

Quest PODCAST



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Episode 2: Buses, Trains & Automobiles - Getting from Point A to Point B August 7, 2021

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Mindy Henderson: Welcome to the Quest Podcast, proudly presented by the Muscular Dystrophy Association, as part of the Quest family of content. I'm your host, Mindy Henderson. Together, we are here to bring thoughtful conversation to the neuromuscular disease community and beyond about issues affecting those with neuromuscular disease and other disabilities, and those who love them. We are here for you, to educate and inform, to demystify, [00:00:30] to inspire and to entertain.

We're particularly excited to be launching this Podcast during the summer months, which celebrate both Disability Pride Month in July and SMA Awareness Month in August, we are here shining a light on all that makes you, you, whether you are one of us, love someone who is, or are on another journey altogether. Thanks for joining, and thank you to our sponsor, [00:01:00] Genentech. Now let's get started.

For anyone with neuromuscular disease or other disabilities, getting from one place to another can be a challenge. On today's episode of Quest Podcast, we will be discussing the various options in accessible transportation from driving adapted vehicles, to riding on buses and trains. We'll examine the various modes of transportation, [00:01:30] what systems have been designed well and which ones maybe leave a little to be desired, and how you can get involved to advocate for improvements to public transportation.

With me today, I have some incredible guests. First of all, I have Chad Strowmatt. Chad is an occupational therapist with 33 years of experience. He earned his bachelor's degree from Texas Tech University Health Science Center, and his Doctor of OT at Rocky Mountain [00:02:00] University for Health Professions.

He has owned and operated Strowmatt Rehabilitation Services, Inc., since 1993, and served as president of the Association of Driver Rehabilitation Specialists in 2004. He has experience in all of the adaptive equipment options required to help people accommodate for changes in physical function.

Next up, I have Jessica Murray. Jessica earned her PhD [00:02:30] in developmental psychology at The Graduate Center, Columbia University, New York in 2020, focusing her research on daily travel and the ways that inaccessibility limits the fulfillment of psychological needs for autonomy, relatedness, and competence among people with disabilities. She advocates for improving transit accessibility in New York City and chairs the Advisory Committee for Transit Accessibility for New York [00:03:00] City Transit.

Last, but certainly not least, I have Josh Cueter. Josh is from Troy, Michigan, and is a graduate of Michigan State University. During his last semester, he worked as an intern with the Equal Employment Opportunity Commission and the Muscular Dystrophy Association in Washington, D.C.. Jessica, we're going to start with you. I personally live in a city that's not set up well for individuals with disabilities [00:03:30] to use, for example, public bus routes.

The city is too spread out for there to be an effective infrastructure for bus routes, or at least that's my assumption of why it's not been better designed for better use and accessibility. There's a special transit that you can use, but it has to be scheduled in advance, which of course eliminates any spontaneity factor.

While it is door-to-door service, the timing and scheduling process can be unreliable. [00:04:00] There's no train system in Austin. Accessible cabs are few and far between and the experience, if we do use cabs, is similar to the special transit experience. Would you mind just talking a little bit about how these issues, the lack of options and the inability to get around as well as the general public affect disabled individuals from an emotional perspective?

Jessica Murray:

Sure. I recently finished my PhD [00:04:30] in developmental psychology and this was the topic of my dissertation. I was studying the idea of basic psychological needs in transportation, and this is a theory that applies to a lot of different domains. I just applied it to transportation and compared people with disabilities and people without disabilities. The three basic needs are autonomy, relatedness and competence.

You could think about how those three needs may be thwarted in [00:05:00] transportation systems when you have a situation like one you describe, where you don't have a lot of options, you can't really decide when and where you want to go somewhere. In New York City, especially we have a very complicated system, and so even if people are really smart, it may be challenging to get around because the system is very complex and navigating it can be a challenge.

Then relatedness to other people, I mean, the way that people with disabilities sometimes [00:05:30] feel taking public transportation is that they notice that they're different. This applies to the paratransit that you were talking about earlier, where there's a separate mode of transportation that's only for people

with disabilities and all of these issues essentially lead to an outcome of less quality of life, lower well-being among disabled participants in this study that I conducted.

