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Podcasts Episode 02: Greg Stilson

Greg Stilson

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Dr. Amy Parker: Okay, good morning everyone, and I want to welcome our special guest today, Greg Stilson, who works with HumanWare, but I know Greg because of some of his leadership work for an organization that I love very much called DeafBlind Citizens in Action. Greg is one of our board members.

But, welcome, today, to talk to our orientation and mobility class. We've got students in Washington state, we will have students in Alaska joining us, and also, all over Oregon.

So, welcome Greg.

Mr.Greg Stilson: Awesome. Well, thank you very much for having me, Amy, and we decided to chat a little bit about O&M.

Amy: Well, one of the reasons why I wanted to talk to you, Greg, especially, is because of your leadership at HumanWare, of course, but also your lived experience with orientation and mobility, and just your knowledge of technology. So, kick us off, tell us a little bit about yourself, and why do you think this matters to the students you'll be talking to today?

Greg: Yes. So, I am a blind individual myself. I was born with Leber's Congenital Amaurosis, it's an irregular type of LCA, so most people with LCA tend to lose their vision right away, or are born without any vision. Myself, I actually was born with quite a bit of vision, but LCA also tends to, at least from what I understand, and this is my very limited understanding of the eye conditions, but, LCA typically shows up with only peripheral vision being available, and I'm the opposite.

My eye condition shows up more like RP, and so, I lost a fair amount of vision early on, but it's been stable pretty well ever since. I'm located in Madison, Wisconsin, and one thing that I would say that is, you know, one of those things that you look back on, that was really important, and at the time I probably hated it and despised it was, my family raised me in that I needed to have all the skills of a totally blind individual. So, in the situation where I would lose my vision, it wouldn't be a catastrophe, I wouldn't feel like I had nowhere to go or would have to re-learn everything.

So, I was taught braille at a really early age, I learned braille and large print at the same time, which really, today, is ... You know I look back, and man, if I couldn't write print and I didn't know braille, there's so many times that I use both mediums every day.

Amy: Wow.

Greg: You know, I look at that as a situation where it was really beneficial for me to have a TVI, and parents that pushed both at the same time. And at the same time, I was taught cane travel and orientation and mobility skills in the fashion of a totally blind individual. As much as I was your typical low-vision kid, and would use my cane during the O&M lesson and then put it in the locker, I, today am always using my cane.

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I was joking with my wife, who is also visually impaired, that we take our dog for a walk on a regular basis, we bring the ... we have a one-year old that we'll bring in a wagon, whatever, and we don't need to use our canes. We take the same routes, it's in our neighborhood, whatever else, but in all actuality, we take our canes mainly for identification, as well, and those type of things. So, let's say there's a new family that had seen us walking with our canes, and then the next time they see us walking without our canes, it's pretty confusing to somebody else to say, "Wait, are they blind or are they not blind? I don't get it."

So, it's as much as an identification tool for us, so that we really give people a clear understanding of who we are, that we are blind people. We're totally comfortable with being blind people, and whatever else, but at the same time, there's been many times where I've taken my dog for a walk, and they're doing construction on one of the corners, and I had no idea when I started walking. So, having that cane there, and making sure that I do use it ... I haven't any life-saving situations per se, I know there's a lot of blind people out there can tell you like, they removed a manhole cover and their cane, or their guide dog saved them, or something like. That. I haven't specifically had those yet, but those are ... we definitely continuously use it on a regular basis. So yes, that's a little bit of my background.

You mentioned technology. Technology is a huge passion for me, both in ... I've been in the business with HumanWare for a long time, and what we focus on is literacy and education, so a lot of my work that I've done is related to braille literacy, and making sure that there's electronic braille tools that are out there to promote the use of braille in schools, and to really help kids, especially in today's digital age, not only use braille, but want to use braille.

