

## Episode 10 – Disability Awareness and The Importance of Faith with Joel Vander Molen

Mike: Well, hey everybody, it's Mike Hoenig from the University Center for Excellence in Developmental Disabilities at the University of Iowa Center for Disabilities and Development. I'm a program coordinator here and more important to this next few minutes that we'll be spending with you, I am one of three co-hosts for this podcast called Disability Exchange. Thank you so much for joining us.

Mike: This podcast is a joint venture between our University Center, which we call the UCEDD and the University of Iowa College of Public Health and we are very, very grateful for their support. We've got another great guest for you today and before we introduce him, I'd like to turn it over to our co-host extraordinaire, Judy Warth.

Judy: Welcome to click and clack of Disability Exchange. We are really excited today because we have a guest who's going to bring a whole new experience to all of us. Mr. Joel Vander Molen and as I'm learning about you, Joel, you've got a lot of array of life experiences, but also aspirations as well, which I hope we'll be able to share and infuse in the people who are joining us in this podcast. So welcome Joel.

Joel: Thank you. It's a pleasure to be here.

Judy: We'd like to start off by learning a little bit about you. Do you mind sharing just a little bit of your story?

Joel: Sure. Well, I have lived in Iowa most of my life, well, all my life and in the same hometown for pretty well all my life. When I was three years old my parents and I were headed on a trip to Des Moines and it was in February of '85, but along the way it started kind of raining and rain in February in Iowa usually don't make a very good mix. My dad was driving. He slowed down quite a bit, but at that time Highway 163 to Des Moines was just a two-lane road. An oncoming truck came and went by us and the suction from it pulled our car into the opposite lane where then we were hit by a second oncoming truck.

Joel: My dad and aunt that were with us did not receive any lasting injuries. We sometimes wonder about his mental state on occasion, but other than that ... My mom received injuries for pretty well everything from hips on down and had a lot of reconstructive surgery and has challenges now with walking. I was the only one in the car wearing a seatbelt and received a C2-3 spinal cord injury. In the 36

years since then, I've learned a few things about life as a quad and I try to do as much as I have been able to do.

Judy: Joel, for those people out there who might not know what a C2-3 spinal cord injury is, could you share?

Joel: Yep. Every level of your spinal cord has a number to it and the top seven vertebrae are called the C-spine, so my injury is between the second and third vertebrae in your neck. It's about the second highest injury you can receive, so because of that I am unable to feel or control anything below my shoulders and I'm also unable to breath on my own. For many years I used a traditional ventilator with tubes and everything and now I use something called a diaphragmatic pacemaker system that is basically an implant or is a different type of vent.

Mike: Has that allowed you to become a lot more mobile?

Joel: Well, somewhat, but I used the regular vent for over 25 years and with that I went through grade school, high school, college and everything that a person at that age does, I used it on my wheelchair and just had a car battery that it ran off of. It really allowed me to do everything I wanted and we learned how to get around things like battery lengths and those shortcomings, but now with the diaphragm pacemaker I no longer have tubes or just noise of the vent so that is very nice. The main thing I don't like about the change is that at least currently there is no support for the system within Iowa and with the vent, I could speak nonstop but now I have to stop every four seconds to take a breath.

Mike: Oh, okay.

Joel: Other than that, it's been a good change.

Judy: Joel, does anybody ever give you any grief and say, "Well, it's nice to be able to slow you down a little bit?"

Joel: My caregivers that have been around a long time, yes.

Judy: I had a sneaking suspicion.

Joel: Yeah, they like it that I now have to stop and I can't speak without ever having to stop.

Mike: So, just out of curiosity, you mentioned going up Highway 163 and knowing your last name being Vander Molen, are you from like the Pella ... What's your hometown?

Joel: Yep, I am based in Pella.

Mike: Okay. I went to Central so I had a feeling.

Joel: Yep, I was in college. I've lived here all my life.

Mike: You didn't stay and go to CUI?

Joel: No. It was a possibility but my parents and I had started working on what it would take for me to go to college in my sophomore year of high school. I wanted to be able to live on my own if at all possible. So, we looked at different schools and looked at campuses and nursing agencies and two months after I graduated from high school, I had two colleges that were a possibility and two weeks before the final deadline of registration it ended up that I could go to AIB College of Business in Des Moines and live in my own dorm there.

Judy: All right, so what did you study?