I think the problems that you described in Austin are problems [00:06:00] that people experience really throughout the country and in a place like New York City, where it's a very dense city, there are multiple options, but people still experience all those same challenges that you have.

Mindy Henderson: Great. Let's talk about train and subway systems. I know you mentioned New York, which is where you're based, and of course, New York has a subway system. From what I've heard, challenges to the subway system or train systems are similar [00:06:30] in a variety of cities. I'm also told that they're not a particularly ideal solution for someone with a disability. Would you describe what the issues are and what kind of experience that creates for a person with a disability?

Jessica Murray: Yeah. New York City is really far behind in terms of the percent of accessible stations we have. We're right around a quarter of all the subway stations have elevators and other accessibility features for people who [00:07:00] are blind or have low vision, or are deaf or hard of hearing. For wheelchair users, the problems are that even in the stations that are accessible, there are big gaps between the platform and the trains.

The signage is not always great and it's not always visible. A lot of our train stations have low lighting and they put these tiny signs that show the wheelchair access symbol above. You have to [00:07:30] really look for it and if your vision's not great, you may get really confused trying to navigate around a subway station. We generally don't have station diagrams here that could help people plan out their trips in advance.

Then we have maintenance issues. The elevators may be out of service and it's not really real-time. So even though there is a reporting system, people may check before they leave and see online that everything should be fine for their trip, but [00:08:00] then when they get to the elevator, it's out of service. New York City also lacks public restrooms everywhere. If anyone's come to visit here, you know that Starbucks has become the de facto public restroom.

Mindy Henderson: Oh wow.

Jessica Murray: There used to be public bathrooms in the subway stations, but those have largely been closed and are used only for employees now.

Mindy Henderson: Josh, I know that you've lived in both Michigan and in the Washington, D.C. area. Let's [00:08:30] begin with D.C.. I know that you actually had a really good experience with their train system. Tell us about that. After hearing about train systems in places like New York, how did the D.C. experience differ?

Josh Cueter: I've definitely heard the stories from New York as well. I was lucky enough, last winter I spent my last semester at Michigan State doing an internship with the

Equal Employment Opportunity Commission, and so that allowed me ... I lived in Arlington. [00:09:00] I ended up using a lot of the public transportation area. I ended up sticking with using the Metro for most of it.

I was lucky enough talking to people that the year prior, there was a lot of construction and updating on the Metro system in the area while hearing the horror stories of half of the city shut down with construction. I was definitely able to take advantage of everything that was recently updated. I definitely saw a difference in some of the updates. There were some new trains [00:09:30] that were thrown into the cycle on the rails.

Some of the older trains didn't have any spots for a wheelchair or strollers and that kind of thing, but these new trains did. It was a nice reserved spot that you could just park right in and didn't have people walking over you or standing over you too much, unless there's rush hour or something. At that point everybody's packed in and just up in each other's space.

Mindy Henderson: Yeah. [00:10:00] The train system really became your primary mode of transportation, is that right?

Josh Cueter: Yes, it did. When I got out there, I wanted to fully experience and understand the best way to travel the city. I had a car out there as well, but I don't have it fully modified for myself to drive, so that would be being dependent on other people. I tried the bus, and additionally Uber and Lyft have a pilot program out in D.C. for accessible transportation.

Mindy Henderson: Nice.

Josh Cueter: [00:10:30] I'd utilize that as well, but that can get pricey at times. I found that the most reliable and cost-effective way was using the Metro.

Mindy Henderson: That's fantastic. What did it do for you emotionally to have that kind of independence while you were living there?

Josh Cueter: It was the freedom to be able to ... Living in Michigan and from Michigan, we don't have a whole lot of medical transportation or accessible transportation, like you Mindy, [00:11:00] where it's using the bus systems and trying to schedule 24/48 hours in advance for something, so there's no spontaneity. To be able to just talk with friends across town and be like, "Hey, I'll just be there in a half hour."

To be able to jump on a train and go and not have to plan and schedule other's people life around mine to be able to run errands or just meet up with friends.

Mindy Henderson: That's awesome. You mentioned Michigan, [00:11:30] and I understand that you're back in Michigan now. What's available to you there to help you get around?

