Disability Etiquette Panel

CAIT DICKEY:
Welcome everyone, good afternoon, my name is Cait Dickey, and thank you so much for being here on a Friday afternoon. I know it's raining, there are a lot of things pulling you away from here. You chose to be here with us. So thank you so much.

Some general housekeeping, for today, we are hoping to make this a super successful event, so I'm going to start off by sharing a visual discussion of myself, because we have some folks in the audience and on our panel who are -- visually impaired. So again my name is Cait Dickey. I am at a white woman pretty tall, and wearing a jumpsuit with jewelry. I'm going to pass it on to my co-moderator, Mechelle.

MECHELLE ZAROU:
Hi everyone, thank you so much for joining us. I'm at the sisters of St. Francis. I'm the chair of diversity and inclusion and equity. (indiscernible) of this event. So thank you for joining us, I am also a white woman, brown curly hair, and pudgy cheeks, so here we go (Laughs)

Go ahead, everybody introduce themselves.

JUSTIN LOPEZ:
I am Justin Lopez, community member of (indiscernible), I am a black male, (indiscernible).

SR. KAREN ZIELINSKI:
I am Karen Zielinksi. I am a white sister. I have short brown hair, and I am wearing a plum top, and I am using an electric cart for my MS.

ALLIE LEATHERMAN:
My name is Allie Leatherman. I am up (indiscernible) wearing round jacket, there is a sweet little service pup to my left, and yes. And their name is Taylor.

BRTTANIE MADDOX:
my name is Brittany Maddox, I am a white woman with blonde hair, gold glasses, and I have a navy blue shirt.

ANGIE GOODNIGHT:
I work at the Ability Center and information outreach, and advocacy. I am blind, and I am a white

woman, with blonde hair and Ability Center shirt on. I think that describes it. (Laughs)

JENNIE GEIMAN:
Hi I am of the independent living ordinate are also at the ability center, I am a tall woman, tall white woman, with red hair, in a cardigan and black shirt.

JIMMY KOLOPAJLO:
Hello my name is Jimmy Kolopajlo, I am a white male who uses a power wheelchair with short brown hair wearing a green dress shirt.

CAIT DICKEY:
Fantastic, those are all of our panelists speaking with us today. Some general housekeeping out to her left, our restrooms and water refill station. And we have some questions prepared, but if you have something that is interesting to you, that you want to continue to talk about, this is an open forum, so we encourage you to ask those questions.

MECHELLE ZAROU:
Just raise your hand and I'll run over with the mic.

CAIT DICKEY:
Wonderful, all right. So panelists. What do you wish people understood about your disability or disability in general?

MECHELLE ZAROU:
And I am just going to ask that you see your name before you answer, because it will help with the closed captioning on the screen. We would love to hear from anyone to start.

ALLIE LEATHERMAN:
I would say, whether you are born with a disability, whether you sustain one, throughout your living experiences, I think it is important to remember at the end of the day you are just as human as the next person.

I think it's important to keep an open mind, I very much understand the people are not comfortable with things they don't understand, but with that comes a reason to understand your own so you can secure your own.

ANGIE GOODNIGHT:
I like people, I hear all the time how I don't look blind. Which is fine, but sometimes it can almost be a bad thing when people – they don't believe me. And then I have to go, "no really, I really am."

Anyways, as a person that is blind, I just want people to know that just like she said, we are all people at the end of the day. I see things differently than a lot of you, but I still see, if that makes sense?

So just because a person is blind, you know, you can hand me something and say take a look at this, and you know, I can really seriously feel with my fingertips, so I just had a baby grandson last Monday. And I was able to hold him and feel his little nose and eye socket, and his chin. You know, I know what he looks like, in my head I know what he looks like so…

BRTTANIE MADDOX:
I can go, I think what I would add is, looking at disability as just another part of diversity as being a human individual, and that if you look at it as just a diverse individual, right, it brings diversity into the conversation. You are starting to remove the stigma of what disability is, or what it has been historically.

So I think, one of the things for myself is not apparent disabilities, so those would be like more common terms invisible disabilities, but I don't like to say invisible, I like to say not apparent disabilities.

Those individuals often have to prove their disability, because society as a whole generally does not believe them, right-click what Angie was saying, that will prove to me that you have a disability, instead of just interacting, and not focusing on, "well, what is your disability, and make sure you explain it to me".

So moving past that and looking at as diversity and interacting as you would, someone without a disability.

SPEAKER:
I think like the other people said very simply, one in four people have a disability, can be mental illness, it could be being deaf, it could be somebody who lives with diabetes, somebody with MS, Parkinson's.

But the thing I hope is we are all human, the unity. Anything that having a disability, the more you listen to this, thank you for coming, because it really touches my heart. When you go home do you think of someone or maybe you have a disability, it could be as common as wearing glasses, or as wearing the center navy blue shirt, which I like.

That is all part of us being human.

JENNIE GEIMAN:
I think it's important to remember having a disability is a group of people that you can join at any point. It's not something just because you're dealing with now it's not something you won't have in the future.

Myself, I was born with a pretty rare bone disorder, but my disability because of that came a lot later, my brother has the same bone disorder and he does not have what I have.

So it is something that is unique to everyone. And something that can change at any point.

JIMMY KOLOPAJLO:
One thing I wish people knew about disability in general is seeing people as a person and not as a disability.

So just like move past (indiscernible) he's a person in a wheelchair, his name is Jimmy.

JUSTIN LOPEZ:
I think the other thing is to acknowledge that (indiscernible) awareness is important and we appreciate it. But awareness does not just adhere to (indiscernible) and spreading more knowledge about it is important part of society as a whole. So we have to do that in order to do that we have to ask questions, we have to be okay with being uncomfortable, and in order to do that (indiscernible) I really appreciate it.

CAIT DICKEY:
That brings me to another question, which is the language we use when we are talking to each other about each other. I understand there is person-first language or disability-first language. I am sure you each have a preference.

