

ROUGHLY-EDITED TEXT FILE

JCC CHICAGO

An Accessible Bat Mitzvah

Talkback with 13-year-old Disability Rights Advocate

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>>RENA: Gavi, I believe it is really important that I don't speak on behalf of you.

And so, I want to begin by giving you some time to share what your disability is and how it affects you.

>> GAVI: My disability is nemaline myopathy.

It makes my muscles weak, so I have a speech impairment and I can't walk.

I use a power wheelchair to help me get around.

I have a trache because it's harder for me to breathe because my muscles take smaller breaths.

>> RENA: How does having a speech impairment affect your life?

>> GAVI: Having a speech impairment really makes it harder for me to communicate with people, and half of it is because of my unclear voice, and the other half is because of the stigma around people with speech impairment.

For example, a lot of people pretend to understand me when I talk to them because they're afraid that if they ask me to repeat myself or type it on my phone, it will make me feel bad.

But it really doesn't.

I actually really appreciate it because it means that they care about what I have to say.

>> RENA: When you and I talked prior to this event, you had mentioned that when people pretend to understand you, or rather don't talk to you at all, that it's a big frustration.

Can you share any experiences that you've had where this has happened?

What do you do when you're faced with these situations?

>> GAVI: I have teachers that pretend to understand me.

One time when I asked my French teacher a question, she responds with a nod, and I can see with her eyes that she doesn't really know what I'm saying.

So I realize that, and then I type it on my phone.

It's also really hard to make friends.

My voice really impacts my social life.

I feel like I have to wait for somebody to come up and talk to me because I feel self-conscious to just go up to a random person and start talking to them because I know they won't understand me.

My friends now have all come up to me the first time we met and started the conversation with me.

I really appreciated that, so I made more of an effort to connect with them.

By coming up to me, I know they care and that they actively want to become friends with me, and they are making an effort to connect even though I am disabled.

Most people my age who don't know me are resistant to talk to me because I have a disability.

>> RENA: So before we got on tonight, I was thinking about how many times someone sees someone who has a communication disability or difference, and resists the urge to say something because they're not sure if they understand, or if they can communicate, which is why I think tonight is so important to demystify those ideas and misconceptions.

Gavi, your Bat Mitzvah got a lot of amazing attention and recognition this past year.

When I read the forward article that interviewed you, I immediately thought, I want to know more about Gavi!

Can you share with us some insights into your Bat Mitzvah?

What was your Bat Mitzvah Davr Torah?

How did you do it?

And what was it about?

>> GAVI: My Davr Torah for my Bat Mitzvah was from parsha shelach lecha.

In that parsha, the 12 spies went to the land of Israel to see if it was fit for the people to live in.

Ten of the spies didn't see Israel for its true beauty and assumed that it wasn't fit for the people.

Two of the spies, named Caleb and Joshua, saw that the land of Israel was beautiful, and that it had all the things they needed to live.

I connected this to my life as a disabled person because a lot of people make surface assumptions about us, disabled people.

They assume that we don't know how to communicate, that we're not that smart, that we don't have a good life, just like how the ten spies didn't dig deeper about the land of Israel.

But the fact is that I am smart.

I can talk.

And I have an amazing life.

Because I have a speech impairment, I needed captions to caption my Davr Torah while I was saying it.

We were in the shul that keeps Shabbat strictly, so having a screen and projector was not possible.

So we came up with the idea to use billboards that have my text on it.

We had 25 billboards, and two people were changing it while I spoke, and it worked really well.

We have a photo from the rehearsal that we can show.

>> RENA: We do have some photos from Gavi's Bat Mitzvah to show, and you'll see the billboards with captions that Gavi was describing, as well as photos of her celebrating with her friends and family.

So if you'll give me a moment, I'm going to share my screen.

So here we have Gavi with her grandfather's Papa Bob and Joel at her Bat Mitzvah rehearsal in synagogue.

And this was Gavi practicing her Bat Mitzvah Davr Torah using the boards as captioned to ensure accessibility.

This is Gavi and her twin sisters at her Bat Mitzvah celebration.

Gavi dancing the Hora at her Bat Mitzvah celebration.

And Gavi's friends entertaining Gavi during the Hora at her Bat Mitzvah.

Stop sharing.

So Gavi, while you and I were coming up with ideas and topics you wanted to cover tonight, one theme was accessibility in Jewish spaces.

Talk to me about that.

What has that looked like in your life, and in your experiences?

>> GAVI: When I was younger, my shul was really inaccessible.

But because I was so small, my dad could carry me, and I could sit wherever I wanted because I didn't have scoliosis at that time.

But as I got older, I got more uncomfortable in places other than my wheelchair because of my back.

Luckily, they renovated it to make it accessible during Covid.

Now they have an elevator, an accessible bima, without any steps, I can get to all of the floors, and they have two fully accessible bathrooms that are spacious.

So now it's much easier to go in, hang out, pray and leave.

The truth is, though, if I have to be grateful for an accessible bathroom, when am I ever going to be equal in the community?