Josh Cueter: For the most part, I do just have a modified vehicle with just a ramp on the side that I can jump in. Then that requires either family, friends or my healthcare

staff to drive me around. Additionally, like I said, I do have similar setup with the bus systems, like you, where I live about a half hour outside of Detroit. It's having to schedule the non-medical [00:12:00] transportation through the public transportation system in the city.

Mindy Henderson: Okay. Okay. How would you describe your life in Michigan with the transportation that's available to you and how that sort of affects your life, in comparison to how you lived and the lifestyle that you had in D.C.?

Josh Cueter: Definitely. It's not necessarily limiting now being in Michigan, but would definitely call it very schedule-oriented. [00:12:30] Just having to plan everything at the very least half a day ahead of time to set up a schedule and find people that are available to help me get to where I need to be. On the flip side of that, living in D.C., if I needed to go run some groceries or errands, I could just hop on the Metro and be wherever I needed to be in 15/20 minutes.

Mindy Henderson: Got you. Okay. Okay. Chad, I want to bring you into the conversation at this point. You work with people all over to help them get vehicles [00:13:00] adapted to drive, and then you do a lot of the training needed to get someone safely behind the wheel.

In fact, I was doing the math last night, I worked with you for the first time about ... I think it was like 25 years ago, to get my first adapted vehicle and you worked with me to get comfortable driving. I have a lot of questions for you, but before we leave the topic of public transportation, what's your take on public transportation as an option for people with disabilities in the United States?

Chad Strowmatt: [00:13:30] It's a great question and it's one of the thing I tell people a lot when I talk to groups of either therapists or healthcare providers. My biggest referral source is public transportation nightmares, because I'll have a client that either felt unsafe on a bus with a single driver and/or they took much longer to get ... I had one of the classic cases we had in Texas, where [00:14:00] we had a consumer sue vocational rehab, because she had gotten her degree in social work, master's of social work.

She would go on interviews and she would basically be done with the interview, let's say at 2:00 in the afternoon. Then at 6:30 that night, when all the employees were leaving, they would still see her sitting outside.

Mindy Henderson: Oh my gosh.

Chad Strowmatt: And saying to her, "Is transportation going to be a problem for you?" She's like, "No, no, I'm just waiting on my bus." So they would withdraw the offer.

Mindy Henderson: [00:14:30] Yikes.

Chad Strowmatt: She sued saying, "Look, I can't finance a vehicle for myself to drive unless I have a job, but I can't get a job because people are perceiving my use of public transportation, and really the inefficiency of it, as a barrier." She really said, "Is

there some balance where we can have my need to purchase a vehicle and become independent so that my time is more efficient?"

That's really, I would say, the biggest thing people say to me. I had a client, believe it or not, who was a ... [00:15:00] He served court papers. Like, if you were being sued or whatever the case may be, and you have to be served papers, he used, in our area, Houston METROLift.

I said, "How did that work? Like you ..." He said that, "They would drop me off at like 6:30 in the morning and I would be waiting for this employee to show up at their office at eight o'clock. Invariably, a lot of people would have attention to me. Like, 'What is this guy sitting out here in [00:15:30] the parking lot just milling around, waiting for the business to open?'"

It was all because of this issue of public transportation and the inefficiency of time. That's really what I see, is that people that have control of their own transportation and really what the other guest said, which is spontaneity, it really does make your day more efficient.

If you have to use public transportation and it is not ... It's not like Josh said in D.C. where he can just get on the bus and 30 minutes later, he's at another part of the [00:16:00] city and can interact with his friends or go grocery shopping or whatever. That's the benefit you get with your personal transportation in that you don't have to preplan everything.

I know in our area, a lot of the people that work that use public transportation have subscription services so they do have priority and they have designated times every day that they're going to use those services.

Again, if there was a last-minute cancellation at their doctor's office and they wanted to change an appointment, all of those things had to be considered before that patient [00:16:30] or that client could say, "Yeah, I can make that appointment at three o'clock tomorrow." When they find out at five o'clock the day before. It's really a challenge. Yeah. I hear that a lot.