Joel: I started with accounting and kind of a dual major of accounting and IT, but after that first semester I figured out accounting would not be a career for me, so I-

Judy: Me too. Me too, Joel.

Mike: Me three.

Judy: It took me longer than a semester. You're clearly smarter than I was.

Joel: But I graduated with my degree in IT and after college I looked for work in the Des Moines area, and that is a whole story in itself, but I did not find anything there and ended up moving back with my parents and I've been doing web development ever since. That is one of my many hats that I do for work.

Mike: Tell us about your web development work. Do you have your own business? Do you work with another company or how does that work for you?

Joel: Well, because of the Medicaid stipulations and that I don't own the business, it's my mom's business that I am employed by, but yeah, it's only me that does any of the work. For a while I was working with probably around 50 separate clients and I had a couple web development companies that I worked with as well. Now, due to health challenges and changes in the web industry in the last 20 years, I don't do a whole lot anymore. I maybe have about half a dozen active clients per month but I still do it somewhat and I somewhat look for new customers, but I had to be very limited around what I can do of how much time things take.

Judy: You know, you said you do web development but you also told us that you have a spinal cord injury that prevents you from moving from below your shoulders. For those people who aren't intimately involved in this sort of stuff, how do you do this?

Joel: Well, there are several options now for people like myself that have absolutely no hand movement. I have a lot of friends that do voice activation and use that kind of software, but I guess I'm old school and that when I was learning about living life as a quad when I was young that I used a mouth stick for everything and that is what I still use now. With that I can type at about 30 words a minute and I just need a regular keyboard and mouse. I set it up on a bedside table in front of me, either in bed or at my wheelchair, and that's all the adaptive items I need. Makes it easy and it allows some flexibility.

Joel: As a kid, I played a lot with toy tractors and trucks and I also did LEGOs on my own. So I would carefully slide them up each other and whack them into place with my stick and through that I kind of learned basic engineering stuff as well, what worked and how I could move the LEGOs around or not. I could have maybe gone into a career of engineering but I don't know how well that would work for me of being from home most of the time. But as I say, just because you can't move or breath on your own is no excuse for not being able to be productive.

Mike: Absolutely, and you talked earlier a couple times now you've mentioned learning to live as a quad, so after your accident I assume that process started pretty quickly.

Joel: Yeah, it did. Unfortunately, being my age, we were taken to Methodist Hospital in Des Moines and they thought about taking me to another hospital in Colorado that was more specialized with my type of injury, but since I was so young they didn't want to take me away from mom. So I stayed in Des Moines and at that time they didn't really have a lot of rehab for someone of my age and disability.

Joel: I remember vaguely of being taught how to use a mouth stick a little bit, but I don't remember going through like six months of rehab and doing things like they do now. I was self-taught quite a bit. Went through early grade school with my classmates and I learned to write just like they did but I used a marker in my mouth. So all my papers that I wrote on were just a markers' length away from my face, but it worked.

Mike: It sounds like you made a lot of adaptations and a lot of creativity have gone on. Did you ever actually go to any sort of a formal rehab program outside of Methodist?

Joel: No. Not that I recall anyway.

Mike: Gotcha.

Joel: I also have very encouraging parents that have helped me a lot through all the years. About the time I was going to go home after my initial injury my doctors and the team said that I needed to go to a care facility or a nursing home because someone with my needs in a regular school setting would get a lot of infections and would always be sick, but my parents knew that God had a different plan for us and they took me home to live with them as we always had before. Thankfully my dad's work had excellent insurance and we got nursing care at home. At first, it was 24/7 and yeah, I went through regular schooling. I went here at Pella Christian Grade School and High School and I never really had any serious infections or illnesses throughout my schooling.

Judy: What was school like? I mean, most of our schools don't have a lot of people who are quadriplegics in it and what was it like because you're a few years ahead of now even.

Joel: Well, I definitely was the only quad at school and the only wheelchair user, but for me it was what I was used to and my classmates just kind of got used to me. For being a small school you get used ... You have the same classmates pretty well your entire journey through school and I was just Joel with whoever was with me. Like a lot of quads, I only got close to a few friends and most of those were gals

but I had some experience of being poked at or being made fun of a little bit, but thankfully not nearly as much as what I've heard from other families that I have worked with.

Mike: So, how accessible is the school? How many floors and if you had to go to a second story for classes or activities, how did you get there?