Where you stand on that? What do some of those terms mean? Maybe some people in the audience do not know what I am talking about.

BRITTANIE MADDOX:
I can start. I would like to say I created an appropriate language guide that is here. It is at the Ability Center table. So you can take it.

It has some phrases like, there are two columns, the "do use" and the "do not use" column. We know that language is tied to culture, and that things change over time. Something might be used now, but probably maybe will not be used in the next 15 years. Who knows?

As far as person-first language versus identity-first language. Person-first is putting the person before their disability. For example, a person with autism. Identity-first language would be an autistic person. Or, disabled person.

So, they take that disability, and that is their identity. Identify as that. Not everybody does. People with disabilities, sometimes like person first language. They may say, I am a person with autism. I am a person outside of my disability. That is what that gets at. Some people say, I am an autistic person. That there autism is part of them, and part of their identity.

I would always say, just ask how that person identifies. Usually you can pick up, when you are talking to somebody, the terms that they are comfortable with. Or, how they identify. But always just ask.

I would also say, just go with person-first language as a default. Unless they tell you otherwise.

JIMMY KOLOPAJLO:
One thing I wanted to add to that, is just like… I would prefer if someone said that I am a person with a visible disability instead of physically disabled. I do not prefer having the word disabled… It just makes me feel like… I am actually disabled. I do not really matter. That is what comes across as.

I would prefer if people said I am a person with a physical disability.

ANGIE GOODNIGHT:
For me, what I said before about you know… If my friends call me, they do not say, hey did you listen to that movie? Things like that. You know, it is OK as you're walking away to say, "see you later."

Those types of things do not offend me. It is all to say you know, hey did you see that movie versus hey did you watch that movie? You do not have to change your language. Some people may disagree.

Someone might say if they are in a wheelchair, I went for a walk with my husband, he walked and I rolled. It just does not sound right. Identifying me, honestly, it does not matter to me either way. That is just my personal preference.

I will slip into the conversation that I am blind, so I am a person with a disability. Again, if whoever is introducing me did not say, "this is Angie, and she is blind." I still get questions like, are you really blind? Yes. I am a person with a disability.

But I would prefer to be, "this is Angie, and she is a person with a disability." Verses, this is a blind person named Angie.

SR KAREN ZIELINSKI:
I also prefer person-first. If I have people that I'm speaking to who are blind or deaf, and I think if you are present to the person (Indiscernible) that you're not trying to offend them. That is an opportunity for me or you to tell me that.

Lots of times people say, I am just going to jump in the shower, or run and get you what you need at the grocery store. And they would say that, and I would say only if I could. But we get it. (Indiscernible) is a challenge anyway.

So when people say that, I am like, oh man if I could only just jump in the shower. (Indiscernible)

SPEAKER:
So if I were to say, Karen, would you roll with me? Would that offend you?

SR KAREN ZIELINSKI:
I would say, "come with me." If you said, let me go to the Franciscan center, and you go up the steps, and I go up the ramp, then… (Indiscernible)

I would say, oh you went with me. And if they get mad and they won't role with you… Whatever.

JUSTIN LOPEZ:
I think the other thing is making sure you do not try to overextend. When people go out of their way to… I guess make us feel more comfortable. Sometimes it is not necessary.

A lot of us have different preferences. For me, it is not is detail oriented about person-first or not. Sometimes when you overextended, it could make it a bit more uncomfortable for individuals. I think it is important just to gauge the person. And it is OK to make mistakes. We make mistakes as well.

When that happens, it does not need to continue on. (Indiscernible) to try to make up for that mistake. It happens.

(Multiple speakers)

SPEAKER:
This is my personal take, of course. I welcome anyone to engage with me in any way. With a -- whether they are coming to me as a human being, in a wheelchair, someone with a disability. I think it is important to break down stigmas and just have a conversation. Some people may not want to be labeled a certain way.

An proceed with caution, and be compassionate and understanding. Maybe you did feel a little offense, but learn how to delicately deliver that to the person. Let them know, could we rewind a little bit, and do not call me this. Instead call me that. This makes me feel more comfortable.

That opens the door for you to have a conversation to decrease discomfort levels as well.

CAIT DICKEY:
Thank you so much. Along that vein, as it bother you when terms are taken out of context to describe different experiences? Like someone who is really organized says, "I am so OCD."or if someone is having a bad day and describe someone as being bipolar?

SPEAKER:
Think it is language that we should stay away from. If that is not something that is your story. That being said, I have been guilty of it myself. Acknowledging if you've done something like that, to know that that was inappropriate.

We are blessed with language in any language, so there is lots of room for clarity of speech. Because what does that mean? I know people think everything is so different. Disabilities affect people so differently.

So I guess I would just ask, what do you mean by that? Get them to embrace the conversation.

ALLIE LEATHERMAN:
This is Allie, life is all about balance and grace. None of us are perfect. I say things that, I offend myself.

(Laughter)

ALLIE LEATHERMAN:
So that is an important part of the whole thing. If we get obsessed with being so careful, and mindful… Like I do not want to upset this person, myself… Forget to just experience it. In some of the most uncomfortable moments of my life, I have become the most reckoning moments of my life.

Where I was able to route myself, and really figure out exactly how I felt. And what my standards were, what my expectations were. And then go on from there. It is important not to take things so personal.

That is by far the most important thing I have taken away from sustaining a disability. You know, not being born with one, I should say.

JUSTIN LOPEZ:
I would agree. I personally do not take it so personal, when it comes to things. Things happen. And it is OK to feel the way that you feel. (Indiscernible)

It is OK to say things… (Indiscernible) someone tells me that there like her, I do not look at them and am upset. I understand it is important to relate. I think you can make yourself over aware. (Indiscernible)

SR KAREN ZIELINSKI:
I also think with what people said, we are not perfect either. So maybe we respond the wrong way, and people may say… I was not trying to offend you. Sometimes we might be frustrated, and say… What drives me bizarre is when people call my electric car to a scooter.