Mindy Henderson: Wow. Okay. Let's talk then about the process to get an adapted vehicle. Would you mind just talking a little bit about what that process looks like and how someone gets started, maybe what their first step would be?

Chad Strowmatt: Sure. A lot of the providers [00:17:00] in the United States, and even in Canada, are certified driver rehab specialists and a lot of them have a background in occupational therapy, or some other type of healthcare-related degree. It depends on what system you're in. The VA for example use a kinesiologist. The majority of the providers that provide these types of driver evaluations and training services are occupational therapy trained.

A lot of the referrals we get and how people typically access the system is they either [00:17:30] are already a vocational rehabilitation consumer, and they are trying to get support to go to college or to try to find a job. They're usually out of

high school, or they are in the last few years of high school and they're transitioning to a more long-term plan.

A lot of times we get referrals from the vocational rehab people, but ultimately the referral is signed by their physician or whoever their healthcare provider is. If I've got somebody that has low vision, let's say, for example, the way they enter the system is through their optometrist or whoever [00:18:00] their low vision eye care specialist is.

That's typically the ... like a traditional medical team. It would be led by the physician or whoever the healthcare expert was in that area that was helping them try to access the transportation options that may be available to them.

Mindy Henderson: Okay. If they're coming into the system through a physician's office, let's say, do those physicians typically know how to navigate this system, how to find you, [00:18:30] for example?

Chad Strowmatt: In many cases, the physicians that refer to us are either at large rehab settings, or they have some type of clinic, like a polio clinic or an MDA clinic or whatever that they are involved with. They do, in many cases, know the resources that are available in that community. I mean, that's part of my job, is to meet with therapists and doctors in different facilities and try to show them that these are some of the choices that exist out there.

That if they need to make [00:19:00] those kinds of referrals to specialists like I am, these are where these ... But again, in our case, if you got onto aded.net, which the Association of Driver Rehabilitation Specialists, aded.net has this search engine. You could say, "I live in Michigan, or I live in Oregon and I live in this particular city." And it would filter you to whoever the provider was in that area.

It would also give you that information about [00:19:30] what kinds of services they provide. Because some of the services I provide are really unique and really is why my area includes more than Texas. It includes Arkansas, Oklahoma, Mississippi and Louisiana. The primary reason is a lot of those states don't have some of the ... like the high-tech controls that could be put in a vehicle that would allow somebody with limited strength and range of motion to be able to drive.

That's really why I travel as much as I do, is because a lot of people have cars, and if [00:20:00] you have a paraplegic injury or you've lost a limb, a lower extremity to an accident or diabetes or whatever, then there are a lot of what I call car programs in the country.

The van programs, there's probably less than 20 that I'm aware of, and of those 20, there's probably in the neighborhood of 10 to 15 that have some of the high-tech options that you might see if somebody has limited strength in their shoulders and decent function in their hands and wrists.

Mindy Henderson: Wow.

Chad Strowmatt: Yeah.

Mindy Henderson: [00:20:30] Is that in all of the United States or is that in your region?

Chad Strowmatt: No. No. That's in all of the United States.

Mindy Henderson: Wow.

Chad Strowmatt: I'm the only one in Texas. There's nobody in Oklahoma, any ... No. I'm sorry. One of my friends is in Oklahoma City. There's nobody in Arkansas. There's nobody in Mississippi now and there's nobody in Louisiana. Yeah. It's more of ... And actually all of us high-tech providers, many of us are really best friends.

We talk to each other about problems we're experiencing with one brand of driving control versus another and a lot [00:21:00] of us either were trained at the same time, which was about the early '90s when a lot of this technology came out initially, and when I met you, the technology was brand new.

We were lucky in that we were ... and blessed that we were able to be exposed to it and then we just fell in love with that kind of service provision for the consumers that we encounter on a daily basis. A lot of us are ... Like, I can call my friend in Virginia. I can call my friend in Pennsylvania.

I got a friend in [00:21:30] New Jersey, California, Canada. All of us know each other really, really well, and know what we have in our arsenal of tools to try to help people become independent in a safe and practical manner.

