Speaker 1 0:31

My name is Timotheus Gordon Jr. also known as TJ Gordon. I am 35 years old. For fun, I like to watch football, follow football. If I pick one team is always Auburn Tigers. "War Eagle!" I currently work at the Institute on Disability and Human Development at University of Illinois at Chicago. I am a research associate there, I identify myself as a disabled person. I have autism, that's my primary disability I identify with I also have a condition called auditory processing disorder, where I have difficulties of locating or processing certain sounds and tones. To be honest, it my disability doesn't really interfere with my daily life as much. In fact, it enhances by daily experiences, for instance, me being autistic, I have certain routines that are followed that I must follow, I must have at least two cups of coffee. I like to receive instructions or tax and written details. I guess it's also social situations where my disabilities affect how I live interact with people. If I'm in an unfamiliar place, I get anxious, or if there's a new situation that arises. I don't know how to improvise. Sometimes, especially if it's something I'm familiar, I did receive not only the initial vaccine, but also the two boosters as well. While I did not feel it was a requirements, I want to get into vaccines because I interact with the community a lot. And I don't want to put anyone at risk. Not even myself. I think it's difficult for autistic people of color to receive the cover and it shots. For many reasons. Honestly, one of the reasons is because for some autistic people sensory overload or sensory issues of a photo of us. We don't like needles, needles, anybody like needles, especially people on the spectrum, they may feel that they are being hurt by a needle, even if it's a little pregnant. is overwhelming. When it comes to talking about the COVID-19 vaccine or any vaccines to either friends in an artistic community, or family and friends in general. I try my best to talk about it. But it's so much misinformation and hesitancy that even when providing accurate information. Sometimes it's leaving up to them to the side within the my circle of friends at artistic community, I believe most of them got into COVID-19 vaccine, especially those who may also have chronic illnesses, and they really need the vaccine so that they won't get affected or possibly infect others with a compromised or not so strong of a immune system for those who did not choose to get Get the vaccine, whether it's by autistic friends of my friends in the disability community. Some of the reasons were due to not knowing what's in the vaccines were with a experienced allergic reaction if they take the vaccine, others acepted the conspiracy theories behind vaccines will the vaccine give you autism or other disabilities? Is this a government plot to control people. However, there is a real concern behind the SD hesitancy, basic insurance in before the 1970s, a lot of medical experiments done on minorities or marginalized people, especially people of color, they did not give consent at all to be a part of experiments, or they were not told what's going on, as resolved. There were many, many, many harms. Even though there are more ethical laws behind experiments, and such people are still afraid of what happened back then, or when it happened again, and that concern is real. And historically, it's real. Those people who have those concerns about medical experiments in the past throughout history, or have other reasons why they don't want to take the vaccine. They tried to convince me not to take the vaccine. But as a researcher, I resumed my research very soon know what I get into. And the bad scenes have no II gradients that are legit, too. So I will find throughout all three shots, other than a sore arm, that's the only thing I got a sore arm that went away after a day. That's it, I didn't turn into a mutant. Another barrier will be maybe the doctors think that because you have a disability, you don't need a vaccine, you don't go out much. And lastly, another reason is even if there is access to COVID it vaccines in certain communities of color. I started believe that even some autistic people in those communities, even in families will be hesitant either because of the sheer travel to give from home to the clinic, depending on the distance, and they'll be a guy spent gas money or bus fare to get to a from two. So that's a obstacle to disintegrated itself. And that's also just treatment of autism. People tried to get vaccines to where they be believed, would it be heard? Or would they be dismissed by doctors? Another difficulty that people on the spectrum of people with disabilities in general, that may happen when receiving care, especially when getting into vaccine is the doctor themselves. And it really goes back to having to go before with your doctor, first of all, and having a doctor that fully understands your needs, your how your body reacts to certain things, or just your overall workings of your body in general. There have been situations where I think it happens mostly with doctors I don't usually see where they don't listen that our listeners will be fully they just check stuff off the box. But that's why it is important once again To select doctors in the first place to understand you, and then in case you don't have that doctor also have a nother set of doctors that have the compassion, the information and the understanding on how to connect with patients with disabilities, especially if they're black, indigenous, or people of color, or even if they,

Speaker 1 10:37

um, a gender other than male, female, I do get nervous because I don't know what to expect. I may come in with negative expectations, it turned out to be positive, or the other way around, or I don't know what's gonna happen. So I already tried to prepare myself and I worry too much about the what ifs. I also get weary with the process of checking by blood pressure, I found out that the best way to monitor by blood pressure is where you give me five minutes to calm down from I don't know, traveling by foot or by public transportation to one place to another or whatever it is, just give me time to calm down law, my heart rate is such and then check my blood pressure, but oftentimes is then they just go ahead and check my blood pressure. And they will say, Well, you burn pressure is high. No stuff I've noticed. I've tried to calm the hell, but give me five years to calm down. And when I calm down, I'm back to normal. I used to be nervous. As a kid when I receive vaccines. I couldn't stay at needles, then. I still hate needles now. But the difference was as a child I didn't have the tools in my toolkit and how to cope with getting vaccinated or getting stuck with needles other than stream cried trying to run away. But then as I gotten older, my body became more used to getting poked with needles. I still hate it. But I tolerated more. One COVID strategies I use when getting any type of shots, I close my eyes and count or pray in my head or meditate in my head. Something too distract what's going on while getting stuck with a needle. Another way that I cope with the process Thank goodness for a video game apps or mobile apps where I could either look at my emails, go to Facebook or play a game to get myself distracted from give the needle it will be very helpful for the clinic in general to find ways to put autistic people at ease, whether it's given us information ahead of time or even given us room to go to to get our minds together or be more at ease. I like those two options personally. There is discrimination in the medical fields is so shows up in many ways whether is lack of doctors of color,