Joel: Well, at that time the Christian Grade School was mainly all one level that the classrooms were on. The front door was a level entrance so I could just roll in there and there were a couple of classrooms in a lower basement that was not accessible. I believe it was either both second or third grade classes were in the basement, but when I got to that age level they just rearranged the classrooms a little bit so that I could easily get to it.

Joel: The gymnasium was in the lower level but that area did have an elevator. So really, through grade school and high school, both buildings at that time were older. They were definitely built way prior to the ADA, but they were accessible enough that I could use them fairly easily and where I could not, the school adapted so that I could still fully participate in that class.

Mike: That's good.

Judy: Joel, I was looking over stuff and seeing that, not only are you a web developer, you're an advocate and speaker and a substitute minister and I did hear you're working on your autobiography. Tell me more about all of this. You've got a pretty diverse and rich interests.

Joel: Yeah, well as I said, I worked with several different websites over the years and one of them actually was the Christian Grade School that I went to. In 2004, I was working on it and I saw that their second grade class did a segment on disability awareness. So, I contacted the guidance counselor and learned that this segment that they do, I was watching a half hour long video. So, I'm like, "Well, I can probably do better than a video, I think."

Joel: I volunteered to go that year and speak with the kids about life with a disability and how to serve God in different means and ever since then I have been an annual speaker at that school as well as several others around here. It's fun. I like working with the second and third graders. You never know what they're going to come up with and just when I think that I've heard all of the questions, they come up with something new.

Judy: What's been your favorite?

Joel: Well, one of the things I ask them is what they think I do for work and I've had some good guesses that I maybe write a book or I guide people at museums. Those are good ideas. Others that stick in my mind are that I am a Schwan's man. I don't know how that would work.

Mike: I wonder where that came from?

Joel: Or that I make pizzas at Pizza Hut or Casey's. One of my caregivers had said that she would pay good money to see me try to throw pizza dough up in the air and catch it with my mouth stick.

Judy: Well, if you can do LEGOs, you might just surprise us all.

Joel: I haven't done it yet, but we'll see.

Judy: You know, if you just put a little adaptation on the end of your stick, you could catch it.

Joel: Yeah, yeah, but doing all the grade schools for several years, that kind of developed into going to colleges now as well, that I speak to pretty well all types of medical disciplines.

Mike: Oh.

Joel: I talk to nurses, RTs, OTs, PTs, EMS and then in 2017 I went before my church and got tested to get my license to exhort is what it's called or it's basically to be a substitute preacher. About the same time I started doing less web work, I started doing more speaking. This year, if everything goes as scheduled, I will have preached 11 Sundays at different churches and I've already spoken at a couple schools this year and yeah. So I say just because you can move doesn't mean you can't be busy.

Mike: That's right and I've spoken many times as somebody ... I've been blind since birth and so I totally relate to you when you say that you never know what kind of questions they're going to come up with, but it is so rewarding and I think usually they come out, I'm sure, of your presentations with a better appreciation for what people with disabilities can do.

Joel: They do, and one of the things that I do is I show them how I write my name with my mouth. Then I have them try it as well and that is definitely a part that they always remember. A lot of these schools I've been back to for many years and when I go back, if some of the older grades see me I often get comments, "Oh you, writing with your mouth. You're back again. Hi."

Mike: That's great.

Judy: Your sessions sound so interactive that-

Mike: They do.

Judy: ... I'm hoping if any listeners are interested in inviting, or even better, contracting with Joel to come and share his wisdom with you, that you will reach out to him because I've listened to a lot of people talk about disability awareness but I love how you get your audience engaged. What do you think I might do for work? Here, try my way. I think that's really awesome.

Joel: Well, especially in working with younger kids, I'm usually with them for about half hour or so and if I just sat up there and talked for the whole half hour, I don't think any of them would be listening or doing anything related to what I'm talking. So, I learned very early on to keep them engaged and I try to, every few minutes, to at least get them to ask questions or do something so that they stay awake and their minds don't completely wander off.

Mike: That is so important and it's just building more memories and more experience and learning for them too.

Joel: I would say with this whole pandemic last year, I was used to going to colleges in-person and I learned to do Zoom interaction and doing meetings that way and it's definitely different but I think it will allow for more areas and not just within my central part of Iowa that I can drive to.

Mike: I was just about to ask about your transportation as to whether you drive and what type of vehicle you use?