I do not know why but it drives me… (Indiscernible) he said, I do not know if he said denigrate or put down an adult person who is working… And uses a mobility aid, chair, or a walker.

And that really hit me. So somebody said it is a scooter, so I said, I like when you say cart. The because it makes me look more like an adult. (Indiscernible) do you know what I mean?

There are different medical terms that people use, that are offensive. And you know… I will not go there but, there are a lot of things. And I think we have the responsibility to say our truth.

When you call me a person with Parkinson's, or MS, or I like when you call my cart an electric cart, I am not 13 years old.

(Laughter)

MECHELLE ZAROU:
One question I have, especially for those of you who have a more apparent disability, how do you feel about people coming up to you saying, "what happened to you? How did you get in a chair? Or why do you use an electric cart?"

I feel like that is intrusive, and you need to be friends before you ask that question. But what do you think?

SR KAREN ZIELINSKI:
I think the best example is the honesty of a child. When I go places, and people are looking at me… I also wear my mask a lot because my immune system is (Indiscernible).

Kids will come up to me and say, "what is wrong with you?" I always say, I am glad you asked. I told him I have a disease where my legs do not work really well, but this gets me around. And they say, "OK, can I have some Cheerios?"

(Laughter)

SR KAREN ZIELINSKI:
God bless kids. If an adult says it, you know somebody here asked if they could ask me what my disability is. I might say, I do not want to tell you. I think people especially in this town, our gracious. (Indiscernible)

SPEAKER:
I think it is also about the environment that you are in. (Indiscernible) I do not think you have the time to ask me…

(Laughter)

SPEAKER:
If we are in a group setting, or out (Indiscernible) I have no problem explaining or going over my story. But the drive-by questions are super offensive, not just (Indiscernible). But I think family or friends who allow this, and have seen this Embark on these turners -- journeys.

But when you asked that question, make sure you understand the setting you are in. Because it does affect how we respond. I have been on campus before, and people have asked me because of time or… I know you have a class.

I use something as simple as, I tore my ACL. But there is obviously more to that story.

SPEAKER:
For me, I take that moment as an educational moment. It's like we are sitting here in front of anyone -- everyone today. My personal opinion, if someone asked me how I lost my site. Or what I do see?

I take that opportunity to let people know I acquired that disability later in life. I have what I call my elevator spiel. This became short, I developed pancreatitis when I was 32 weeks pregnant, I went into a coma, I woke up. And then people are like… "Wow!"

I take it as an opportunity to educate people, and I always say, "I may have a disability, but my life is just as full as everyone else's, other than I cannot drive a car." I take it as an educational opportunity.

JIMMY KOLOPAJLO:
I think usually you should not ask them what their disability is if you have no idea who they are. I don't feel like I would need to tell them, if I know them for a little bit, for a while eventually I would, but it's just normally I would rather tell someone what it is once I feel comfortable with them.

Which I am find people ask, but it's just like in the first time you meet, I don't feel comfortable with people asking, I just feel like that isn't the right (indiscernible).

ALLIE LEATHERMAN:
I find this part of the disability life to be a little bit comical at times, which might seem a little insensitive. Depending on who is asking, and when and where the circumstances are. I make up a pretty odd story about why I am in a wheelchair. So you may have heard different stories, that is OK. (Laughs)

You know I think it is about balance and grace and delivery and execution. I agree with you about you know, people get more offended with people asking what's wrong with me than I do. I like to chat your ear off about whatever is under the sun for whatever is humanly possible. But again I think it helps to break down the stereotypes.

When my brother and girlfriend his girlfriend for the first time, they asked my brother what I wanted to eat. And I said this is not how it's going to be for the rest of my life.

It's important to be mindful of those things. Disabilities, it is the largest minority group, they don't discriminate – it happens every time. As somebody who is in the minority group, I think it's important to broaden everyone's horizons, and different afflictions that everyone ends up suffering from, it's not so bad.

I get to go to all the coolest concerts, I got front row parking, when I get a menu, just to make my friends laugh, I always turn it upside down and open it.

BRTTANIE MADDOX:
I think just going off of – it kind of depends on the situation in the environment you're in, and I think one thing that probably irritates me more although as I have gotten older it is not irritating me as much, so I have an accessible parking pass, and I use it at times when I need it.

But people will see me as a younger looking person using an accessible parking space, and give me funny looks. They are rude, I have had somebody come up to me really really and say, "why are you parking here, what are you doing?"

She wanted me to prove, because to her I think she wanted me to get out as a chair user, right? And I don't owe you an excellent nation, like you are not the parking police, go about your business, why are you bothering me?

But I think it's that assumption, in society, of who qualifies to be a part of the disability community, and if you don't look like you should belong there, then there are many people who take it upon themselves, they think it is their job, their duty to call it out.

And she didn't know me, and I don't think I've ever seen her again in the parking lot, I thing I would say I was very upset that she decided she needed to talk to me like that, but you know, it is those moments, what is the reasoning behind you asking me that question? You know, so I think your intent, the person's intent also goes to it. It can make it uncomfortable.

JENNIE GEIMAN:
To go off of Brittany, I have what is a contracture elbow and hand which is just a fancy way of saying it's crooked. And some people say, well you should not call it that, but it's my arm and I can call it whatever I want.

Part of working at the Ability Center I was also a teacher for about eight years. I never told them right away what was wrong with my arm, because I wanted them to come and ask question. Without me putting my perception into them. And my perception, my disability has drastically changed over time.

I've had my crooked arm since I was two, I was born with a rare bone disorder, that is my elevator speech (Laughs) So… And if you ask me how it happened, that's what I will say, and then walk away.

My relationship with my disability has drastically changed in my early 20s, if you asked me if I had a disability, I just would've looked at you and been like what does that mean?