Mindy Henderson: Yeah. It really is amazing. I mean, the car that I have today, just to give people who are listening an idea, it's all levers and touch screens and buttons. Things that are within maybe two/ [00:22:00] three inches of my hands that I can just reach a finger out and touch something to turn on a turn signal or whatever the case may be. My car kind of looks like the cockpit of an airplane.

That's what they can do with these technical systems. It's really amazing. Chad, who would you say is a good candidate for driving an adapted vehicle?

Chad Strowmatt: I thought long and hard about that when you sent me that question. [00:22:30] The ideal candidate has ... Let me back up. Let me say, the easiest candidate is somebody that has multiple extremities they can use, that have about four to five inches of range of motion, and then good strength or dexterity within that range of motion.

That doesn't apply to everything because a lot of our ... When you think about the clients that we see that have medical conditions that affect the trunk muscles or affect the shoulders and the hip curl, their function is a lot of times distally oriented [00:23:00] so they've got good control of their hands and wrists.

As long as their arms are supported well, they may not be able to lift their arm above their head, but they can get to things and control things really, really well

within that limited reach envelope. But we can harness that movement. When somebody has that ... For example, our spinal cord injuries, it's more gross motions. They have very poor dexterity, very poor fine motor skills, but they've got good gross motion skills.

The technology can adapt to fine motor skills that might [00:23:30] be harnessable or more gross motion skills like you would have with a spinal cord injury or an amputation or whatever. The clients that are not usually successful, usually have gotten to the stage of their condition, where they've got poor head control, like they don't have great strength in their neck so the G-forces of the vehicle are causing them to really struggle to keep their head up.

Those are not usually great candidates and/or their endurance is extremely low. Like for example, [00:24:00] in Houston it would be really common if you lived, let's say in Katy, and you had work downtown or even in the Texas Medical Center, it's at least 30 to 45 minutes one way. You have to have at least functional endurance that can tolerate that level of endurance for that period of time.

Most of our clients that we get if they can drive and we get them set up, that's part of what we change, is the resistance or the strength required to operate these controls so that they have this capability to do two, three, four [00:24:30] hours at a time without having to take a significant break.

Mindy Henderson: Nice.

Chad Strowmatt: To me, as long as you've got good head control, and you've got a decent range of motion that we can even accommodate with special mirrors, unless there's something unusual ... The other things that make you a poor candidate are things that we consider unpredictable. For example, seizures. Seizure disorders that are unpredictable, obviously that wouldn't be cool. If you have a heart condition that you black out or whatever.

All of [00:25:00] those things are really from a medical model determine ... Spasticity is another one that I encounter on a regular basis. Somebody who has uncontrolled spasms and the spasms result in lack of control, of their driving controls, yeah, that would be a poor candidate. But pretty much everybody else, as long as they have the cognition and the vision to be able to do it, we can harness things for really limited strength and range of motion.

Mindy Henderson: Nice. Nice. If there's any question in somebody's mind about whether or not they are a good candidate, like you were saying, [00:25:30] they could talk to their doctor and then part of what you do, or other professionals like you, is to come out and evaluate people with different equipment and see what may or may not work for them, correct?

Chad Strowmatt: Exactly. Yeah. I mean, I've got ... It's so funny because I was trained initially at The Institute for Rehab and Research, which in our area is commonly known as TIRR. I think when I first met you, I was a staff OT at TIRR and we had just gotten that van [00:26:00] that you end up driving and learning to drive initially.

In those days I had one car and one van and since I've been in private practice since 1993, I now have 10 vehicles and each one of those vehicles is slightly different. A lot of them have multiple driving control options, but each vehicle has a specific purpose. The reason I bought it is to be able to provide certain types of services to clients that I've seen in the past or that I anticipate in the future.

Yeah. A good evaluator, [00:26:30] if they come out and they see you and they don't have the technology you need, or at least you've tried some of the low-tech stuff and it doesn't work, then you want that provider to be able to give you the opportunity to try other devices. That really, to me is the beauty of a good CDRS that has a good comprehensive program. They've got lots of choices, different brands of equipment.

