

Amy: Well welcome everybody to our orientation and mobility podcast. [Lane McKittrick 00:00:12] are you there with us today?

Lane: Yes I am. Thank you.

Amy: Great. Well I want to welcome Lane who is our special guest today on our orientation and mobility on the go podcast. Lane is a PhD student and more importantly she is also the mother of four boys, two of whom have Usher Syndrome which is a leading cause of deaf blindness but Lane's here to reflect with us today on both her personal experiences and her professional experiences, what she's learning on this journey. Particularly, Lane will share a little bit about the goals of her sons' orientation and mobility specialists as well as her own reinfection as a graduate researcher in self-determination and other discoveries. So I'm very excited to have Lane because of her versatility and because of her role in the community. Welcome and tell us a little bit about yourself, Lane.

Lane: Yeah, so thank you so much for having me today. Amy mentioned that I have four boys, two have them have Usher Syndrome. The oldest one is going to college next year, he is almost 19 and then my youngest his birthday is today he's turning 10, and those are the boys that have Usher Syndrome. So we've been working on these types of skills for several years. We've had many different IEP team members and O & M specialists working with our children and so I'm happy to share those experiences with you.

Amy: Thank you so much. Well, along the way tell us about your sons have engaged with orientation and mobility and maybe for our listeners too, just refresh our collective memory on the impact of Usher Syndrome itself.

Lane: Okay. Yeah, so both of my boys were born profoundly deaf. They do use cochlear implants to hear and their vision loss is progressive. So, it starts at about between the age three and five where my children started to experience night blindness and have difficulty seeing in dimly lit situations. As things progress, they end up with some blind spots in their vision. My oldest son has progressed to the point where he has about 15 degrees of vision left that he's dealing with. My 10 year old although he really is experiencing night blindness at this point and does have some pockets of vision loss throughout his peripheral vision but does pretty well seeing if the lighting is okay.

Amy: That's really helpful Lane to think about the experience of being deaf first and also having vision loss and sometimes people don't recognize deaf blindness as its own unique disability. They think it's a this plus this equals deaf blindness and really deaf blindness affects all kinds of aspects of learning. Would you reflect a little bit more on that for your sons and your own professional experience how people who are deaf blind put information together in different ways.

Lane: Yeah. So both of our boys are in the mainstream classroom. They receive consulting services from the teachers of the visually impaired but the person that they see most often is the O & M specialist and obviously the O & M specialist had worked with the gen ed teachers to really figure out what the needs are in the classroom. But we have seen, our district doesn't have anyone who has a familiarity with the dual sensory lab.

They may have seen a couple students, but they had to gain knowledge through working with our kids about how to figure out how to best serve our kids because of that dual sensory loss.

For instance, my son is in the fourth grade and if you look at his hearing, stand alone he doesn't seem to be impacted very much in the classroom and same thing with vision. I mean a lot of times he does really well in the classroom but sometimes if he's tired or maybe it's really bright out and the teacher's standing in front of the window and there's a lot of glare or the lighting is just off or it's really loud there might just be a lot of sensory things going on. He really can be impacted a lot by that dual sensory loss. Sometimes that really can be hard to understand for teachers because if you just look at the deafness or the vision loss as a standalone they seem to be doing well. But you add that dual sensory loss and sometimes it can become a challenge in the classroom.

I've seen it also be really a challenge from an O & M perspective and we still haven't figured out exactly how to deal with it but a lot of times my son will have difficulty crossing the street safely because sometimes their hearing is quite well with the cochlear implants but sometimes they can't localize and determine where the cars are coming from and so we really did struggle to try to find the best way to have them safely cross the street because it just looks a little different for them and it depends on the situation. So, collaboration with other agencies with the Hellen Keller and the VR agencies have been really helpful because we've been able to get other team members to give us some ideas and strategies.

Amy: Thank you so much for sharing that insight and just the complexity of the picture and putting together information in unique ways. Really I think of working with people who are deaf blind is such an honor. You learn so much from individuals who are deaf blind who have that experience and then you also learn so much about collaboration and thank you so much for sharing about the role of the orientation and mobility specialist in particular with your sons. Could you reflect a little bit more, Lane, on what you've learned from your sons directly and maybe how it has inspired you to do what you're doing as a PhD researcher?