Amy: Yeah, right. Those skills are more viable than ever, and it's not that technology has pushed braille away, it's transformed and enhanced braille use. It's expanded it and made it even more-

Greg: And I say it simplified the life of the kid. When I was younger, I remember carrying two, three textbooks in my backpack, and by junior year in high school, I had the strongest shoulders ever, because I was lugging around all this braille. So, today, a device like the BrailleNote or the refreshable braille displays and things like that, you can carry a whole library of books in your backpack in a device that's less than a pound. So, it's pretty incredible the way that things have changed and expanded so that blind people can have the same type of digital access as say, somebody with a tablet.

Amy: You know, Greg, you've sculpted such a beautiful picture for us, with your family life, with the advocacy and the strength of your parents, your family, the TVI partnership, the importance of O&M. You've shared so much with us. In thinking about braille now, and thinking about wanting to share mobility and technologies that interface with those literacy, like you said, with leadership, and with travel, can you reflect a little bit more about how those technologies may, not only empower different people who are blind or deafblind to lead full lives, but almost to advance in society as well? You know [crosstalk 00:07:18]

Greg: So, I talked about-

Amy: Image ... Yeah, go ahead, go ahead.

Greg: No, no, no, yeah, you're right on it. I talked about literacy and the reference of braille, but I've always been a believer that there's such thing as environmental literacy as well, and that is something that is, in my mind, a basic human right for somebody who is blind, or deafblind, or visually impaired, to be able to ... Picture it this way, Amy. If you went outside, you're a sighted individual, if you went outside you could look around and see the businesses, see the street signs, see the things immediately right in front of you. A blind person doesn't get that luxury. They have to go through a significant amount of research, or question and answer, to be able to obtain that information.

That equates to environment literacy, but it takes a significant amount of time to build that picture in their mind, to say, "Okay, I'm looking north, there's a Chipotle that way, there's a Starbucks that way, I'm here, okay, I'm kitty-corner from the Starbucks." You're kind of building a map inside your mind, but it's based all off of question and answer, "What's that way?", or experience, "Oh, I smelled that coffee shop as I was walking by." You're building an understanding of your location as time progresses.

At HumanWare, and this is something we've been super passionate about since probably about the year 2000, is building a way for a blind person to get an understanding of where they are and what's around them immediately. That's really where technology can come into play, and it's not new concepts today, but back when we started this project, back in 2000, it was. It's funny because the GPS and orientation access, for people who are blind or visually impaired was way ahead of the mainstream usage of GPS.

Amy: That's true.

Greg: Before sighted people were using GPS in their car on a regular basis, we ... I remember working with Mike May, and having a backpack with a giant laptop on my back, with wires all connected all over me, with a GPS receiver. The running joke is always that you looked like you were going to go into outer space when you got to street corner, and that's really where it all started. The device was called the "Strider," and it was ... I don't even remember the GPS accuracy. It wasn't very accurate, but what it did do is, it incorporated some of the maps that were available, so as you were approaching a street intersection, or approaching different locations, it would orient you to where you were in the space, in relation to other streets and things like that. As time progressed, they were able to build in what were called, "points of interest."

So, businesses today, and it's even more plentiful now, especially with social media and things like Foursquare and Swarm and Facebook all having check-in options, that now businesses want to have all of their information on the web, so that when you walk past the Starbucks, or when you walk past a coffee shop, or something, your phone's gonna buzz and say, "Hey, you should check in here." So, all of that mainstream access has

allowed us to focus on tools that are directed at those with visual impairments, and the advent of the smartphone has really progressed the awareness of GPS even further.

Today, there are more choices now for accessible GPS connectivity and orientation awareness and things like that, via the smartphone, via specialized tools. One of the devices that we're gonna be launching here in October is called, "The Victor Reader Trek." It's a different approach at GPS in that, one of the things that I've always said, especially in regards to orientation and mobility, is that it's really hard to focus on actually using correct O&M skills when you're trying to swipe on a touchscreen as you're walking.

