

I want to study theater which my current college didn't offer. I craved an

academic challenge in an environment full of passion and drive. I

transferred to New York University and moved to New York City in junior

year of college. I went from a small suburban college of 700 students to a

40,000 student university in the heart of Manhattan. I took theater classes

with Broadway professionals. In addition to my studies I saw about a

show once a week. I'm not going to lie, it was a hard transition. I had to

leave my therapist who helped me overcome my agoraphobia. I stupidly

started to wean myself off of my medication. Words of wisdom, do not do

that. I started working with a new therapist who I still see over 8 years

later. I was challenged academically and in life, and I graduated from

NYU with honors. I was accepted to a graduate program at NYU's Tisch

school of arts where I received a Master of fine arts degree in musical

theater writing. As I continue to grow and heal, I struggle to keep my

mental health straight. My mother with whom I am very close cautioned

me not to share my story. She was nervous about how I would be treated.

I listened and I kept my secret. I hid my past so far inside me that I felt it

pushing its way out. I should be proud, I thought. I shouldn't have to live

in cryptic Facebook posts.

On the 10th anniversary of life day I came out about my mental

illness. The theater person that I am, I wrote a musical memoir cabaret

about my mental health journey, and I shared it with the world, having it

performed live. I was terrified. I wanted the world to know, but I couldn't

help but hear my mom's voice in the back of my head. Once I began to

share my story I started getting positive feedback from people who have

experienced panic disorder, agoraphobia, and other mental health

conditions. I was helping others. I could use my struggle for good. I've

been expanding the cabaret show into a full length musical, a song from

which I'm excited to share with you. In the song towards the end of the

musical, the protagonist leaves her house for the first time in six months.

Marissa Davis, Anessa Marie.

(Applause).

(Piano).

(Singing) Left shoe first, then the right. Steady. Tie the laces, not

too tight. They're worn and forgiving, old strangers to my feet, but they

have to hit the ground to make their lives complete. Open the door.

Open the door.

Get your coat, hat and gloves, slowly. Brace the bitter, warm it with

love. The wind chill is brutal, but autumn felt the pain. I didn't know the

leaves, but winter still remains. Open the door. Open the door.

Moses spent 40 years in the desert. And I spent six months in my

room. Almost dead, I said choose life. Before I died, I cried I choose life.

I choose to live, I will not hide from fear, from panic, from love. I choose to

live. I choose to give. I choose to try. Today I do not die.

Take a breath. Then let go. Exhale. Eyes stay open, start to

grow. Open the door. Open the door.

(Applause).

RACHEL KUNSTADT: Thank you. If I had known when I was a

house-bound agoraphobic 16-year-old that a decade later I would be living

in New York City working in professional theater and inspiring others living

with mental health struggles, it seems silly I would get anxious about public

speaking. After all these years I've gotten really good at pushing myself

out of my comfort zone.

Later today I will be cofacilitating a discussion with Allison Kleinman,

the director of the JCC Special Needs where we can answer your

questions on taking charge of your mental health. If I may pose one

question for you to ponder, I ask what is your life day? When did you

choose life? Thank you.

(Applause).

RABBI JULIE SCHONFELD: As we make the transition now, we're

going to go from a powerful moment of music from the heart to another

powerful moment of music from the heart that perhaps we can all

participate in together. People may or be familiar with or may be hearing

for the very first time the beautiful powerful words of Rabbi Nachmam, Kol

ha'olam kulo Gesher tzar me'od Veha'ikar lo lifached k'lal. The whole

world for all of us is a very narrow bridge, and the main thing is to have no

fear at all. So those who know the song, if you will step outside your

comfort zone because I don't sing very well, regardless of how comfortable

I am with it. So that we can all sing this together.

Debbie.

DEBBIE FINK: It's quite something to follow owe.

(Violin).

Kol ha'olam kulo Gesher tzar me'od Veha'ikar lo lifached k'lal.

Kol ha'olam kulo Gesher tzar me'od Veha'ikar lo lifached k'lal.

Veha'ikar lo lifached k'lal.

Veha'ikar lo lifached k'lal.

(Applause).

RABBI JULIE SCHONFELD: All the world is a very narrow bridge.