Accessibility doesn't mean just that I can get in.

It means accessible bathrooms, the community is welcoming and inclusive, and the commitment to make all things that happen in that place inclusive.

>> RENA: I'd love to take a pause and invite everyone who's watching to think about the spaces that you gather in, the spaces that you go to, your workplaces, your communities, and think about the spaces that aren't accessible, and the places that are, and what you could do to make them better.

Up until I met you, I did not know what volt hockey was.

I never was an athletic type myself.

And now that I know what it is, I want to know more.

Can you share with us what volt hockey is and how did you get involved?

>> GAVI: Volt hockey is basically a motorized version of sledge hockey.

You can drive the sled with a joystick, and as you can see from the pictures, we use a stick that's shaped like a "T" that controls the ball we use.

This sport is played on a court, and for a game, you have three people playing on one team.

Volt hockey is trying to become a paralympic sport, but for that to happen, it has to be on three different continents.

And right now, it's only on two, North America and Europe.

I've been playing volt for six years now, and I absolutely love it with all my heart.

I have had so many cool experiences from it.

For example, my team and I just went to Sweden in September to play in the World Cup of volt hockey!

Denmark, Sweden, Norway, U.S.A. and Canada all competed in that tournament.

My team got bronze in our division.

We have also had a North American tournament that was set in Toronto, where I live, and our team won the whole thing.

A fun fact about me is that I was the first female volt hockey player in Canada.

>> RENA: Awesome!

How is volt hockey adaptable for you?

>> GAVI: Another thing I love about volt hockey is that the sleds are very adaptable and customizable.

customizable.

For a person like me, who doesn't like sitting on surfaces that aren't my power wheelchair, volt hockey sleds are very customizable so people like me can feel comfortable in them.

Volt hockey is such an amazing sport because it allows people would have significant disabilities to play a competitive, adaptive, and most of all fun sport.

>> RENA: So we have some photos to show you.

Again of volt hockey.

So I'm going to share my screen once again.

Here is Gavi and her Gold Medal, winning and the winning team at the North American volt hockey tournament in May 2023.

Gavi and her gold medal winning team again at the North American volt hockey tournament.

Photos from the World Cup of Volt Hockey in Sweden in September 2023, and the flags of the participating countries and athletes from Canada being introduced.

Photos of the World Cup again in Sweden in September 2023.

The flags of the participating country and the athletes from Canada being introduced.

And this is Gavi participating in an anti ableism campaign.

I have a couple things blocking the screen.

There we go.

This is what an athlete looks like.

An image of Gavi sitting in her volt hockey sled.

Wonderful.

So let's talk about school.

You're in eighth grade now, right?

How is school going for you?

What are things that you love about school, and what are some things that you wish maybe were changed to make your experience better?

>> GAVI: I go to school at Deer Park, and it's a really good academic, fun, inclusive, amazing school.

I really love it.

I have been there for seven years now, and I am a proud DP student.

The kids are super nice and welcoming, and the teachers, too.

I am involved in three clubs: LEAD, Crew, and Difference Makers.

In terms of improvements, the elevator is so slow, and so small.

Multiple times this year, it took me ten minutes to get from one floor to another because so many people were in line for the elevator.

Remember, Deer Park has a lot of students that are in wheelchairs who use the elevator.

But for a grade 8 student like me, who has classes on a lot of floors, it impacts my life a lot to have only a slow and small elevator.

This is a crazy story.

On the first day of school this year, at the end of the day, the elevator broke down!

And I was on the second floor with another student in a wheelchair, and we had to wait an hour until the fire department came.

And my dad came and carried me down the stairs.

And the firemen had to literally drive my chair down the stairs while holding it up so it doesn't break.

So one thing that could be better at Deer Park is a new, and improved elevator.

And preferably more than one!

>> RENA: When you and I were talking, Gavi, we talked about bathrooms being a huge challenge.

It's something that many take for granted, the simplicity of using public bathrooms.

Tell me more about that to the level that you're comfortable with.

>> GAVI: At school, going to the bathroom impacts my day a lot because I need two EAs to help transfer me to the toilet and back to my chair, and they have to be free, and I have to be free.

And it takes longer than a non disabled person would take.

Sometimes the EA that usually helps me isn't there, so I have to use a lift, a mechanical sling that carries you to the toilet and back to the chair without a human person lifting me.

But I don't like the lift because it's less comfortable, and it takes way longer.

So all of this affects my class time, and how much time I have with my friends.

Sometimes I miss recess.

>> RENA: What are some of your hopes as you enter high school next year?

>> GAVI: I hope that I can make a good amount of friends, and that my teachers are nice, and that the school has a good community, and that school administration thinks about accessibility.

Like, if they have a big event somewhere or a school trip, they think about, "is the place we're going to accessible?" Or "is the subway stop accessible?".

And "can she have friends to go with her because she has to go to the elevator?" I want to be in clubs and help out around the school.

>> RENA: I know you have two 16 year old twin sisters, which I think is so cool.

