

Hi. My name is Lane McKittrick, and I'm the co-founder of the Hear See Hope Foundation with my husband Todd. I wanted to spend some time today sharing our experiences in raising our two boys that have Usher Syndrome, and in particular talk about our experiences in working with their IEP teams.

A little bit of background about our family. There's more on the Hear See Hope website, some videos and things like that, but just a little bit of background. We have four boys. Conner is almost 19, and he has Usher Syndrome 1B. Cole is 17. Hunter is 11. Dalton is almost 10, and he also has Usher Syndrome 1B. Both Conner and Dalton were both born profoundly deaf, started to have some vision loss (night blindness symptoms) at the age of three to five, and were also having significant vestibular delays. They were really late walking, sitting and they also still work through vestibular challenges today.

Currently, Conner, based on his last eye exam, has about 15 degrees of vision left. Dalton currently just has night vision issues and also has a few blind spots throughout his vision, but overall not too much vision loss at this point, at the age of almost 10.

I'm interested in this topic and I have had a lot of experience working with IEP teams so wanted to share those experiences. What I found out is that a lot of times it's stressful in trying to advocate for your child, because I know for myself, I didn't know a lot about deafblindness, or anything about Usher Syndrome. At the time that Conner was diagnosed, there wasn't a lot of resources on the Internet. The Usher Coalition didn't exist at the time. It was really difficult to try to find families to connect with, and try to find information and to have that knowledge so that you knew how to help your kids. So I really want to try to help other families be able to find ways to advocate for their kids and in trying to find out how to meet their kids' needs, because that dual sensory loss really can make an impact in the classroom.

A little bit about that dual sensory loss. What I found over the years, in particular in those younger years where the vision loss isn't too significant, is that I think often people misunderstand what the impact of that dual sensory loss can be. For our children, they both have received cochlear implants and they hear with cochlear implants. In school, they have FM systems that the teachers wear to help them to be able to hear and get all the information that they need in the classroom. So from just looking at them you may not realize they are impacted. They can hear in the classroom unless things are really loud. Their vision isn't significantly impacting their ability to be successful in the classroom. So if you just take those two things alone, you think that they don't really need a lot of accommodations and modifications and services.

But it just depends on the situation. It depends what the lighting is like, how loud it is. There's many things that can impact. It could be how tired they are during the day, the topic that's being discussed during the day, if they're sick.

Tons of things can impact what's going on in the classroom for them. I think that's often misunderstood by both the teachers and all the adults and people that are working with them, sometimes they just don't understand that.

It's important, I think, for IEP teams to work together collaboratively. It's really important for somebody to be on the team who's knowledgeable about deafblindness and that dual sensory loss, but because it's a low incidence disability, a lot of times there isn't someone in the district that has knowledge about deafblindness on the team.

Parents and families often times feel like they're the ones that need to be knowledgeable and bring that expertise to the team. I think it's important to really clarify those roles, and who's bringing the knowledge. Each team member should respect each person's role and the knowledge that they bring, because often times the IEP teams are larger. There might be an audiologist, a speech and language pathologist, an OT/PT, a teacher of the visually impaired, an O&M (orientation and mobility) specialist and other team members. Each team member has an important role to play in that child's education, as well as the parents and the rest of the family. I think it's really important to respect each person's role, and make sure that families are equal members of the team, because the student has, no matter who it is, has individualized needs that could look very different than another child who is also deafblind.

For us, it was a little bit stressful, because although our team has been amazing, but we just didn't have anyone in the district that had extensive experience working with children who were deafblind in a mainstream setting like ours. So this required me to become an advocate and become knowledgeable about deafblindness, about Usher Syndrome, about what it meant, connect with other families who had been through similar situations or were going through the same situation as I was.

Throughout that, I learned so much about deafblindness, about working with IEP teams, about the impacts of dual sensory loss, about vision loss, about deafness. I've met so many amazing people and families along the way. It led me to go back to school to learn even more, because I realized that it is such a low incidence disability, and just we need more people to be knowledgeable about deafblindness and the dual sensory loss.