And the only thing for all of us is to have no fear. We are going to prepare

now to transition to our next segment. Shelley.

DEBBIE FINK: Feel free to stretch here, whatever part of your body

you want to stretch, stretch it.

SHELLEY COHEN: We have a few minutes. If anybody wants to

stretch. DEBBIE FINK: We invite everyone to come back to your seats or to

a new seat because we are about to start the next part of our program.

SHELLEY COHEN: It's a long afternoon, but it's really quite

emotionally packed and we hope you are getting a lot out of it. As we are.

We are now really fortunate to hear from Lori golden, a trail blazing

self advocate who leads disability advocacy in the corporate world. Lori is

the ability strategy leader at Ernst & Young. She will be interviewed by

Debbie Fink, RespectAbilitys Director of outreach and impact on Jewish

inclusion work.

DEBBIE FINK: Thank you, Shelley. Lori, thank you for joining us

today. LORI GOLDEN: My pleasure. I need to learn how to turn on the

mic. Now it's working. I'm a quick study.

(Laughter).

DEBBIE FINK: You're a trend setter, as Shelley said, at Ernst &

Young, a company that employs a mere 260,000 people, and is one of the

biggest accounting, audit and financial services consulting firm in the world.

As I was walking the streets of New York City, I looked up, and there was

Ernst & Young loud and proud. I want our participants to get to know you

both personally and professionally. Let's start with the personal. How

are you today?

LORI GOLDEN: I'm great. Very excited to be here. This is really

energizing.

DEBBIE FINK: Great. We are excited that you're here today.

You yourself have said that you are an open book, and you have had to

discover the art of your self-advocacy. Will you please share what

invisible disabilities you live with, and like Goldie locks, address the

challenge of over sharing versus under sharing versus sharing just enough

which we'll get to a little later.

LORI GOLDEN: Sure. First, I tend to use the term nonvisible

disabilities because to me the term invisible carries tones of purposeful

concealment, or hiding. There's obviously no shame and no reason to

hide. Unlike some of the panelists you heard from, I acquired my

disabilities later in life. When I was in my 20s, my back kind of suddenly

collapsed and I was diagnosed with degenerative disc disease. I spent

weeks at a time in bed. And later, a few years later I was diagnosed with

fibromyalgia. Today -- every couple of years I acquire new disabilities. I

have osteoporosis, and a narcolepsy like sleep disorder, chronic migraines,

and a whole litany of conditions in addition to what I started out with. It

actually took me a while to come to grips with the value of being as open as

I needed to be; sharing what I needed to share in order to get an outcome I

wanted. And for me, and disability work is what I do professionally, people

are on this, where health and safety are a consideration. It's really

important to share as much information as you need to, to keep you or

others around you safe or healthy. If performance -- I don't mean just

performance at work, but meeting interpersonal expectations is a

consideration in terms of your disability, you need to share just enough to

set appropriate expectations so that you don't appear to disappoint

somebody's performance, or behavioral expectations of you.

Sometimes actually sharing around a disability can bring you closer

to people. One reason to share often, and one value in sharing, at least

some information, can be it brings the two of you together. I recently went

on vacation for ten days with a woman I didn't know very well. And we

shared a lot with one another about our own disabilities, and family stories,

and everything else. And it brought us a lot closer together. We all kind

of find that in our lives. So you need to decide what your parameters are.

DEBBIE FINK: Thank you so much for sharing. Yes, it can be a

bonding experience to share with others, and to get that validation, and to

go from there. Thank you.

Pivoting now to your professional hat, wearing your professional hat

at Ernst & Young, you're an EY strategy leader. Can you briefly share

some of your strategic, innovative disability advocacy programs that you

have brought to the work place?