So, we've designed a device that actually is a stand-alone device. It's totally separate from your phone battery, which, all of us know that if you use GPS on your phone, your battery's gonna drop exponentially when you start using it. When it all comes down to it, a blind person needs a phone to be a phone, and if they need to call an Uber, or need to get a ride, or get stuck in a situation where they don't know, if your phone battery is dead because you were using your phone constantly for GPS, then you've got some other issues.

So, this device is tactile-oriented, so physical buttons that you can find immediately, everything is one-hand operable, so that if you're using a cane or a guide dog, you can press ... Every function on this is a tap or a tap and a hold of a button, so you're not actually doing multiple-finger swipes and multiple-button presses, and things like that. It's really designed at the blind user, and most importantly, it's giving you clear understand of what I would call, "intersection configurations." So [crosstalk 00:12:37]

Amy: That's amazing, yeah.

Greg: Well, it's so important, because you, as a sighted person, you could be halfway down the block and notice that, "Hey, I'm approaching a four-way intersection." A blind person doesn't get that information until they're standing on the street corner and listening to the traffic patterns.

Amy: Right.

Greg: So, with a device like this, in comparison to other smartphone GPS's that are designed for sighted people, is when you're driving in a car, you don't really care whether it's a four-way, a three-way intersection, cause you can see that. All the GPS says is, "approaching Main Street" or "crossing South Street" or whatever.

Amy: Right.

Greg: A device like this is really designed for a blind pedestrian, so we actually have different modes of information for when you're walking you'll get a higher level of clarity when understanding different locations. For example, as I'm approaching a four-way intersection, it'll way, "approaching four-way intersection of University Avenue crossing Main Street." But, where it really shines is, if you cross a three-way intersection, and

that's one thing that is really confusing at times, because you never know which way a three-way intersection is facing. A regular GPS would just say, "Main Street crossing Main Street," but you don't know if that main street goes all the way through, or if it's a T intersection going just left, or a T intersection going just right. A device like this will say, "Approaching three-way intersection with Main Street on your right," so you clearly get a sense of, "If I'm on the right side of the street, I'm gonna have to cross the street, but there's gonna be no cars coming from the other side, because it's a T intersection." So, that's-

Amy: That's incredibly powerful. Yep.

Greg: Well, yeah, it's an example of how we, as an O&M population here, there are different requirements, and that's why, since the advent of the smartphone, I've been a huge proponent of saying, "The mainstream grasping of accessibility is such an incredible wave that we're encountering, and it's gonna open up more access to information than we ever have seen before." However, a lot of people are thinking there's this one-size-fits-all approach, and I see that as sort of a dangerous situation, because a blindness population, to be totally environmentally literate, you need all the details, and a device that's designed for a sighted driver, or an app that's designed for a sighted driver, gives them the details that are important to them. But not, specifically, the details that are important to me.

So that's really where I want to caution, cause I've worked with a lot of students who are going through TVI programs, and O&M programs, and things like that, and this one thing that I wanted to make sure that I'm clear on is that there are multiple choices out there and that it's not a one-size-fits-all approach. And, especially, as time progresses, I know a lot of TVI and O&M teachers who work with students with multiple disabilities, and the smartphone, the swiping, the multiple-finger gestures, it may be overwhelming for them. So, to be able to utilize a tool that is one button to do this and one button to do that-

Amy: Well, what about seniors, the aging population, or for people that are in transition, that maybe, have been sighted or partially sighted most of their lives? Their mobility is changing, in maybe more than one way, maybe they're losing a little more vision, maybe they're losing some flexibility, and technology wasn't a part of the way they grew up, so thinking about situations for different people.

Greg: We've done a lot of work with the VA hospitals, and for veterans who are wounded in combat, and things like that, and they lose their vision suddenly. There's a couple of situations that stand out in my mind with what we do with regard to O&M, because, as I said, we're focusing on things that are important to a blind person. I would say one of the most challenging scenarios for a blind person, outside of indoor travel, which we can get into in a little bit, is open-area travel.