That's another ... kind of a biggie in my field in that we don't want everybody to have the same 'brand [00:27:00] name' of driving control. The more flexibility and the more options we give our consumers, to me, the more informed consumer they're going to be and the more successful they're going to be long term.

Mindy Henderson: That's great. That's great. I have one more question for you, Chad, and then I want to go back to Jessica and Josh with a few more questions. Clearly, people probably could gather from listening to this conversation that some of this equipment is kind of costly, and so finances can be an [00:27:30] issue. Can you share a little bit about the cost to getting a car adapted and how to inquire about some financial support? Because there is assistance out there.

Chad Strowmatt: Absolutely. I would say that is one of the barriers. People will hear or they'll talk to somebody or they'll hear, "Hey, man, my car is \$95,000. There's no way I can afford that on the salary that I make at the job I'm in." One of the biggest resources in the United States in many, many [00:28:00] states, I'm not aware of any state that doesn't have vocational rehab services.

So when I do work in Arkansas or Louisiana or Mississippi, or Oklahoma, wherever, most of those clients are in the vocational rehab system within that state. As long as that person is pursuing an education and is pursuing employment, the vocational rehab services providers, they provide the assistance needed to assess, train and to acquire the [00:28:30] equipment. In some states, they have some assistance to purchase the vehicle also, but in many states they don't.

You just have to buy the 'chassis' of the vehicle that will be able to be modified to meet your equipment needs and your accessibility needs. Then they basically would fund the remainder of those costs. In many cases, we encounter clients that will buy, let's say a Chrysler Pacifica and the Chrysler Pacifica's probably in the 35 to \$37,000 range right now, but all the adaptive equipment [00:29:00] to make the van accessible and to make the vehicle drivable by this consumer is funded by vocational rehab.

Of course the VA offers funding for service connected veterans. There are independent living service providers that are in different states. Those are more for folks that don't work, but still need to have some accessible transportation options. ILS services do fund that. The funding there is less and they are very cost-conscious, so if [00:29:30] it's a low-tech modification, let's say like mechanical hand controls in a car or a truck, they sometimes will do that.

When it comes to more high-tech stuff, they're probably more reluctant to do that, unless this person can show that they're the leader of their household and they have to be able to go grocery shopping for their elderly parents or whatever, then ILS services are available for that too.

Mindy Henderson: Okay. Perfect. Perfect. Jessica, let's go back to you for just a second. I know that a lot of [00:30:00] what you do today is advocacy for transportation systems. I'd like to talk about sort of root cause for just a second. What do you believe is really at the root of the problems that we have in making transportation more widely accessible?

Is it purely a financial issue with making the kinds of changes to the infrastructure that we need? Is it the awareness of the significance of the problem to the disabled community [00:30:30] or something else entirely?

Jessica Murray: I think it's a little bit of both, but definitely the funding issue is, to me, the most important thing that we can do to fix the problem. The MTA here in New York has said for decades that elevators are very expensive and that's why they can't make more stations accessible faster. They say the federal government needs to give them more money for this.

I mean, ultimately I think it's budgets are moral documents and they [00:31:00] haven't really prioritized accessibility over the last 30 years either. That's why I think it's a little bit of both, but there are currently some legislators that are trying to finally address this problem. Senator Tammy Duckworth has introduced a bill called the ASAP Act, All Station Accessible Program modeled after Chicago's ASAP plan.

That would establish a federal grant program as part of the Surface Transportation Reauthorization Bill [00:31:30] that would provide money specifically for accessibility improvements. They're proposing \$10 billion over the next 10 years to help transit agencies across the country finally make their system fully accessible.

Mindy Henderson: That's fantastic. What would your recommendation be for anyone who might be listening? How can someone most effectively advocate for that program or just for improvements in general?

Jessica Murray: I would say call your [00:32:00] U.S. senators and representatives and ask them to cosponsor the bill. If there are local public transit advocacy organizations, get in touch with them and make sure that they know about it and can advocate for it. Yeah. It's really just a matter of building the public support that can put the

wind in the sails of the state senators and representatives that will have to vote for this bill.

