

Transcript

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Karen

Hi and welcome to the Here Hear Podcast. This is season 4. We are a team at the hospital for Sick Children in Toronto, Canada. We are hearing healthcare professionals, researchers and clinicians who are aiming to understand and possibly improve quality of life for people with hearing loss. In season 4 of the Here Here podcast, I had the distinct pleasure of turning the microphone inward to our Hear Here podcast team to hear their very valuable insights and thoughts. So you're going to have the distinct pleasure of listening to Maryam Othman, May Wang, Nimrat Chani, Sofia Olaizola, Maria Khan and Anika Gasee. Enjoy.

[MUSIC]

Karen

Alright, welcome everyone. We are having an amazing chat with the Hear Hear podcast team, who are an incredible group of young people, who are sharing their experiences with all of us on this podcast. This will be our season 4. I'm Karen Gordon. I am a professor at the University of Toronto, the Archie's Cochlear Implant Lab, where I work is at the hospital for Sick Children and without further ado, I want to invite our amazing Hear Hear podcast team. So, why don't we start with Nimrat?

Nimrat

Hi, so my name is Nimrat. I joined this team because I am a person, I have cochlear implants and my own audiologist has inspired me to help others, which which is why I wanted to be in this team so I can help the future kids and inspire them and give them confidence the way my own audiologist did. And I'm a second year University of Waterloo. I look forward working with this team.

Karen

Amazing. Ok. Thank you. Nice to have you Nimrat. Ok, what about Maria.

Maria

Hello everybody. My name is Maria. I am currently a second year audiology student at University of Western and I was a graduate from University of Waterloo. I have been on this team for I've lost count at this point, but I've joined because my younger brother is a

bilateral cochlear implant user himself and, just growing up knowing about what he's going through, how like his our audio, his audiologist helped our family out a lot, inspired me to like you know what, this field is really cool and also hearing is just really interesting, so that's why I'm currently in my program and currently a part of the lab.

Karen

Amazing. Thank you. May.

May

Hi everyone. My name is May Wang. I'm a second year undergrad at the University of British Columbia with a major in nutritional sciences. I joined this team because, well, I was born with single sided deafness and I was a SickKids patient for close to 10 years, so I joined this team with the hope to connect with others that share similar journeys and also help raise awareness around hearing loss.

Karen

Sophia.

Sofia

Hi everyone. My name is Sofia Olaizola. I am a graduate from the University of Toronto, currently working as a research coordinator at the Hospital for Sick Children. I joined this team because I was also born deaf in both ears and I wear a cochlear implant on my right side. I've always been very interested in connecting with others with hearing loss and hearing about their experiences and sharing, and hope to be an audiologist one day as well. So I look forward to chatting with everybody today.

Karen

Thank you so much and I have a very special place in my heart for all of these guys. And if you have not heard the previous episodes of discussions with this amazing team and podcast created by this team. After you listen to this podcast, go back to those because they're also incredible. So this time we're going to think, and we're gonna actually ask this group to think way back to when they were small and they started school. And I want to hear from you guys about what you found to be, you know, the happiest, you know, happy memory back from elementary school. And then we'll talk about some of the challenges you might have had as a lot, you know, as a young person going to school for probably the first time. Tell me a little bit about your school experience.

Sofia

When I think back on elementary school, I feel super lucky. I think that I had such a great group of classmates at school that I'm still friends with to this day, so I've been friends with these people for 20 years and there was a small group of us. Honestly, it was as if I wasn't deaf. They I think they forgot half of the time, which I guess can be a good thing and a bad thing, but I feel lucky in the sense that I was always treated as normally as I could have been. And I appreciated that. When I think more towards the supports that I received at school, I was also fortunate in the sense that I had the same itinerant teacher from the 1st grade to the 8th grade. I was with her for eight years. She knew me so well, she became such a close person to my family. Her and my mom are still friends to this day. But it wasn't always like that. I was not the most cooperative itinerant teacher's student growing up, and I can't remember if it was Tuesdays or Wednesdays, but she would come once a week and you know the school system would give us the tiniest storage closet for us to work in, and we would be in there in this little supply closet and she actually was really amazing because she was also studying to do her auditory therapy training and it was kind of convenient because when I was nine years old, so up until nine years old, I had just one cochlear implant. And then when I was 9, I had a surgery to have my second cochlear implant. So during that time, my itinerary teacher was also doing training to be an auditory therapist. She, you know, used that opportunity to try and train my left ear. And I was totally uncooperative. I had no interest at all whatsoever. I used to hide from her. I knew she would come pick me up at 1:00 PM, so I would raise my hand and go to the bathroom at 12:55 because I thought maybe if she came to the class and didn't see me there she would leave. But every time I was totally surprised when I would come back from the bathroom and she was still there waiting for me so, yeah, in hindsight, I can appreciate her so much, I think in that moment I was awful, but when I look back now, I'm so grateful to have had her because she really, really tried her best with making things as successful as possible for me, for trying to educate my teachers on how to use this equipment.

Karen

You bring up a really good point on the itinerary teacher. Many people listening may not have any clue about two things you talked about. One, that somebody who was born deaf could be in a classroom with out any other child with hearing loss, which was your case. It sounds like. Everybody else had had normal hearing, but the one of the things that was provided as a support was a teacher who we call an itinerant teacher, specialized to work with children with hearing loss so they'll know about, you know, the extra little help in language and listening, and also would coordinate with the teachers around what you were working on, probably in class and could take you out of the class is what you're describing to work on those things, maybe work on some language, that kind of thing, right?