Lane: Sure. So when my oldest son was probably around the age of nine and 10, he was beginning to learn Braille. That's about the same time that he started to learn how to use the cane and work with the orientation mobility specialist on a regular basis. But at that point in time his vision wasn't too [inaudible 00:08:12], we're just learning those skills. So, when we first started working with the O & M specialist, it really was strictly that O & M. How do they learn how to use the cane? And so that was pretty narrowly subjected at that point in time. And then as he got older, that person that was on our team became very ... We have this great relationship with her and she began to really understand our family's needs and my son's needs and so what I saw happen was really like in middle school that it started happening, is that she would [inaudible 00:08:53] and in collaboration with us, ask him what his future goals were for after high school. What does he like to do? What kinds of places does he want to learn how to go to? So, up until that point it was really, he was only going to places that his family was going to.

Does he want to learn how to go to the ice cream store? Does he like chocolate, does he want to go to the chocolate factory? Or what are his interests?

And so the O & M specialist was really great about asking him what his goals were both from the recreation and leisure perspective but also just from a career and post-secondary perspective. And then she really sort of worked with our family to figure out how structured those times she meant with us, that time weekly, she would plan us routes to get to those locations. She would plan outings to go to the bank, to set up a bank account, learn how to use online banking, to figure out how to do budgets, work on organizational skills with him.

As he started doing [inaudible 00:10:09] and typical college [inaudible 00:10:12], she went up to the disability office with him and helped him. She really was a support person. She led those meetings in that point in time. But, she helped him gain those skills necessary to be able to do that. She helped him maneuver the food court at his new college campus. She helped him work on shopping and when they come up with plans they're doing that together so he's telling her, "Look this is what I wanna be able to do when I leave and go to college" and so it's really been a great collaborative process. She's really good at keeping our entire family in the loop about that cue and if I see something that he's struggling with, I can communicate that with her and make sure we're working on the same things with him.

So for our youngest son, I sort of felt like we started a little bit late on all of this for my older son, it's worked out okay but I always wondered: what does it mean to start working on self-determination and some of these other skills in school setting and things like that, younger. So, orientation and mobility specialist has been working, probably started at the age of eight for my younger son. But really what does it mean to have a vision loss and a hearing loss and working on those self awareness skills? Like what do you tell people when they ask you about your cochlear implants or why you have a cane? She is starting cane training with him and he really likes it. Helping him work on self-advocacy skills. The age of nine and 10 is really really ... He's sensitive about his vision and hearing loss and he really doesn't know what to tell people about it and he doesn't want to ask for help in the classroom and so she helps by doing role playing with him. Helping him come up with those confident ask for help when he needs it.

And these are all working together. I've been leading the effort but we've been teaching him to be involved in his IEP meetings. And so the O & M specialist, she's really interested in this, has been helping him gain those skills too. And so when they meet they kind of do a combination of cane lessons and we'll be working on self-determination and goal setting and just understanding what deaf blindness means.

Amy: It is incredibly powerful, Lane, to talk to you about this because this expanded role, which is really an integral role of the orientation and mobility specialist in supporting self-determination and communication ... You know I heard you reflecting on teaching someone, or at least supporting them and exploring how can they communicate about why they use a cane or how will the communicate about their cochlear implant or hearing aid with other people, that's an essential role of the orientation mobility

specialist. Can you reflect a little bit more ... You wear two hats as a professional you wear a hat who's studying to get your PhD but you also wear this hat as a mother. Would you reflect a little bit on the value of having professional partners, as a mother, what is it like to have a professional partner that helps support this self-determination piece outside of the family? We know that the family's essential and that it begins with the family but I think sometimes as a family member myself I think about how valuable it is to have that professional partner. Would you reflect a little bit on that?