For example, we're talking about college and university campuses, and things like that, that's in many cases, a university campus is what's called open-area, meaning that you're dealing with pedestrian paths, and it's not actual vehicle traveled routes that are gonna be on the map. So, one of the things that we focus on is actually allowing a blind

person to, with their O&M instructor, drop landmarks, or breadcrumbs, that will, almost like beacons I would say, at each of their buildings, so that even if you're not gonna get exact turn-by-turn directions, you will get as-the-crow-flies instructions, so that you get an understanding of ... Say I'm going to the chemistry building, okay? I'm at my dorm, and it says, "The chemistry building is 450 feet, 11 o'clock." So I know that I need to go straight and slightly to the left, and you can repeatedly check your progress. It's almost like a "getting warmer" game that you play with this, so that you know that you're heading in the right direction. You're not gonna get the, "Turn left at the dining hall," and you'll be right there, but you will get the idea that, once 11 o'clock turns into 12 o'clock, you know that you need to head straight ahead, and as that distance decreases you know that you're approaching the correct way. So, open-area, with the VA hospitals, we've encountered a lot of veterans that may live on farms or in rural areas, and their mailbox.

I remember very clearly, a story when I was in tech support, when I started at HumanWare, with our old trekker product back in 2007 I'd say, there was a guy, all he wanted to do was ... He had just become blind, and he was struggling to be able to get from his front door of his farmhouse, to his mailbox, which, if you're aware of a farm land, a mailbox is often very, very far away from the house. So, what a device like this does is, it allows him to drop a landmark so him and his wife walked over and they stood by the mailbox, he hit the record button, he said, "my mailbox," and it dropped the landmarks right in front of the mailbox, and now he dropped the landmark in the front of his house, and from there, he's able to get back and forth from his house to his mailbox. I'm sure, as time progressed, he got that route down further and further, but it gave him that confidence, and I think that, that's really what the environmental literacy allows a blind person to do, is get out of their comfort zone and go explore, because there's a huge fear factor, if you don't know where you're going, you always have this fear of, "Am I gonna get lost, and am I gonna be able to get back home?"

Amy: It can be paralyzing. Yes, it can be paralyzing.

Greg: It is, absolutely.

Amy: We cannot under-estimate that. And it makes ... We have to, as orientation mobility professionals, and really, allies, for the community, and of course, some orientation mobility specialists have visual impairments themselves, but remembering that fear factor. And as you said, What's important to the person? What's the purpose in their lives? What's meaningful to them? The only people that can determine that are the people themselves. For people with multiple disabilities, maybe it's with support of a family member, who notices what's important to them. So.

Greg: You know, I remember talking to a ... well, now he's retired, but a retired O&M teacher, who said, "You know what? Every different student that you're gonna have, is gonna have a different route that they want to achieve. One person may want to travel the world, and do a route in Australia, they want to be able to get through the airport, the want to do something, do some traveling, whatever, and everything else. That's their goal, and they're your most advanced traveler, and they're fearless." And then, you may have a student that says their goal is to go to their friend's house that's at the other end

of the block. Everybody has different levels of independence and environmental awareness and environmental literacy, and giving someone these tools that will give them the confidence, maybe that student will want to go to the friend's house at the end of the block, and then maybe they'll make another friend, who is on a different part of the bus line, and they want to take the bus over there.

That type of, being able to achieve one goal, and then say, "You know what? I was able to do that and I didn't get lost, and maybe my combination of my cane skills and my O&M skills, and then having this electronic device that tells me what's around me, that gives me the courage to be able to go try something new." So, I think that's really where, and I travel all over the world in my job-

Amy: Yes, you do.

Greg: Sometimes too much. A little too much if you ask my wife, but anyway.