LORI GOLDEN: Sure. But before I do, I'd like to kind of harken

back to a discussion the panel had around terms, disability, abilities. And

to my day job at Ernst & Young. At Ernst & Young we tend to talk as

much as possible about all abilities, or diverse abilities. That's not to say

we never use the word disability in an employment context. It has very

specific meaning. We know that in terms of the ADA, and employment

law. However, when we universalize, we make disability not a small thing

that is seen to affect a few people. It's harder to marginalize an

experience that almost everybody has, and we all know that disability is on

a continuum. We have all had disabilities, or will have disabilities at some

time in our lives. So to create a binary that there are people with

disabilities, and there are people who are typically abled seems to me a

false binary, and not very helpful to anybody. I'd rather focus on the fact

that each of us has a unique combination of abilities. Some of those are

more welcome than others. And those wax and wane at various times in

our lives. I mentioned every couple of years I acquire a new disability.

So we are trying to change the frame of reference by changing the

language that we use.

Now, some individuals see themselves as disabled and proud. And

that's great. Far be it for me or Ernst & Young or anybody to tell any

individual how he or she should identify. We also -- I was talking about

that, we also have two initiatives that we're really proud of that were

launched in the last couple of years. One is around neurodiversity. We

specially source, train, on board, and support individuals on the autism

spectrum to do very high level professional work. I think what's notable is

that we are hiring for aptitude and then we're training for skills. We're not

just hiring people who happen to have relevant work experience or

education experience. But we're hiring people who we know have a basic

ability and then we're going to train them to use that ability. And the other

is around mental health education and awareness, to equip all our

colleagues to understand if somebody that they work with or know might be

struggling with a mental health issue, and give them a framework for how to

be supportive. Taking something that seems really complex and scary,

demedicalizing it, breaking it down, and making it approachable so we can

help one another.

DEBBIE FINK: Thank you. I think specifically based on Rachel's

piece prior to this, it's just so critical that companies, corporations like yours

are addressing the mental health piece in the work place. Kudos to Lori

for leading the way.

Now we get into the real stuff about self-disclosure which you prefer

to call sharing.

LORI GOLDEN: Yes.

DEBBIE FINK: The first big word is in front of us, the starting point,

two letters. It is IF. If to share. Can you speak to that? And it's

relevant to women -- anybody with a disability, or any other struggle. Can

you address the if question?

LORI GOLDEN: Sure. I started talking about that before. If the

condition we'll call it is going to impact how somebody views your behavior,

then it might be appropriate to set the expectations. That doesn't mean

you need to name something. One of the most useful strategies that I

stumbled on years ago when I was coaching somebody with Asberger's

who had run into a lot of issues at work because he was blunt, and very,

very honest as people with Asperger's tend to be. Didn't perceive when

he crossed a line and offended a lot of people. He would raise his voice

and not realize he was raising his voice, and on and on. His work

performance was great, but nobody wanted to work with him. So there

was a real problem. And what we worked out was a script by which he

would say when he was beginning to work with anybody new, a client, a

colleague, a supervisor -- look, I'm a big guy. I really mean well. But I

want you to know because I think it behooves us in working together to

know our work styles that one ideosyncracy I have, sometimes I tend to put

my foot in my mouth. I can be really blunt and I don't mean to be. So do

me a favor, and give me a heads up if I say something that seems too loud,

or too curt. Sharing some information -- he never named it, never labeled

himself. But setting an expectation and letting somebody into that

expectation, and letting them be part of the solution, letting them help is a

way to get closer to people. It's a fantastic bond. And it sort of

innoculates you because it's much harder to hold it against him if he's

raising his voice or shouting if you've been warned and if asked for help

with it. The same thing goes for almost any disability situation. Give

people a heads up where they can help you, and ask for help. That

doesn't mean you need to label.

DEBBIE FINK: That is such useful advice. Thank you for that.

The next big question, again it's the goldilocks. We pretty much

addressed it to some degree, how to share. Is too much to share? Is it

too much, too little? You can touch on it again.

LORI GOLDEN: You said it when you said just enough. I'm not

being coy here. What's just enough depends on your personal style,

depends on your relationship with the person that you're speaking with,

depends on the context and the purpose. So if it's a personal relationship,

and you are close to somebody or want to get close to somebody, you

might share one set of facts. If you are requesting an adjustment at work,

in how, where, when, or with what tools your work gets done, also known

as an accommodation, another word I don't really like -- then you might

share another set of facts. If you are like me, somebody who really wants

to let people in -- that's an important value for me. I want people to know

me. Then you may share more. My best friend, who has a disability,

values privacy above all else. In all aspects of her life. And she shares

almost nothing. You need to determine what's right for you to fit the

context and the purpose for which you're sharing.