Mindy Henderson: Perfect. Perfect. I'm going to make sure that we put a lot [00:32:30] of the information and the resources that you're all mentioning in the show notes so that people can follow up and look into some of these things. Chad, back to you for just one final question, and then I'm going to give Josh the final word. Chad, what questions should someone ask themselves if they want to go the driving route and get an adapted vehicle? What should they ask themselves to decide if driving is a good option for them?

Chad Strowmatt: One of the things that we [00:33:00] commonly try to talk about during the evaluation process is really, what does it cost to own a car? What does it cost to insure that car? A lot of states, even if they fund ... like if the vocation rehab services funds the modifications, they still expect that consumer to insure that equipment so that if there is some accident in the future or a fire or whatever the case may be, where that equipment needs to be replaced, that auto insurance [00:33:30] policy would be able to cover that cost.

The cost of those things are really, really important. A lot of the vocational services providers, like myself, or let's say the state employees that are involved in these kinds of activities, they have like a formula. They sit down and try to figure out what does it cost just to live and what does it cost for your housing and what does it cost for transportation?

Then they compare that to what your income level is and balance those two so [00:34:00] that you can truly understand, is this something I can afford to do? Does it make sense? The one thing that I think that we touched on earlier is just really this issue of man-hours. How many man-hours does it take a day for you to work? If it takes six hours or five hours a day of man-hours to get your transportation needs met, is that independent driving going to reduce that?

Is that going to make it down to two hours in a day instead of five? What is that going to allow you to do? Is that going to [00:34:30] make you ... You can select your ... There's been studies that talk about depression levels and independence levels and marital status. All these things are intricate with the ability to be independent in transportation. I even see them in relationships.

If I've got an unbalanced relationship where one person is really dependent on their spouse to manage their transportation, there can be a strain there. When both partners have that ability to do that, when somebody can pick up [00:35:00] the kids from school or take them to soccer practice ... I remember one of my most recent clients that was the first thing he wanted to do, was take his daughter to soccer practice, because he had not been able to do that for several years.

It was just a huge thing for him. That's really what made my heart soar when we were able to help him achieve that level of independence. It was really cool.

Mindy Henderson: I love that. That's great. Josh, like I said, I'm going to give you the final word here. What are your thoughts [00:35:30] or wishes on how cities could improve bus and train systems for people with disabilities? What would it mean for your life if improvements were made?

Josh Cueter: Definitely. It's like it was previously mentioned, money and priority is a huge aspect that is holding some of these modifications back right now. For that to be brought to the forefront and updated to [00:36:00] help is something that would definitely just improve quality of life to allow me and others like me to not have to worry about scheduling and get that spontaneity back, or even just get it to begin with.

One thing that is promising, like I previously mentioned, is these pilot programs that like Lyft and Uber and these private companies are doing to provide accessible transportation, but it is very [00:36:30] limiting still and few and far between. I've read about cities like London, who they're ... I think they call it their black cabs. I've read that all their cabs are a hundred percent accessible.

To what extent that is and defined I haven't been able to experience that, but it's that sort of universal design that would be a huge benefit to the community to be able to have [00:37:00] that flexibility and not have to worry about, "Oh, my city only has a handful of accessible vehicles that I need to schedule and make sure I can have one available and can schedule one for me.

Mindy Henderson: Absolutely. So well-said. Just to sort of echo your sentiments, from my perspective, to live in a city where you feel prioritized as a human being and you mentioned universal [00:37:30] design, and to know that any bus or cab or train that is available to anyone else is also available to you would be ... I don't know. Just what that would mean for life and for independence and quality of life, like you said would be incredible.

Thank you all for your time today and for sharing your expertise [00:38:00] and your experience. I know that there are a lot of people listening, who I think will be very interested in all of the things that you had to say. Thank you again for your time.

Chad Strowmatt: No problem. Thank you.

Jessica Murray: Thank you.

Josh Cueter: Thank you as well.

Mindy Henderson: Thank you for listening. For more information about the guests you heard today, go check them out at mda.org/podcast. To learn more about the Muscular Dystrophy Association, the services [00:38:30] we provide, how you can get involved and to subscribe to Quest Magazine or to Quest newsletter, please go to mda.org/quest. If you enjoyed this episode, we'd be grateful if you'd leave a review.

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