Lane: Sure. Sure. Yeah as a parent before I started my journey of learning a lot more about special education, I had no idea what the extended core curriculum was. I had no idea that there was anything more than working on those active [inaudible 00:14:22] skills in the classroom and so since one of the main benefits for me was to have those team members, special team members being able to really explain the importance of those different areas: self-determination, independent living skills, career, technology, things like that. And a lot of times families may not be ready to work on those things. But I think just having the educator be there to really explain what that is to families is really really important and I found it so valuable. It's collaboration with other team members, it's collaboration, like what I mentioned, with other agencies and things like that. But it's all making sure you're working on the same goals together. And [inaudible 00:15:18] is something that I really had never heard about before and it's one of my own research interests.

As a family member I would always get, I would be fighting for services and I really had no idea what to do to support my kid. Always looking to other families and networking, I'm a family leader in the field and so I spend a lot of time trying to figure it out but I had a lot of really great IEP teams that an O & M instructor in particular that really took the time to know our family and know my kid and it was critical because they were really able to understand where we're at and I know that they may have shared what self-determination was maybe a few years ago, but I wasn't ready to hear it at that point in time. It was really great that we had that relationship so that they knew when it would be the appropriate time to bring it back up and say, "Maybe we should add an IEP goal in regard to that this year" or "Maybe we can focus the next couple of lessons on working on these skills. What do you think?". So it really has been helpful.

But thinking about it from a professional perspective, the other thing that I learned is that you know there are barriers to teaching them. A lot of time I see my own and the structure that works for my kids. There's so many different things to work on and it's hard to prioritize all of it and it's not necessarily a lack of time but how do you prioritize all of that and so it's been helpful to have that partnership to talk through and to help her. And a lot of these things, I know from talking to other [inaudible 00:17:03] and O & M instructors, that sometimes there's confusion whether or not it's something that you work on specifically or an overarching skill you're going to work on as you're working on other things.

And so as I reflected on the role of the O & M instructor and how they work with my kids it struck me that self-determination, for instance, is huge through all of the things that they're working on and when they're working on living skills, they're always asking,

"What do you want to do?", not just "Hey we're going to be working on money management today", but having to think about those goals first and then getting to the independent living skills. And when they're out and about doing those outings, I'm always asking what the student wants to do and letting them take the lead in starting to make those choices for themselves. I think that all of those things sort of happen together in that collaboration with the family and other members of the IEP team is critical.

Amy: You know what I love about this conversation, Lane, is what I hear reflected in all these elements that you're talking about, the elements of trust, and building trusted relationships. Trust, really effective in collaboration, comes through that trusting relationship and I heard you reflect on the trust that developed between the orientation and mobility specialist and the individual so your sons, as young developing people, on and into adulthood that they may work with orientation and mobility specialists in different point in their lives. So there's that trusting relationship and then there's the trusting relationship that the O & M has with the family to develop that collaboration.

You and I were at this wonderful international conference lately, that's Blind International Network of the Americas and you also shared sometimes what happens in families and professional partnership when trust breaks down, when there's a break in that trust. And I know today we're focused so much on what's working and the positive things that have happened, could you reflect on some of what you've learned through your research about trust and collaboration?

Lane: Sure. First off I wanted to, when you were talking about trust, one of the things as a parent specific to working on the issue of an O & M instructor working on these skills is making sure that ... For a parent it's kind of scary to think that the purpose for my O & M instructor who worked my son who he rode the bus by himself. He wanted to go the bus step, face in transfer, really a couple hours and he was quite young and she was in the car behind him to make sure they were doing this. It's trying to find that balance between facing independence and although I see the benefit, it's really hard as a parent ... You're trusting that O & M instructor to know what's best and know what your child is capable of and become that part and that takes trust. So that's critical for that relationship but it's important overall because you've seen that point depends if families are getting what they need and there's not trust between those team members, conflict can occur in IEP meetings.

That communication piece of it is extremely important and so as I was mentioning, this is what we're working on or this is what I found when I was out working with your child, maybe you can ask them about it at home and really just having that constant communication and really just asking the family, "What do you want that communication to be?". Some people like a lot of communication, some people don't want a lot of communication but really just talking about it and making sure that you understand that trust is really the whole thing that holds it all together because once you've lost trust that team is not going to be very successful in helping that student meet their IEP goals and it's just going to make a future conflict.