Unknown Speaker 14:40

especially those who specialize in autistic people or any developmental or, but just ad disability in general. There's also lack of cultural understanding of how to treat a have

Speaker 1 15:01

people who are marginalized communities as well, it doesn't have to be just racial minorities or people with disabilities, it could also be immigrants or ignorance of the LGBT plus community overall ignorance just to potentially kill autistic people of color. If they are not treated right, or if people don't consider what people notice the races go for. Yes, it is too bad that we have to have the conversation. Especially when it should be human nature to find a way to make some people feel better and at the best, no matter who you are. Unfortunately, we have to have discussions and information on how to understand many types of patients. Mainly because either they don't understand or they don't want to understand what they mean. The importance of being your own advocate is very, very key. I personally say that the best advocate for your rights all you need is you. It's kind of like with Burger King, have it your way, and the job of the medical providers or your doctors. Partly to take care of you but also take care of you in a way you want to be taken care of. So that means adjusting what you usually do as a doctor in order to understand it fulfill the needs of whoever you're taking care of so be it.

Speaker 2 17:30

So I'll tell you a few things about Max. Max is 25. He has Down syndrome. He may also be on the spectrum. He is an incredible musician, brilliant musicians.

Speaker 2 17:46

He can play hundreds of songs actually on the guitar. He plays in a band. You've got I think two songs out on Spotify right now and another one coming out on May the fourth. Why is it coming out on May the fourth you might want to know these were big Star Wars fans here

Speaker 2 18:11

Max exercises a lot does a lot of yoga. You love to go on long walks and he loves the ocean. He's a surfer Max also has a job. He works at Starbucks. He's been doing that for about five or six years. What jobs do you do the job? You do Reese? restocking and what else you wipe off the counters? Yeah, and sweep a little bit. Sometimes you do the dishes, right? Very good at doing dishes too. It's a great job for him. And they've been really good to him. Since I think people have pretty low expectations. Nobody expects like a person with Down syndrome to be really good at something like no one should be surprised. But people are very surprised that you know, he doesn't tie shoes or do buttons. He plays guitar. And piano. Going to the doctor is definitely a big challenge for Macs. And it's always been a big challenge. And I think part of that is fear of the unknown. I think that's a big part of what's scary for probably all of us, but especially for someone who maybe doesn't fully understand what's going to happen even if it's explained, and also can't necessarily express their fears along the way and what they're what they're feeling like what he's really feeling. You might get the sense that he's anxious about something we don't know exactly what it is. And he for whatever reasons isn't able to say that when he was younger doing vaccinations was definitely challenging. And we definitely fell behind on some for a lot of reasons. But just getting it done was pretty tricky. Like for me personally, what I dread is is not ever knowing how Max is going to react in any given moment to what happens so so for me as the parent like I'm always triggered by so many things. Along the way that now you carry all that with you. So like, I know all the things that have happened in doctors offices and in hospital settings before. And so I'm expecting any of those things to happen at any moment, including like, getting smacked in the face or somebody out like worse than me getting smacked would be somebody else getting smacked. So like, you know, sitting back and watching the nurses try to work with him. And worrying that he might do something to one of them. Like, that's what's on me. For him, I think it's really just not understanding and not knowing what's going to happen as many times as you explain it. Now, vaccinations and shots are easier for him now, because he's especially since COVID. He's had so many, the first COVID vaccine, I didn't even know if we would get it done. And we actually went to a special clinic that was put together for people with disabilities with a disability advocacy group that we know about, and the Sheriff's Department. And they were really patient and really careful. And it was only for people with disabilities that day. And everyone there knew that they were going to accommodate whatever your needs are. So someone had a kid that wouldn't get out of the car, they went to the car. And if like with for Max, I said, he's not going to do well, in a big room with tons of people around. So we went into a smaller private room, you know, with just a couple of people. And like for max speed is good in some cases. And in the case of a vaccine, you just want to get in and do it and get out and not spend a lot of time blood draws a little different. So floodwall is probably the opposite. I don't even know how often most people have to get blood drawn. But I imagine you're supposed to do it at least once a year. And I think it had been four years, maybe even maybe even more since we'd had blood drawn. And there are, especially for people with Down syndrome, there are a lot of things that you need to look out for medically that you need bloodwork to look at. So just like you know they're at an increased risk for leukemia, thyroid disease, I'm not going to be able to name all the things. So going that many years without having blood drawn. I know a lot of people do it. But we should be doing it probably more frequently, not less frequently than like the average general population. Definitely that some of that's on me, because of my fear of going back and trying again to not wanting to put him through that, like the last time that we had blood drawn for Max, the only way to do it. And anyway, it was about five years ago, his dad and I both had to hold him. And even I think one of the nurses in the doctor's office, because he's really strong, had to hold him while they do the blood. And we did it but there was screaming a lot of screaming like a lot of crying. Max may not have been the only one. And it wasn't a good way to do it. And I think that the doctor's office, the personnel in the doctor's office didn't know any other way to do it that didn't occur to them that there might be another way to do it.

Speaker 2 23:17

I can't speak for Mac's, but I can sort of guess what he's feeling and what I've seen before and I think that as he gets more familiar with something and understands what's going to happen, he's willing to do a lot more things but what I know doesn't work is when you force him through something like in a hurry before he's ready. Definitely, I've learned that