Now I'm like yes, I have a disability, it's this, that, and the other thing. Things have added to it, chronic pain has added to it, and so now I'm a lot more open about it than I used to be.

One of the things that has always kind of been a trigger for me is a person's tone. There's a big difference between, I see that you have a disability, or I see that you have a contractured limb, or a limb difference. Could you tell me about it.

That's a lot different than people coming up to me, and I've had this happen to me many many times, and it has become comical - people coming up to me saying, "Oh my gosh what is wrong with you?"

In just about that tone. For me tone plays a large part in whether or not I will engage in the conversation, with a stranger.

To kind of just discuss it, but I think as I have gotten older, my ability to kind of put what they are asking in my feelings to the side has changed too, so a lot of it comes down to the tone of the question asks, whether I know you.

And it's my story, if I don't feel like hearing it in that moment, I don't have to.

CAIT DICKEY:
So we have plenty of questions prepared, but there are so many of you here, and I'm sure some of you have some questions. And at this time we would like to open the floor up to take some questions... Don't be shy.

SPEAKER:
One thing I always like to say when I talk to people at the Ability Center is that no question is a bad question. So please think about that, today is the day to ask us your questions.

SPEAKER:
I would just like to ask what you think about this. If it's just me. But I really don't feel good when I am in a group and someone says, "Now everybody stand."

And there I am in the middle of a group, I can't even reach because everybody around me is standing and I am sitting. So I can always, to me, I would think, I was in a group once and it felt so good because the person said, "Everybody who wants to, stand. Anyone else may sit."

Now that made me feel good. Because I certainly didn't want to stand. What do you think about that? Is it just me?

JUSTIN LOPEZ:
I would say, your setting matters. The people you surround yourself with, are super important.

If they are individuals who understand what you have and what you are going through, then they will be able to make that proper phrasing, so that you feel included.

There's also times where you also need to know where you're going into, and the environment you're in, because there may be something that you have to do, or it's uncomfortable, for your disability, that you didn't think about when you went into it.

So I think it's a balance, making sure where you are heading in who you are surrounding yourself with.

SR. KAREN ZIELINSKI:
I think this is really poignant, it can be hurtful, a lot of times it is happened, I too might not stand.

And I think, I guess I would definitely say something to the presenter, because I would just say, you know what, I cannot stand, I don't have the capacity to do that, and you made me feel excluded.

Which is the big thing. We are part of you. Our differences are sometimes imitations. And it kind of goes to what you were saying about you know, being blind or having your elbow (indiscernible) or whatever it was. I think the group at the MS society think it's an excellent name that it's a hidden disability but you look so good.

You dress better than I do many days, but that's a visual thing. And you know, I can write a book, I almost have on parking spaces. I was at Kroger's once, and I had to go in for a prescription once for a cold about a year ago. I parked way back in, like Slovenia...way back.

I parked at an angle at a van with a ramp. I went in to the pharmacy, I went out and there was something blocking the ramp.

I said, now what. I can't walk, so I had to go in, and you go to the speakers place, and the guy was right in front of me at the pharmacy.

When she came out and said there was nobody here – there was no parking, I was here and there was 19 places. And I said you know, just don't do it again, otherwise if you have to use a handicap bathroom.

And he said he had vision problems, and that is true that is a disability. But for somebody who has a 900 foot wheelchair, it's for mobility things.

There is a sub quote too, that I saw a beautiful young kids running out of their grandparents SUV at Myers, and I followed them into the store, and I am sure I said, I'm not mad, but I think you should know, just awareness, I'm aware of saying that to people. Again the parking thing is great, and then they say I have a (indiscernible) and it's not accessible.

I said you know, truck drivers backup my van and parking lots, now just do this, it's going to be...

And I think that awareness, even today if you are aware in a parking lot, and just because it is a young lady, you look so good, that is a judgmental – it's more about the person saying well maybe they do it...

Either a friend of mine who has MS, and one time I went to a grocery store, there was one van thing and she parked in the ramp, which is illegal.

She said I was waiting to get into my van, and I Leave I did that. I just ran in. Anyway just running in, I'm sorry – you pulled the cord.

SPEAKER:
I was going to do it (Laughs)…

SPEAKER:
I'll be loud I got an old (indiscernible) voice. I want to complement what Allie said with an experience that I had, and because we have so many nurses at school.

Just to kind of point out the importance of what you're saying in talking to the patient, in talking to the person instead of the person that brought them there.

Is it my job then, my mother was very vocal, she said talk to me I'm the patient!

Should I, and I don't know, I don't want to take away from the person, but should I have said to the nurse or the doctor, she's the patient, speak to her?

SPEAKER:
I would think, again nothing in life is one-size-fits-all. You know, and I mean that is so important to remember, each of us have different disability on the board.

Each of you having something that cripples you in your personal life. We all have something that we struggle with, that we can't, you know articulate in a good way, that we take out on people, that we project. Whatever that internal demon that we have.

I wish people would keep that in mind when they are approaching anyone, whether it's up position in a patient relationship, a friend relationship, a strange elevator running.

Whatever it may be, just think how would this make me feel? Thinking before your speaking, I wish I would've listened to my grandparents when they told me that when I was younger.

I've really gotten myself into pickles not doing that. And it is true.

There is true weight in those words. Just take pause and make sure before you say something, could this be offensive? Will this be offensive? And that answer might be yes. And if you choose to still do it from there, then just prepare yourself to be educated, or told off or whatever and take that little seed with you, and learn from it.

SPEAKER:
I would say two things. One is educating, if you're at a doctor's office. The other is advocacy, advocate for that person to say, could you please talk to them.

I can tell if the doctor is looking at me, or the person with me. There is nothing wrong with the way I can comprehend. The same with a person that is deaf. And they have an interpreter with them.

It is really easy to look at the interpreter, and talk to the interpreter as they are signing the patient. But you really need to look at the person, not the interpreter.