Amy: Absolutely. Absolutely. Essential. Other reflections that you have on maybe some research that you've done with families that talks about: what are some ways that people can support trust? You've mentioned communication as one of the most essential ways. Is there anything else that you've discovered in your work as a professional or as a parent?

Lane: I think that, I've done quite a bit of research on self-determination and how that's taught and also just looking at IEP teams dynamics in collaboration. What it does come down to is a lot of the communication, knowledge and competency, for families to really know that there's somebody on the team that really knows their area of expertise and that builds trust and more important than that, knowing about deaf blindness for instance but knowing what that child needs. As families really can feel like you have an understanding of what their child means then that is a real effective way to build that trust and have that relationship being really positive for the IEP team and then that will lead to improved student outcome. So I would say that probably, I mean there's lots of factors that factor into it but I think that trust, communication, knowledge of team members and knowledge of the disability and the individual needs of the student are really really important. If the family's feel like team members have that, then that trust is gonna be there.

Amy: Absolutely. I have another question and it's more related to the transition process. Which you're living. You're living with right now.

Lane: Yeah.

Amy: Getting older, moving on, becoming an adult. What advice would you give to orientation and mobility specialists about that balance. So as a young adult moves into those young adult roles and gets prepared for leaving, how should an O & M specialist balance communication with the young adult and with the family to maintain that trust? Maybe particularly if the family is less certain about the child transitioning into this role? Can you talk a little bit about that?

Lane: Yeah. So first off, for my older son, he didn't intend to transition into his IEP meetings until he was 16. And at that point in time, he wasn't actively participating with the IEP team meeting at that point in time. We just looked at him and said, "What should we write on that transition part of the IEP? What do you want to do when you grow up?" and he was a teenager, he didn't know at the time. So I would say that what my hope is for my younger son is to be able to have those conversations earlier. And that helps not only the student, but it helps the family. So, if you start to have those conversations about what the future goals are at the age of 16, that's quite late and so it doesn't give the family enough time to process what steps they might need to take in order to make possible. And it's hard to come up with a plan in that point in time. So if you can start having conversations earlier, I believe it will really help prepare families and the students to be able to do that.

That's very important and it's hard to find the balance but for us, as my student got older, the trust was there between the family and the O & M instructor so we were able

to, and my son's a pretty big communicator, so they would have most of the conversations about this but then the O & M instructor would connect with me every couple of months and we worked out this plan that they would work on all of these things. If they needed me they would come and they would communicate with me but, most all the trust needs to be between my son and the O & M instructor because I'm trying to teach him to be independent and prepare himself for college.

But, I want to make sure that I know what's going on too so it doesn't happen all that often but every couple months we always check back in and my son's always included in those conversations too so that we all know and everyone's on the same page.

Amy: That is really great advice. And I really just appreciate you Lane in opening up and sharing this time with our students today, with the listeners. Is there any other advice that you would give, kind of as closing advice, to orientation and mobility specialist in training and maybe bare in mind too the whole range because I know you're familiar with the students that may have multiple disabilities, working with adults that have diverse needs. What kind of advice would you offer to this group?

Lane: Yeah. So I would just say a couple things. I mean I think I said that collaboration with families is really critical and really understanding where the family's coming from. And sometimes they may not be ready and just being aware of other things the family might be going through. I do believe that [inaudible 00:27:45] information is possible for all students. It's gonna look different but it is possible. Just really finding a way, when I talk to a lot of [inaudible 00:27:57] it's really just finding a way, something that works for that particular student and finding a way to communicate with that student. There's just various ways to do that, it's just not giving up. If you need help, asking the family and asking different team members for support because there may be something that's working for them that you can tap into. I just think that the role of the O & M instructor for us has been really critical because you're out and about and trying to work on those skills out in the community and so it gives you a really unique opportunity to make a huge impact on a student's life and so I'm just really thankful for the O & M instructors that we've had and I'm just really excited for all of you to go into the field.

Thank you so much.

Amy: Thank you so much Lane. It's been a pleasure talking to you and we'll stay in touch.

Lane: Okay, thank you.

Amy: Thanks again, take care, bye-bye now.

Lane: Okay, bye.