Tell me about your relationship with them.

>> GAVI: My sisters are very different people from each other.

They're fraternal twins.

And I have good relationships with both of them.

I like to play games with both of my sisters.

With Ashira, I like how we always act funny around each other and we play board games like Banana Grams.

But sometimes we get into fights about our differences.

Sometimes, I lie in bed with Eliana and we watch "Modern Family."

I like how when we're sad, we comfort each other, and how we can tell each other things.

But she's a lot older than me, so we have different views on what's cool and what's not.

Like, Eliana thinks fashion is really important.

But I don't.

I love Tate McRae, but she doesn't.

>> RENA: What is it like being a disabled teen in a family of non disabled family members?

>> GAVI: Sometimes I feel badly because I limit the plans and the choices of where to go and when to go and how to go, because all our plans as a family, like trips, have to be accessible.

And obviously I need more help than the average person.

I'm pretty okay with that, but sometimes I feel guilty about needing help, but I know that I shouldn't be.



>> RENA: To our audience, what do you want to tell them about how to be an includer, and what to do and what do you want teens to know?

>> GAVI: If you're in an environment where everybody is talking, and you see a disabled person being left out, talk to them and interact with them.

And if they do have a speech impairment, don't be afraid to ask them to repeat themselves because you actually want to get to know them instead of pretending.

If you're making a plan for an event that involves a big community, think about how it can be the most accessible to everybody.

Make your mind "disabled oriented", and make it a priority.

For teens at school, make friends with disabled people.

Because actually knowing a disabled person helps open up your mind.

>> RENA: I know from my personal experiences, I remember people staring at me because I had scars and looked different when I was growing up.

And I always wished parents would have responded differently than they did.

So in a similar lens, what would you suggest to adults to say to kids when they stare?

>> GAVI: In my experience, when I'm going down the street in my power chair and a kid is staring at me, the parent sometimes grabs the kid like I'm about to run over them.

They take the kid away from me, giving that kid the thought that they're supposed to be scared when a disabled person in a power wheelchair comes near them.

Instead, they should tell them to smile at me or say hi, because it's friendly.

Instead of staring at us like we're weird.

The kid would learn that some people have disabilities.

Some people don't.

Everybody's different.

And if you meet somebody who is different, don't stare.

We know why they're staring, and it doesn't make us feel good.

>> GAVI: Gavi, I knew that this was going to be a wonderful conversation, and I am so grateful that you chose to spend your evening with us.

Thank you to everyone who joined us tonight.

And don't forget to join us for virtual adaptive yoga this coming Sunday at 10:00 a.m. Central Standard Time, led by Melanie Waldman.

Thank you, again, Gavi!

I would like to open it to questions if you have any.

Gavi's parents can definitely support Gavi with answering.

If you want to send them directly to me, again, to the host, I can look through them.

Gavi, comments are coming in.

This is unbelievable.

Amazing!

So great to hear from you!

So if anyone wants to send me a comment or a question, we have some time.

Another one said thank you so much!

Thank you so much for this amazing start to the month, Gavi.

You've given us so much to think about!

No questions because she explained everything so well.

Thank you to you and Gavi.

Whoa, whoa, whoa, they're coming in so fast.

Whoa!

It really makes me pause to consider how accessible our program is and how everyone can access prayer, even community.

Great job!

I'm so proud of you.

Gavi, you're amazing, and truly inspirational.

Great discussion.

Thank you, Gavi!

>> GAVI: Thank you!

>> RENA: I'm going to ask Ali, if you want to support Gavi with this one.

Gavi, what is your vision for your future?

Is there something you want to do?

Places you want to explore, changes you want to make in the world?

That's a pretty loaded question.

>> GAVI: I want to be an activist.

And help make the world more accessible.

And, yeah.

>> RENA: Awesome.

Great job, Gavi!

You pointed out a lot of things that most of us have never thought much about, and I really appreciate that.

Gavi, you have educated and enlightened us.

Awesome!

We love Gavi and are so happy to know you as part of our NM community.

Okay.

Another question.

If there was only one thing you could do to help change accessibility for the world, what would it be?

>> GAVI: Make houses all accessible.

>> RENA: Amazing.

Amazing.

Another one said you're already on your way, Gavi.

Amazing.

This one says oh, I love this.

What country can we lobby to get volt hockey going?

I want to see you in the Olympics!

>> GAVI: A country in Africa, Kenya.

>> RENA: Awesome.

Yes, houses should be more accessible.

I wish they were.

>> GAVI: Yeah.

>> RENA: Any more comments or questions before we wrap up?

Well, Gavi, thank you once again.

Thank you, everyone, for tuning in.

Thank you to our live captioner, Tammy, for her exceptional live captioning.

And again, if you would like to join us for adaptive yoga on Sunday, we would love to have you.

Thank you all so much, and have a lovely evening!

>> GAVI: Thank you!

Bye!

>> Bye.

Thank you!

>> Thank you!

>> Bye.

>> Bye.

[Presentation concluded].

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