Joel: Yeah. Unfortunately, they have not invented a chin control vehicle yet, which my mom thinks is a good thing. So, I use a full-size van that has a drop floor and lift outside. Currently, the vehicle I use, my

parents purchased in 2000, a '94 Ford van. It's getting close to 200,000 miles on it, but thankfully my dad is very good at mechanics and has kept it going all these years. It has gone for many summer trips out East for another place I volunteer at and it's got me around for what we need.

Mike: Great.

Judy: Joel, what's your heart's calling? What makes you feel most alive?

Joel: Well, as I said, I do a lot of things but for me, no matter what description I am, for first I am Christian, and I study God's word daily and God has graciously given us His Son for forgiveness and has told us to live and work for Him. I know that I have a couple challenges and I am not able to do things that most people would consider quote, normal, but I have been extremely blessed and being able to have caregivers and loving parents and that and everything. I try to work as much as God has allowed me to do and to always stay busy and to not dwell on what ifs or woe is me but to look at the positives and the abilities that I've been given.

Mike: Well, your faith has certainly carried you far. Just awesome. I am curious. I know that Caitlin, our third famous co-host who wasn't able to be here today, is actually the person that connected us with you and she said that you served on the Olmstead Taskforce. So, tell us a little bit about that.

Joel: I have been on the Olmstead Taskforce for two years and it's a three year term on those. I do a couple volunteer activities and well, most of what I do is volunteer even though I say it's work, but the Olmstead Taskforce is tasked with making sure people with disabilities in Iowa are able to live as independently as possible. I've been with them trying to offer advice from my experience or others with my disability that I've known either currently or in the past in the state and just ways I can offer to help with, say, editing papers and that kind of thing or just from a different perspective that I may have.

Joel: One of the other volunteer activities I do is a week-long camp for children that require ventilator systems and that's for kids ages six through high school graduation. That's at a place near Indianapolis. I've volunteered there for 16 summers and with that I've also had experience in different needs for families with complex medical needs. The two combined I kind of get a different perspective, I guess.

Mike: Well, I'm sure that really gives you an opportunity to be a role model too and I think speaking from my own personal experience I know how important it is. Kids may not even always recognize it at the time because of their age, you know they're still growing and developing, but seeing people like yourself who are successful and have such a positive attitude has to really make a positive impact on them.

Joel: Well, I hope that I do, but really the week of camp is a way to recharge my batteries as well. I was a camper for seven years and some of the kids now have the same diagnosis that I do, a high-level spinal cord injury, but we get these kids of doing normal camp activities. Arts and crafts and fishing, maybe doing some boating, but we also do things like swimming, even kids that are on a vent 24/7. We go up a 50-foot-tall tower and we even have a zip line set up.

Mike: Wow.

Judy: Sounds like fun.

Mike: It does.

Joel: Of course, one of the first years that the zip line was set up, just for the kids' safety, I made sure that I tested it for them before that.

Judy: Took one for the team.

Joel: Right. Right, but yeah, it's a short ride but where else can a quadriplegic on a vent get to do things like zip lines and enjoy fun activities that way?

Mike: Absolutely.

Judy: You know you were talking about your work on the Olmstead Taskforce and talking about some of the needs that you see in our state, I mean, if you were going to pick, what do you think the top three needs that just people with disabilities in general need, things that need to change?

Joel: Well, one that has been growing over the last couple decades and especially in the forefront now is a lack of caregivers. A lot of my friends, they are not able to do much independently. They don't have caregivers that can help them so their family has to stay up with them at night and be with them during days. It means that the parents or whoever is working with them are not able to work as independently as they would like. So yeah, nurses or caregivers in general are a huge item.

Joel: Number two goes along with that is funding for it. Funding for caregivers. In Iowa, it's if you don't have private insurance and you need 24-hour care, as I do, you can only get full coverage if you're in a nursing home. That obviously is not something that is you want to do, and your independence or doing anything productive can't really be done too well in a nursing home. So, being able to get the needed funding and being able to stay at home would be number two.

Joel: And then the third one I think would be awareness of that people with high-level disabilities are able to be productive in the community and can do light volunteer work or even some paid work. We don't have to just sit around and as a lot of people think of us, only be a drain on society. That's not the case at all. Again, for working, that of course requires infrastructure of being able to get around or having reliable internet and that kind of thing that cascades into more needs, but I would say those are probably my top three.

Judy: Those are so well-stated.