But, if I go to a new hotel, that I've never been to, even as much travel experience as I have, I am free to admit, there are times when I don't feel like exerting the effort to go find a restaurant nearby.

Amy: Right, it's paralyzing.

Greg: You're right, it's paralyzing because sometimes if I ... let's say that I don't have a GPS tool, or something like that, it's a lot of work to be able to ... Number one, muster up the courage to go out and to be able to get back, and number two, to be able to go understand exactly, because, I hate to say it, but sighted people don't always give the most accurate directions to a blind traveler.

Amy: Oh my goodness, no. "Over there, by the Sycamore tree." Yes, or, you know, very

Greg: "It's right across the street by that neon sign," something, whatever.

But, it's one of these things where the creation of these type of device, whether it's a smartphone device, whether it's a specialized device, like the Victory Reader Trek, it gives you that ability to be independent. To independently research, "Oh, there's an Italian restaurant that's nearby," or "There's a Mexican restaurant that's nearby." Now I have the freedom of choice, and I don't have to just go to the concierge and say, "Hey, what's good?" And they tell me one thing, and I'm like, "Well, alright, I gotta go there then, I guess, because that's the only thing that's here."

So that's really where, I would say, that devices like this, and access to information, and that's really all it is, is getting access to the information that's around you. It can be in a number of ways, whether that's with the tip of your cane, the smells that you pass, or from an electronic device that.

Amy: For all three, right? Putting those things together, all three. And I think, some of my blind and deafblind friends have shared that it can be exhausting. As you said, you're

traveling, you're tired, your whole purpose is not to become an expert in the area where you're visiting, maybe for just a day-and-a-half. Your real goal is to be there is to lead a technology conference, or to give a talk, or to meet with friends. It's not necessarily to learn every nook and cranny of the community so you can plug-in to what's the most immediate needs that you have, for that reason.

Greg: You know, you're right, and sometimes it's really just ... But I'll tell you where environmental literacy or understanding has changed the way I look at things. In the early days of my travel, whenever I would get to a hotel, I would always want to know point A to point B routes. Okay? So, I need to get from here to here, I have a meeting tomorrow at this time, and I need to make sure I can get from here to here. I would choose hotels that were nearby, that I could potentially walk to the destination that I needed to go.

Now, with a device like a Victory Reader Trekker, a smartphone, or something like that, you're able to actually go A to B to C to D, because as you're walking you can hit that "what's around" button on the Trek, and say, "Oh, there's a coffee shop, and after I get done with my meeting, maybe I'm gonna want to go there," or "There's a Walgreens and I need to pick up some toothpaste because I forgot it on my flight." So, there's options now that previously weren't there. I think that is crucial, that now you have the ability not to just go from point A to point B, but you can make educated choices, just like a sighted person saying, "Oh shoot, there's a Target there, and I forgot to pick up something."

Amy: Exactly.

Greg: I didn't have that ability.

Amy: Well, let's go back, and, before we wrap this up, Greg, and I have so appreciated everything that you've shared today, speaking to the students who are listening and reading our textbook, and hearing these interviews, exploring all of this. What would you say to them about the importance of old-school cane skills, old-skill orientation skills? We believe so strongly in the power of technology for all people, and particularly for people who are blind, visually-impaired, deafblind. But, what would you say to them as an argument or a realization that you can't lose those other skills that you need, whether it be working with a dog guide, working with some human guide? You know, how [crosstalk 00:27:07]

Greg: I can tell you-

Amy: Yeah, go ahead.

Greg: I can tell you that it's a fine line to walk, because If you don't have a good ... and this is actually in all of the marketing material and all of the documentation that we designed for any of our GPS and orientation devices, it always says at the very beginning it says, "It is recommended not to use this device unless you have solid," I don't remember how we word it, but the equivalent of "solid cane or orientation mobility skills." The reason

being, is because technology is inherently distracting. You will get distracted, temporarily, with the voice speaking to you, or whatever else, and if you're not using good cane or guide-dog skills, you can put yourself in situations you don't want to be in. So, hammering home those ten-and-two taps, and making sure your positioning of the cane is dead center. Whatever skill you're teaching, it's absolutely crucial that that student ... insure that they know how to use the old-skill tools.