DEBBIE FINK: Thank you so much. Thank you. It's very well

articulated. Then we get to when do we share it? The big question.

When? LORI GOLDEN: I'm going to sound coy again. But when situations

demand it, or when the situation could be improved by it. So again, you

need to think through why, what, when, how according to what your goal is.

If you are asking for somebody's assistance at work to change something,

or you're asking somebody to help you out with something that is difficult

for you to do, or you're wanting to get close to somebody then the purpose

and the context helps determine when and where you share. If you are

sharing with a supervisor, or an HR person in kind of a formal context, who

is representing an organization that you're working for, then that's private

information. And you may share it in a very kind of private closed doorway.

If, however, just to give you the opposite end of the spectrum, you are

sharing because you want to empower others, you want to be a role model,

then you share in a public way. I had a really seminal moment about four

years ago where I was on a panel talking about disability, nothing to do with

my particular situation, and I was with two other women and none of us

appeared to have disabilities. Very well known disabilities advocate who I

knew, who knew a little bit about my situation approached me after and she

said that was a great panel but what a shame nobody with visible

disabilities was on that panel. And Lori, it would be great if next time you

share that you have nonvisible disabilities. So people know that there's

somebody up there with disabilities speaking. And I said to her, oh my

gosh, but this isn't about me. I don't want to turn the topic to me. The

focus should be on the content. And she said, it is. But understand that

by not saying that, people could come to the conclusion that there's nobody

with disabilities who has something worthwhile enough to say on the panel

because you're not making it obvious they're not seeing it. So you have a

responsibility. And it changed the way I approach things.

DEBBIE FINK: Thank you. That's key. Yes, making sure there

are women on a panel when a conversation is happening, a panel is

happening that we all sort of look at that representation in terms of ethnicity,

et cetera. This is putting the D of disability back into diversity.

Last but not least, we are running out of time. But is the with whom?

You touched on that. We don't have the time to get into it, but perhaps at

the table you can address with whom do we share the information? And I

would love for you at the table, at the break out to address their legal

limitations versus the person's legal right. What the individual can do with

the information once it is shared. But we'll wait and we can sort of push

that out. Do you have a short nugget that you can address that with?

LORI GOLDEN: Address --

DEBBIE FINK: A closer.

LORI GOLDEN: Well, if you're talking with somebody who is

representing an organization in a formal capacity, then confidentiality

applies. If you're speaking with somebody in another context, then you

can ask for confidentiality. But it's on the person's honor. That's the very

short answer.

DEBBIE FINK: Concise. Thank you. And you'll be able to ask

many more questions of Lori and Ila at one of the small group sessions,

which is about self-advocacy. Lori, this has been so valuable. And I just

want to share -- we're going over time. But just a really quick question I

have for you to close-out. 20 years ago, if you had a Pearl of wisdom you

wish you had received 20 years ago or more, what would it be?

LORI GOLDEN: This sounds so obvious. But know yourself.

Know what you're comfortable with. There is no -- Ila said it. She and I

talked about this beforehand. But there's no one right answer. What all

of us here speaking, and in the tables can share with you is a framework

for how to think about things. But it's up to you how to apply that

framework. So don't let anybody tell you that, quote, you should disclose,

or you shouldn't disclose, or how much to disclose. You need to decide

and all we can do is help you run through those considerations.

DEBBIE FINK: Thank you very much. Let's give Lori a round of

applause.

(Applause).

Great. Thank you. Lights up still. Now, as I said, Lori, Ila will be

cofacilitating the taking charge of yourself advocacy. You can continue

there. Now this is a moment of transition where you can all take 10 to 15

minutes -- 10 minutes to schmooze, have a nosh, use the bathroom.

SHELLEY COHEN: But before you do that, I just want to conclude

the live streaming portion of our program, RespectAbility and the JCC

Manhattan thank all our live streaming attendees for joining us. Please

complete the survey online. Enjoy the rest of your day. Thanks.

DEBBIE FINK: Good-bye, live streamers. Thank you for joining us.