Mike: They are.

Judy: You know I'm disturbed because I do work in employment when you talked about how you really do have your own business yet it can't be in your name. You can't be identified as the proprietor. Could you explain to people why that is?

Joel: Yeah, I'll do that and I'll back up a little bit too though.

Judy: Okay.

Joel: I finished my classes at AIB in February of 2003. By that time, I was working with Vocational Rehab. They helped fund some of my nursing so I could stay on campus. After classes were completed, they required me to hire a job coach. I'm like, "Well, okay. I think I can do it okay on my own," but I did that. So like any college graduate, I put out my resume all over and I got several interviews. AIB said I actually had the best resume on campus at that time that they had seen in a long time, but all the interviews I was getting were through my own effort and I noticed the job coach really didn't get me very much.

Joel: Well, by early June I was working at a temporary job at West Des Moines and I had to meet with Voc Rehab because they asked me to come in for a meeting. The job coach was there and said that he had spoken with a friend of his that owned a couple businesses and said that my description, that

nobody would ever hire me because of potential costs to their medical insurance. He gave me the number to a few area nursing homes, said, "Call them and don't bother us again." So, that obviously wasn't what I liked and-

Judy: And obviously is not their mission. I mean, yeah, if someone from Vocational Rehabilitation is listening, they're going to be cringing right now because that's not their mission.

Mike: I hope so.

Joel: And this was only four months after I had finished my classes as well. I had not been looking for work at that time for about a month and a half because I had a temp job already and I wanted to dedicate my time to that job, but I stayed in Des Moines for a few more months. During college, I started doing a few websites, one for my church and then just a few others that came. When I moved back home I'm like, "Well, you know what? Let's just keep going with this."

Joel: Medicaid and Social Security make it ... I am sure there is a lot of people that can explain it better, but my income or what assets can be to my name are very limited. If I am the owner of a business and can therefore write checks from that business, then the business assets would be counted as part of mine and therefore I would end up losing my Medicaid and Social Security and that would be a whole mess and not anything that I could be able to do. As I've told some people, it's a situation that I either have to make basically nothing and use state and federal services or make a six figure salary that pays very well and spend most of that on medical needs, that I probably wouldn't be very much ahead in the end.

Judy: Mm-hmm (affirmative).

Joel: So, that was why my-

Judy: Thank you so much for sharing.

Joel: Yep.

Mike: It's a very good description or example, I guess. Well, it's not an example, it's reality for you and the sad thing is that it's a reality for a lot of people and people that aren't in that situation are not forced

into those kinds of decisions and it just seems very unfair that you are. I think that, like you said Judy, I hope somebody from Voc Rehab is hearing this and if there is any sort of direction that people are still giving people to contact nursing homes that that ends.

Joel: Well, one of my web clients is actually associated with Voc Rehab and they've heard my story as well. They are not a very active client, but it's still ... I met, in the same building or the same room with them working on their website design and covering all their needs, the same place I was told that I would never find work.

Mike: How ironic is that? Well Joel, as we're kind of wrapping up here, we always like to end with a question and that is, it's kind of a tricky one, but I think you're going to have an answer. If you could think about a legacy that you would like to leave, and actually I think you're already leaving a legacy, but you're obviously still very active, what would that be? What would you like people to say a hundred years from now or whatever amount of time that one of the things that Joel really left us with is?

Joel: Probably I would say that I had significant challenges in my life but through it all I made sure to serve God as much as he enabled through the, as I say, the different abilities that I have been given and did not just give up and wait for something to come that possibly never would.

Judy: And Joel, what's your superpower?

Joel: Optimism, I guess, or being thankful for what I've been given. I'm human and I have down days and don't always be as optimistic as I should, but that is what I strive to do at all times as much as possible.

Mike: That's a great superpower to have. I would just like, Joel, to thank you for taking the time to meet with us today. I've certainly been inspired. I've learned a lot. I think many of our listeners will feel the same way and take a great deal out of what you've had to say. I'd also like to thank our audience for joining us for Disability Exchange and we look forward to sharing the experiences of many interesting guests with you in the future.

Judy: Thank you very much.

Judy: Thank you for joining us today on Disability Exchange. Disability Exchange is produced by the University Center for Excellence in Developmental Disabilities, which is housed at the Center for

Disabilities and Development at the University of Iowa. Special thanks to Kyle Delveau for the music contribution.