I had a little bit of an ah-ha moment as Conner was transitioning. Over the years, I had been attending most of Conner's IEP meetings by myself, and he wasn't involved. I think it just came down to the fact that I was so tired and I had spent so much time advocating for him that I sort of forgot that he really should be involved as well. It was an ah-ha moment, because he was the age of transition, and so they invited him to the meeting. They invited him, so I brought him in, thinking that he was going to be participating actively in the meeting, but that was not the case. He was just invited. The only part of the

meeting in which he was asked to participate was when we got to the part of the IEP, and they all turned to him and said, "Conner, what do you want to do after high school?" He wasn't prepared for that question. He was, like any teenager, "I don't know. I guess I want to be an oceanographer," because he'd just seen an oceanography video. They wrote that down, and then they went around their merry way and started going over the rest of the IEP. He wasn't asked to participate in any other way in the initial IEP transition meeting. That was it.

IDEA states that students need to be invited to participate at the age of transition. I would argue that they should actively participate in those meetings at that point in time, and that's what the intent of IDEA is, but he had very little knowledge of IEPs and his plan. At the time, his team was making decisions for him, and he didn't really ... I mean, he had some idea of what his accommodations were, and he was doing great in the classroom, and he's always been a strong self-advocate, so it wasn't a problem, but it was stressful on me in particular because I felt like I was the most knowledgeable one on the team about deafblindness.

That's when the ah-ha moment came about. I realized that, actually he's 16 years old. He's the most knowledgeable one about deafblindness on this team, not me. So I thought, "How can I reduce my stress and teach him how to do this himself, teach him how to oversee the IEP process himself and advocate for his needs in the meetings, just like he does in the classroom?"

I spent some time really going over IDEA, the IEP process, and teaching him what he needed to know in order to actively participate meaningfully in those IEP meetings. Since then, he has led his last two IEP meetings, at the age of 17 and 18. It's been amazing. There have been many benefits. I feel like the IEP is more student focused. He's making decisions for himself. His IEP goals are now aligned with his post-secondary plans of being a geneticist. When he first looked at his IEP at the age of 16, when I was going over it with him, I said, "Well, here's your IEP and the goals that are in your IEP", and he looked at me and he said, "Well those don't relate to my plans of being a geneticist." I think that's great. Now the goals are aligned with his future plans. He had major input on determining what those goals were going to be.

I feel like the team dynamics have shifted. There's more equal power distributed. All the team members, including myself and Conner, are all equal members of that team, and we all have different roles to play in supporting him in being successful in his education. There's benefits with the family. I feel like I have less stress. It's allowed me to focus on other things. I can focus on really supporting him on being a good strong self-advocate for himself. I can focus on teaching him to be self-determined, to make decisions for himself. I find joy in being able to teach him how to do those things instead of me doing it for him.

I now see, he's going off to college next year, and I can see the strong self-advocate, self-determined individual that he is, and I know he'll be successful as he transitions to college. Right now, he's taking several college courses and he's advocating at the college with the disability office by himself. He comes to me if he has questions, but he's doing it all by himself, and it's going really, really well. Those are benefits for me too, so instead of feeling that stress, like it's all on me, it's been really great, because so much responsibility has shifted to him and he's been very successful in being able to do that himself.

I got to thinking, "Well, that's worked so well for Conner, what would that look like for Dalton?" I began researching this topic, because I wondered, "Could Dalton be involved in his IEP at the age of nine? What would this look like, and how do I make this happen?" I realized the key was self-determination. I realized that no one was fostering self-determination at school. It wasn't part of his IEP. I really realized that self-determination and fostering those skills for Conner was really what ... That self-determination, that self-advocacy skills is what helped him to be successful in being an active participant and leading his IEP meetings. I really started to think about how do we teach Dalton those same skills, and it looks different at the younger ages, but it's still possible.