So if any of you have taken a call with the operators… And you know, I had to learn this. I have been at the Ability Center for 15 years. Took some learning. But when I receive those phone calls, I completely cut that operator out, and I asked questions to the person.

You know, do you need… Whatever it may be. I do not say to the operator, could you please ask them this…

It takes a little practice. But I do not think you're being nasty or mean, just by saying, could you please talk to them? You are there, either as a support person, you know whatever… But they really need to talk to the actual person.

SPEAKER:
I have a question about saying things like, "I understand." I have a teenage son who has a disability, sometimes I would say like, I understand. And sometimes he gets upset, like I do not understand. (Away from microphone)

What would be…

JENNIE GEIMAN:
I had that argument so much when I was a kid with my mom. She would say similar things. Finally when I got older, was able to think about it a bit more, I would say, I get what you're trying to say. You have been a part of my story, you were my first advocate, and you have been my biggest advocate.

Could you maybe say that you empathize? Because I was the one dealing with the issue, with what people were seeing as the face of disability (?). She dealt with a lot.

Some people were not very nice to her because of that. So I know she is dealing with some things that maybe I do not understand. She has gotten a lot better with that. (Indiscernible)

That was probably the biggest thing that kind of helped our relationship, and helped us move forward. (Indiscernible) to advocate for myself. I'm still like, mom come with me and advocate for me. And I am in my 30s.

I mean, you care, and you are doing your best.

JUSTIN LOPEZ:
I think the other thing is just... I understand… I have gotten frustrated because you might not. But you do. You've gone through that journey with your son. It is not the same journey that he has.

But the biggest thing is using a phrase like, I hear you. That in itself is a sort of acknowledgment.

SPEAKER:
(Away from microphone) I think what is important to note is that… When you are at places like University of Michigan… (Indiscernible) that you do not be intimidated.

It is OK to say, excuse me, could you slow down? I do not understand that. (Indiscernible)… What we understand at that appointment… (Indiscernible)

JUSTIN LOPEZ:
I want to comment on that, because I think I wish I would have known that when I was younger. I remember vividly when I was learning about my condition, (Indiscernible) and I did not know that at the time.

When I was around 14 or 15, I was going in with a basketball injury, and doctors were using these terms… And phrasing that I did not know anything about. It wasn't the fact that the terms were used, it was the way they were talking like I was not even there.

That was super disheartening, it made me upset and frustrated. I think that we have future doctors and nurses in the room, also it is OK to have that conversation. It is super important.

But to make sure that you're doing it in a space that is professional, but also (Indiscernible) to the patient you are working with.

JIMMY KOLOPAJLO:

I completely agree with Justin. I have been in some doctors appointments with the doctors and nurses do not talk to me, they talk to each other.

I have been in some doctors appointments where people try to talk to my mother instead of me. They just feel uncomfortable talking to me about it. But they really need to talk to me, because I am the person dealing with it.

I need to know my medical problems as much as my mom, but I am the one that needs to know it the most. Because it is my body.

SPEAKER:
How do you feel about being called an inspiration?

(Multiple speakers)

SPEAKER:
I will take this first if no one minds… This is my personal take, of course. I sustained a spinal cord entry about nine years ago, and 42 days and 37 minutes… But who is counting

(Laughter)

SPEAKER:
I struggled big-time, myself to work myself through that. I went from being a fully capable, social butterfly, physically able to being someone who rules around quite slowly, and not very quickly if my battery is dying.

So it took me… I had to kind of inspire myself. I had to navigate those waters myself. Or someone who does not know anything about my own journey to call me a hero, or inspirational, that I am out here buying tampons myself, or something like that…

(Laughter)

SPEAKER:
I have learned to take it with a bit of grace. Like every answer I have had, it is all about balancing grace, and a great deal of humor I have found works well as well. I do not personally get offended by it.

I know that people's intentions are trying to be supportive, chummy, and that is a great sentiment that I do not want to get lost in how offensive that really can be to someone. I have pretty thick skin, it is hard to offend me.

I would probably offend all of you before you would offend me.

(Laughter)

SPEAKER:
Is a perspective to consider, I would say. But I will ask if they want my autograph, if they would like to donate money, or gifts to me at this point.

(Laughter)

SPEAKER:
I use it to my advantage now. That is what I have learned.

SR KAREN ZIELINSKI:
This one really pull my chain. The assumption that someone is an inspiration, and people might say… You did this or you work here… You wrote that…

And I am like, I can't believe you did it, and I asked why. Just because I cannot walk well. But the assumption is, just because someone has a disability, they will give something to them… Did they deserve it? Or do they just want the prize?

We are just like you. If we deserve to win something, then we do. (Indiscernible) I do not want to offend anybody, but I read something, it started when (Indiscernible) was starting and they had Crip Camp, it was on Netflix.

(Indiscernible) people had physical disabilities, they could not walk, it was just a great event. It was powerful. They called each other… You went to college so you are a "super gimp (?)" which is offensive but that is what they called each other.

I do not know, it is like assuming… Oh, she did something. It is a whole complex thing. I like what you were saying… Oh you're such an inspiration but it is not that.

JUSTIN LOPEZ:
I think we are repeating ourselves. But setting matters as well. Being an inspiration by going to the grocery store and grabbing something off a shelf… I do not see that act as being inspirational. But I don't know.

But being able to accomplish things is one thing. You guys do it as well. But I think about myself, it helps thinking about it because I work just as everyone else does.

I was informing my leadership team of why I was not going to be at work today and when they found out they were like, "that is such an inspiration." I comically laughed about it… (Indiscernible).

If I would have just said, I was taking today off, they would not have said that was inspirational.

(Laughter)

JUSTIN LOPEZ:
So it is about the setting.

BRITTANIE MADDOX:
One thing I would add, the way people are described as inspirational, like look at all the things you have overcome, it is infantilizing. You are talking to someone who may be 65, 45… But you're talking to them as though they are one or two years old. Like they just took their first walk, oh my gosh!