It's funny, because we've seen a number of different iterations in the cane. I'm sure that you remember, Amy, there's been so many attempts at sonar canes, and different things that ... and they never succeed, because right now, I hate to say it, but the white stick that we've been using for so many years is incredibly powerful, and the same thing with-

Amy: It really is, actually.

Greg: Yeah, it's so funny. There's different material that canes are made out of, I have myself three different types. I've got a folding cane, a straight cane, and a collapsible cane. So, I use them in all different ways. But, the reality is that they all provide me different situations. I like to take my collapsible cane when I travel on a plane, because I can collapse it quickly and put it away, and I like to take my straight cane when I'm walking the dog because if I'm moving faster and my cane hits something, it doesn't collapse on me.

Amy: Right.

Greg: So, the reality is insuring that you have those skills, that your understanding of how to position the cane so you protect yourself, and then as I said, the identification as well. Making sure that other people know that you are visually impaired, so that they're aware of it and that they're gonna go around you, or they're going to understand if you do run into them. I can tell you that, in my younger years, when I was very against using the cane, I would run into people and I would tell them that I'm visually impaired, and they didn't believe me. So, it's important that [crosstalk 00:29:59]

Amy: He just say that, "Oh, he can see." I've heard teachers say that, and it's the complexity of what someone can see, under certain conditions, with enough lighting, without the glare. So yeah, people can really easily misunderstand.

Greg: So, but once those skills are there, and what I actually have heard many O&M teachers say is "make your student" ... A lot of orientation mobility people actually introduce, and this is oftentimes for the low vision kids that are apprehensive on using their canes, they've actually introduced the technology earlier, to get them interested, and they've actually used the technology as a reward mechanism to get them to use the cane.

An O&M teacher that I've talked to in the past many times said that he would make his students do a traditional ... I think he would do a few street crossings, routes, and things like that, and he said, "Alright, if you're able to do this successfully, then our next route will be with the GPS." So, he used it as a way to entice the student to say, "Yes, I want to

succeed just using my cane, and then I'll be able to have fun with the GPS, and get more information about what I'm passing."

And, it was funny, because he said while they were walking and they were crossing the intersection, they would smell something, and they would say, "What's over there?" The O&M teacher wouldn't tell them, because he said, "Well, if you finish your route, you'll be able to figure that out yourself." So, it's interesting how students can be really excited about GPS, and excited about technology in general, and how that gives them the drive to ensure that they are able to complete those old-school routes, and things like that.

Amy: Greg, thank you so much for spending time with us today. I hope that we'll be in touch again, and, if you wouldn't mind sharing some of the links of the products, and the ideas that you've referenced, I'll reach out to you via email, and harvest some of those links, so that we can make sure that those are posted with this podcast.

Thanks a million. I really appreciate it.

Greg: Absolutely. It's been my pleasure, and I always love to have these kind of conversations. It's so fun to talk to others who are so passionate about this field. So, as I said, our company's name is HumanWare, H-U-M-A-N-W-A-R-E. The website is www.humanware.com. We have a ton of how-to and snapshot videos, and just a ton of video content about our different solutions. We design anything from audio book players, to braille devices, to low-vision tools, there's a really cool one out there called "The Connect," and then, as I said, the orientation and mobility tools as well.

So, go to our youtube channel, and just type in "humanware" and you'll be able to find our actual youtube channel there as well.

Amy: Greg Stilson, the Director of Marketing, Development, and Product Development to HumanWare, an advocate, a leader in his own right, a family man, thanks for joining us today. Take care.

Greg: Thank you.