We went ahead and met, when we met with Dalton's IEP team, we added some self-determination goals, and Dalton's O&M instructor is actually working on those goals on a monthly basis with him. For a nine year old, that's looking like understanding his hearing loss; understanding his vision loss; being able to explain that to others; learning how to make decisions for himself; learning how to self-advocate; if he needs to sit someplace else in the classroom, to be able to feel comfortable talking to his teacher about that; if he can't hear something, if the FM system is not working, to be able to self-advocate for that; to be able to describe his deafblindness to his friends, to anyone else that's asked him about it. He has accommodations and modifications on his IEP, and to be able to talk with the teacher and really indicate when he needs to use those accommodations and modifications.

As a result of all of that, I invited Dalton to come to his last IEP meeting. Although he didn't lead the meeting at the age of nine, he attended. We asked him how his year was going. He shared that with the team. He wasn't having the best year in the classroom. I think hearing his experiences directly from him really made a difference. It was different than hearing it from me. So it was a very positive, I think that the whole team really had a better understanding of what his needs were. He could better explain it. It's helping him to be a better, a stronger self-advocate for himself.

As a result of him attending that last meeting and participating and sharing his experiences in the classroom, since that point have been much better. He and his teacher have come up with a plan to determine when he needs to use his accommodations and modifications. They've figured out a way, without

disrupting the rest of the class, to be able to give her a cue or a sign so she knows that the FM system is not on, or that he can't see or hear something. So it's been great.

What does the future hold for all of this? We're going to continue to build on these skills with Dalton. My hope is that we'll just continue to support both Dalton and Conner in their efforts to become self-determined and self-advocates, and learn how to work with their educational planning teams themselves. I hope to show other families the benefits of student involvement in IEPs. From my experience, there's less conflict, there's more clarity on roles if students are involved. The IEPs become more student focused. It's easier to promote self-advocacy if students know what's in their IEP. It's hard for them to know what they have the ability to ask for if they don't even know what their IEP goals and their accommodation and modifications are that are available to them. Student involvement in the IEP is a good way to teach and foster self-determination.

I really want to find out if other families have the same experiences. Do other families see the benefits of actively involving their students in their IEPs, and is this happening in elementary school? If we give our students the skills to participate in the education planning, will it allow parents to shift their focus from feeling like we need to advocate for our kids just ourselves, which can sometimes be stressful and lonely, to supporting our children as they advocate for themselves and become more involved in their own educational planning. Those are some of my focuses in the next year.

Some advice to families. I think what was the most important to me are realizing that you do need to take time to grieve. Find other families to connect with as you work through those different stages of grief, and as you advocate for your child. Usher Syndrome is progressive, each year looks different. The vision loss looks different. The vestibular disfunction might change. Everything looks different every year, so it poses challenges to the IEP team. Sometimes you just really have no idea how to help and how to make your child successful, helping them be successful in the classroom. So connecting with families and really building those relationships has been really helpful.

I think enjoying the gifts that your child has. For me, the thing that helped me the most is when Conner got to the age where he was able to share with me and say, "Mom, I am okay with who I am. Don't be sad about it. There's a reason that this all happened, and I'm here to help others. I can do anything that I set my mind to. So just help support me in doing that, and don't feel bad about it." I know that I approach every day enjoying the gifts that my kids have. That would be my advice. Then also just taking time for yourself. I don't do very well at that, but I think it's also really important. It's still a goal for myself.

My advice to educators is to do all you can to understand the unique needs of a child like Dalton and Conner. Understand that you might not know all the answers, and treat those families as equal members of the team, and appreciate the knowledge that the families have and that they bring to the table about the their child's deafblindness, because it can look different for every student. Find ways to involve students in their IEPs, and help teach those students how to be strong self-advocates. It can look different. At a really young age, just inviting them, having them put something together, even pictures or anything about their experiences in the classroom, and teaching them how to just share a small piece on how the year is going. All of that's going to just help them when they get to the age of transition and they need to start aligning those goals for post-secondary as well.

I hope this has all been very helpful. Please feel free to reach out to me if you have any questions at all. I'm happy to help in any sort of way. You can email me at, the email address is also on our website, [www.hearseehope.com](http://www.hearseehope.com). My email address is [Lane@hearseehope.com](mailto:Lane@hearseehope.com). Thank you so much.