I always say, if you congratulate someone I baking a cake, and you're like, congratulations that is awesome that you got that job. But you do it for everyone… OK you can make to make it, but do not be like, writing some flowery, inspirational quote on the cake. It is just like… Cool…

(Multiple speakers)

BRITTANIE MADDOX:
You just say cool, that was great, here is a cake, enjoy it.

SPEAKER:
To jump off of what Brittanie was saying, because I have a crooked hand I do get that sometimes. Because I bake and crochet. It comes back to me as well. If they are like, oh my gosh, that is so cool! I'm like, yeah it is, I want to be on Bake Off someday.

(Indiscernible) that is a different thing to me. When I was a kid and that would happen, I would use it to try to get things like, they said I was inspirational…

(Laughter)

(Multiple speakers)

SPEAKER:
That is funny.

SPEAKER:
I have another audience question unless someone has something additional to say.

SPEAKER:
Do you guys find that when you are interacting with others who also have a disability, that there is a judgment within the group? What your disability is invisible, and I am in a chair, so my disability is more important? Or that there is a hierarchy among the community itself?

SPEAKER:
I never came across anything like that, personally. Again you know… I will often joke and say, you know us blind people stick together.

(Laughter)

SPEAKER:
And before I lost my sight, I did not know hardly anybody. But now that I have been disabled for 25 years, I know all kinds of people who are blind. Chair users. It is the company you keep as well.

SPEAKER:
I think that I have encountered that. That depending on the group, because at the end of the day, people with disabilities as a group… It is a diverse group. A lot of different thoughts, coming from different backgrounds, areas of the country, the world…

And so, every group, not everyone thinks the same. They have their own bias. So I do think that in some communities there are people who, there is a hierarchy of disability.

And I think if you can recognize it pretty quickly – I would just be like, I do not want to hang out with you people anymore. That is annoying. But I do think that because groups are diverse, that there will always be those individuals who I think…

Personal experiences powerful to you. It is your life, it is your experience. And you feel very emotional about it. And so, I think people bring that into a group, and there could be some people with different types of disabilities who will say like…

I mean I am a chair user, I am blind, so I kind of trump your experience. I would say. I have noticed that in different places.

SPEAKER:
Hi my name is (Unknown Name), I'm a former (indiscernible) here, and so I just recently in the recovering process of tearing my ACL. Back in October.

And I found there is a lot of frustration (indiscernible) I couldn't stand very long, or I find there is comedy towards me. But I also don't want to be a party pooper...

So other ways that like... (indiscernible) for kind of feeling left out times.

ALLIE LEATHERMAN:
I would say, get even. (Laughs)

I mean there is some truth to that. I mean, after I became hurt, I was set aside from my able bodied friends and I felt really crappy about that.

So it took me a couple years but I found a group of people that have an injury just like mine and that helped me flourish, and gave me a whole new perspective.

And my friends saw that too, and it makes in together, and now we do things that are wheelchair friendly, able-bodied friendly, and if I am careful who I select my company now, and if it's a matter of set me on the chair, or account so I can experience it, in close ways that are humanly possible without getting the full Monty, then they do that for me too.

SR. KAREN ZIELINSKI:
That is why were here. Inclusive. And that is a side affect to disability. Ability in its whole essence is trying to integrate people with different his abilities into different life experiences.

And when you can't -- when you tear your ACL as an athlete. That is just what you needed to do, you needed your peers to do that, so many times people say you know "what is this party, we didn't think you could make it?"

And that is the biggest thing, it is hurtful sometimes when we didn't want to ask you because we feel bad you couldn't do it. And I say ask me, let me say no, that is what you would do to normal people.

I think inclusion, I mean your homework is to invite somebody who you know maybe the kid at the table who is bullied, that is another psychological disability from your part or their parts. But include, we are all people, why do we always look at differences.

While my blindness is worse than your blindness, because I'm not totally blind. We are all humans.

JUSTIN LOPEZ:
I think that the other thing I would add about my disability is that it's tough to think ahead. Where I'm going, who I'm going with, my surroundings, one thing that you will find is that your friends will also, not always but slowly adapt to that.

That next time they go out, after they've made that mistake, they will probably think about that? Right? Especially if they saw how frustrated you were in that moment.

And I think it's important to use your voice and speak on it because they won't know until you say something. They're not mind readers, unfortunately. (indiscernible)

That is something that you have to do, you have to voice it out, so that when the next time it's going to be more (indiscernible) for them.

JIMMY KOLOPAJLO:
This is Jimmy speaking. I play sports, sorry I forgot (indiscernible) but I've been in that situation, but like eventually like some of my friends have adapted.

Like some of my friends, they used to not ask me to hang out with them if they have to go to their house and they were having a party there. Eventually they realized that sometimes I can get in their house too. I can bring a portable ramp with me, and then I can get into certain houses.

So like, eventually like, my friends have adapted to include more with every thing. Like sometimes, if they want to do something but I couldn't be a part of, they just wouldn't ask me.

But now they started to realize that sometimes I can be part of it. They just figured out what I can and can't do, and they feel bad I cannot do some things, and they want to do it with me. And they will make time to do something with me later.

SPEAKER:
I wondered if anyone else... (indiscernible) I won't even tell you the details, but I would like to ask has any family member that is had the person in their family with this challenge or the other, had trouble understanding it or has anyone with a disability had family (indiscernible)...

SPEAKER:

I think we're all like...

SPEAKER:
Mine is invisible, so people don't get it.

SPEAKER:
It so I have rheumatoid arthritis, and ulcerative colitis. And I've had rheumatoid arthritis since I was a teenager, and I have had ups and downs, I have crooked fingers. Right?

RA affects me, and ulcerative gliders has affected me. And a lot of my family members, especially in the beginning for my ulcerative colitis, I have an ostomy bag now, it's a bag on your belly forever. That collects stool.

So, I will have that until I am in the grave. But when I was initially going through all of my really difficult periods after the birth of my son, my family would say oh, would you just need to eat better, like if you just eat better, or take some vitamins, then you will be fine.

It's like I am literally bleeding – this is not good now, and they would say no I'm sure your fingers will get better as you get older. You know and it is very dismissive of what I am experiencing.

But they just don't understand, if I am having difficult days, I can't get up and walked to the kitchen today, like can you just make me some coffee or something. I wanted to sit and have some coffee. And they say oh you can just do it just try.

And eventually I just stop talking to those family members, which is hard, that is very hard, we are human we love our families. But it cost me more stress and pain to just hear their comments.

It's that I don't need their comments, you're clearly not – you're not going to attempt to get it kind of, and just uttering out this uses advice, you're trying to give me advice, but I have just cut ties with those people.

And I just move on, and that's hard, you have a grieving. Right? But you are empowered, you are a human, you have experiences, you – your life matters right?

In what you're going through matters. And even if they are family member's, and they diminish that experience just because their family does not mean they have to stick around. Right? Because everyone is entitled to feel important, valued and not be dismissed, no matter who it is.

JUSTIN LOPEZ:

I hear you and I just want to note, I think I don't speak for everybody but we have all been in that moment, right?

That frustration, that pain, the upset. That you add. We've all been there, and you know everything you have to be okay with the effort that you have given in that situation.

You've done enough to the point where you've done your best to explain it, and you have to be okay with that. And then you also have to be okay if they don't understand, you have to unfortunately you can't keep doing that over and over again because at the end of the day it's going to affect you and the people you're around.

So it's a tough process, but you have to acknowledge and put yourself first.

SPEAKER:
This is genetic… This is genetic, my children will have this. They are adults, and I struggle. And I have no clue, and I have risen above it, but I love my children. And I want that to stop, I just don't like (indiscernible).

SPEAKER:
It's kind of like the mom sit over here, I understand. They might say they understand, but if they are not at the point that you are, they are not so understanding obviously.

SPEAKER:
I have a genetic disorder as well, and it runs through my family, we always joked that family reunions, our help group, because the only other people I've met with the condition that I have are in my family.

My brother has the bone disorder, my dad has the bone disorder, a bunch of my cousins on my dads side, a bunch of my cousins.

I'm going to call it deformity, that makes some people comparable, but that is what I call it. I am the only one in my family who has it to that extent.

Over time, I have learned because for me, I don't want to cut my family out because of that, for me over time is come down to understanding that to a certain extent they had to let go of their ideas for me.

So, again I won't get into the whole big detail. You know when your kid is born, you have certain ideas for them, certain things you want for them out of life. And to a certain extent, I mean there is a letting go of that.

So to a certain extent, I know because I have talked to my parents about this. They had to go through a grieving process of she is going through this, she is going to deal with this forever, it's just not going to be you know, a General in the Air Force.

She's not going to be doing – well I am not athletic, so I would not be doing backflips anyways (Laughs) and I know a lot of people... They had to go through a certain extent, but they had hoped for...

And I have seen that with some of my family members who are still going through the grieving process, with it.

That they are not the same spot that I met, and I can only hope -- help them so far. With their acceptance, but their understanding of it.

Just trying, that is the only I can really say, depending on what you want to do, if saying goodbye to that family member is not an option.

Keep trying, just be with them where they're at, and that is hard. For me, it's like I don't get why you don't get this, what don't you understand about this? (Laughs)

But as best as you can, best for your own mental health, you know your own self feeling, just try to kind of meet them where you're at. And it took me a lot of therapy to get to that point. So… That is a whole other aspect for another day.

ALLIE LEATHERMAN:
It will be fast I promise.

Family doesn't have to be the people that you are related to. Perhaps some of the most profound impacts that people in my life have had on me are not related to me at all.

And they help me really navigate the waters of my disability. For more easier than the people that I live with. Who did everything in their power to understand where I'm at.

But it was a matter of me finding people who were in my position. Where I can feel out, and what solutions have you found for this problem? Or what problems have you found for the solution. If it was ever the other way around?

Whoever you have to find, and whatever depth you have to go to to find those people to make that work for you. You don't stop looking for them, because they are out there somewhere.

SPEAKER:
Hi, my name is Veronica. Should people reach out to shake hands with someone who has a mobility disability, or a prosthetic or that something about was wanted to know when you meet someone who has a disability. I just want to know what is the most respectable way to greet someone?

JENNIE GEIMAN:
For me it depends, I don't like to have my hand shaken.

There is a couple of reasons for that, the most prevalent is that because of my conjectured elbow, limb difference, I have a lot of pain, and if you shake it the wrong way, it goes numb. And then it gets painful, and that can last for a few hours, sometimes that can last for a few days.

It appends and how strong – so I don't like to have my hand shaken. I don't really like to be touched that much either because of it. But it depends.

SPEAKER:
The Ability Center used to have a great video, it was called the 10 Commandments. We do not show it anymore. But one of those commandments was on handshaking. It said that it was OK to do a left hand shake with somebody. But it was successful -- acceptable.

JUSTIN LOPEZ:
(Indiscernible) I cannot even tell you… The high-fives, and awkward hugs I have given. I think just try to do your best with being present, and…

The person will be more understanding if they are like, OK, (Indiscernible) I do not think they will judge you on that instant moment.

(Multiple speakers)

(Laughter)

ALLIE LEATHERMAN:
This is Allie, I would tail coat that. I was try to remember that they are nervous as well. They see my weird little hands and are like… Oh my God, what do we do?

So I try to make them laugh, make them feel… No one is more uncomfortable in any given situation than I am, I guarantee it. I assume that they are uncomfortable as well. I meet them on the bridge, it will go over better than us being on two different sides of the river.

All of these questions are fantastic, and wonderful. And to consider being able-bodied having a this ability. But it is so important to remember that it is not black and white. Nothing in life is, there is so much gray area.

(Indiscernible) have an open mind, and be ready to have a different perspective. Inc. of things differently, things that you have been used to for your entire life are not how it is. It can change at the drop of a hat.

Then you will have to adopt a whole new set of rules and guidelines that you are floating around this orb with.

SPEAKER:
Think that somebody… (Indiscernible) sometimes I say, can I give you a hug with your shoulder? A lot of times people do not know if they want a hug…

I will just go like that to tell them that I am available. (Indiscernible) you know, the cart, not scooter, or power chair, that is an extension of you. And you're not really supposed to go…

(Laughter)

SPEAKER:
You are just an inspiration for letting me do that…

(Laughter)

(Multiple speakers)

SPEAKER:
Again, I feel like if you are going to go to them and say, what do I do with people now? Do not stay away. If you come trying to be a nice human being, we get it.

Just like all of the different disabilities… Just because you are mobile and you can do stuff, you might have an appliance on your body… Or your arms may not work, so you cannot get coffee.

Once you get into a comorbidity, something is wrong and something else gets weaker… Or you have a chronic disease a lot of stuff can go wrong. Just like you, your knees might hurt today, and we need to respect you. No one is perfect.

So I am inspired by all of you.

SPEAKER:
Shaking a hand with a blind person can be pretty funny.

(Laughter)

SPEAKER:
It just can be comical. And again, (Indiscernible) and I do not want them to be embarrassed. I am like, I instantly will say a joke or something to break the ice. So I feel my humor has really brought me (Indiscernible).

SPEAKER:
We are wrapping up here, the last question I wanted to ask about Allie, interactions with your service dog. How should we approach her or not at all?

SPEAKER:
If you have any chicken nuggets, popcorn, pieces of pork… Feel free to make she accepts gifts of all kind. Technically, just like the wheelchair is an extension of myself, so is my dog.

I am a little bit lax on most of the rules that the Ability Center has… But please do not tell on me. I am terrible with my service dog. If anyone wants to pet her, feel free! But when she is out, and she is working if we are at a store, or more serious circumstances, I still do not tell people, no. But they do ask.

She is also a great icebreaker for me. She is really cute! And Stinky…

(Laughter)

SPEAKER:
But she knows people will just pat her anyway. Despite my giving them permission or not. And that is why it is important for her and I to have such a tight bond.

Because she pushes the envelope as well. She will perhaps (Indiscernible) with a stranger, or rule over with a stranger and ask for belly rubs.

But it is pretty hard to get me in a corner where I will lash out at you with anything disability related. I cannot say if I was that way before, I do not remember.

That is another disgraceful subject. You see a cute dog and you want to pet it. I want to pet other people service dogs. When I see my friend service dog, I just had it. Which is an example of what not to do.

(Laughter)

SPEAKER:
Use that as a conversation piece, honestly. Taylor knows more people in the city of Toledo than I do at this point. People are like, Taylor, hey! And I'm like, who is that?

SPEAKER:
Do you mind people asking what Taylor does?

SPEAKER:
She occasionally rolls in roadkill, or poop. That is a relationship with my dad, who then needs to bathe her. She will pick up anything I dropped, from a piece of paper, credit card, my phone… Remotes.

She can take my jacket off, she can go get help, she can open drawers and doors, and the refrigerator. She may or may not have the ability to bring me a couple of beers every once in a while. But she does not like cold things in her mouth. So that is selective.

(Laughter)

SPEAKER:
I do not remember what my life was like before her. I thought her for four years, I have been hurt for nine years. She absolutely changed my life. And she gets bark box, has dresses… She is not the typical service dog. I hope.

Because I feel bad for anyone else in my position with her.

CAIT DICKEY:
We are down to our last five minutes or so. If we have any more burning questions we have time for one more.

SPEAKER:
I just heard someone start to say something…

JIMMY KOLOPAJLO:

It was about the handshake. I was going to say the best way to find out how to shake someone's hand is to ask them.

For me… (Indiscernible) I still think it is something people should… I am in business so I think a handshake is very important. And I cannot really do that. So if someone reaches out to me, even if they do not touch my hand, it seems like the same thing to me.

SPEAKER:
Thank you so much.

SPEAKER:
OK, superfast we will get one more.

SPEAKER:
First of all I want to thank all of you. It is so needed and I appreciate it. One question, if someone has a disability, and accessibility issue… What can they do? Say someone needs a service dog or a wheelchair, how does someone go about getting that type of service?

SPEAKER:
Good Question.

SPEAKER:
The Ability Center.

SPEAKER:
You will probably get me. Just call the Ability Center. No question is a bad question. That is what we are here for.

SPEAKER:
The Ability Center is an incredible organization, and absolute staple. Call therefore giggles…

SPEAKER:
I do have people that call me because they are having a bad day. And again… Angie, you are such an inspiration… I get them to smile. Put it that way.

I just absolutely love talking to people. And getting those individuals… They are having a bad day, I am there to listen. Most of the time, by the end of the call, they are good. I make best friends all the time.

SPEAKER:
She does. I can attest.

SPEAKER:
I do. I have some elderly women who are begging me to go have coffee with them. And we all live in the same neighborhood. How crazy is that? I am a bit busy but… Anyway! Call the Ability Center. No question is a that question, and that is what we are here for.

To help people, and serve people with disabilities, and people without disabilities.

SPEAKER:
I would like to thank each and everyone of you for coming today.

(Applause)

SPEAKER:
I would like to think the Ability Center for donating their time, expertise, our community members, Jennie who is a Lourdes University alum, and Jimmy who works at (Indiscernible), and thank you to all of our panelists.

I know many students are here for credit, and also because you really wanted to be here.

(Laughter)

SPEAKER:
Make sure that you sign in, because I appreciate you being here, learning, and growing with us. So thank you.

(Applause)

End of panel.