Sofia

Essentially, her job was to connect with the principals, the teachers and everybody who was responsible for my education and sort of develop a plan that would work well for me. For example, you know, making sure that my seat was in the front of a class, making sure that the noise environment was conducive to my learning. Exactly what you said, Karen, that she's connecting with the teachers. I would say her job is primarily working with that staff as opposed to actually the part of taking me out of class and working with me. It was more just making sure that I'm receiving whatever additional support that I needed in class.

Karen

I bet you the other the other guys here on the on the team have other stories about their itinerant teachers. Did you all have itinerant teachers?

Nimrat

I had mine from grade one to grade 12 and I was not nice to her. Like now I realize she was, she did almost everything for me, like she tried a bed, even though she knew how awkward I and how insecure I was. Cause in elementary school, we had a classroom and she would come in in front of the class to the teacher's desk, and it would be like, 'Oh my God. Like who is she and why does she have to leave every week?' and oh my God, like I used to literally wave my hand, like can I go to washroom? Can I like go on a walk, can I do something and not be with her, but like you know, ever since I entered high school, I kind of realized what was her role and why she comes. Because back then I was just kind of really insecure, insecure. I didn't anyone to think oh, like, I'm leaving a classroom to meet a teacher. Like, I don't want anyone to think less of me as a student because in elementary there's a lot of rumors. Oh, like, why does she leave the class? Who is she? Who is the teacher and all that?

Karen

Yeah, it's so hard.

Nimrat

At my graduation, she came to greet me and I was like, so shocked. I had to like say thank you and apologize to her. And she was, like, laughing. Just like she has so many students who would just like me, so insecure in the first half school, another half, they just grew up.

Karen

I totally understand that feeling of being singled out is not always wanted, right? May, I saw you smiling to yourself about the itinerant teachers.

May

I was just like remembering how, you know, when Nimrat mentioned like the other kids in the class would just, 'Oh my God, you know, like, why is May being called to the office?', 'Who is this woman who's taking her to like private room?'. But based on what I'm hearing, I feel like, I also had an itinerant teacher, but I think my experience was a bit different in that my teacher only came once per term. I remember in elementary school she'd come like once in the fall and then basically it was a 10 minute talk in a room to ask, you know, 'How are things going?' and 'How are your seat arranged in the class? Is it going ok?'. And then she'd check back in the coming spring. So I didn't have that many interactions with her. And though I had like the same teacher for like a really long time, I didn't find it that effective, maybe because of like just based on you know my condition, but the positive note that I remember and like you know throughout my life was, because I kind of blended in with the normal group I had the opportunity to like make the decision of whether or not I wanted to tell others about my hearing loss. If I didn't feel comfortable, I have that decision to not disclose my condition and no one would really know unless you know, like there's some other interaction. But I think that gave me like the flexibility that allowed me to, like, feel more comfortable where I am.

Karen

Do you remember things like Sophia was talking about being placed in the front of the class. That kind of difference?

May

I had an IEP which I think indicated that a preferred seating arrangement was needed, but for the most part I think I had to navigate these situations myself and I remember, each year getting a new like homeroom teacher, I would be the one who would have to talk to the teacher privately, maybe after school or some other time and ask you know, can I find a seating or like, I've also had teachers that like because they have the IEP information, they would come talk to me and then like it was pretty easy to arrange.

Karen

That sounds like a good. I see we have Miriam, who's joined so maybe you can just introduce yourself quickly and then I'm going to ask you about your memory of itinerant teachers.

Miriam

Hi everyone, my name is Miriam. I currently go to school in London. And this is my second podcast with the group. So I actually had an like an itinerant teacher. Is that what you guys call them? I just call them a helper teacher. I had one at every point in elementary and kind of phased out towards middle school, and that was a personal choice. I think maybe going to school in Toronto, where maybe like a lot of kids in your class that can sometimes fly under the radar. But the manner of which I was being pulled out of class such that they would call me down from the office and I would be over the announcement system. And sometimes a teacher would come wait by the door with an ominous yellow folder in her hand and looked like I was a suspect in something. And so, I do remember feeling embarrassment when I was a kid, and I definitely have sometimes intervened and been like, hey, like instead of calling me down, can I just pop out of the class on my own? I'll meet you in the hallway and then that way the kids won't give me a hard time about it and say, oh, man, I'm getting called into the office. I don't even know where that feeling stemmed from. At the end of a day, they were giving me much needed help. I needed that one-on-one with them. Sometimes I would talk about my feelings, what's going on at home, how I'm coping with everything. Sometimes it was very therapeutic from a mental perspective. Sometimes we would just play games and it would be my moment of relaxation and de-stressing from the very stressful hearing environment of the classroom. Other times I'd have a teacher pop in to help me with my speech and just sort of corrected my impediments and so it was very useful for me, but I think the fact that I was feeling very different from the rest of my classmates hindered my ability, ability to participate in this session. I'll be honest, I don't think I put my whole 100% towards it when I was a kid. But then I got to middle school and I was very conscious on my mind that I wasn't pronouncing certain letters right. And I began to actually put an effort and I saw the results much faster too. I didn't put two and two together when I was a kid that the more I resisted, the longer it took for me to achieve the outcome we were hoping for. But when I actually put that effort in in middle school, I managed to complete the speech pathology course in a few months, and it was actually some huge improvements to my speech, and then by the time I got to high school, I think they gave me the option to opt out of it, and I ended up opted out of it because I wanted a more seamless integration into the high school environment. Everyone knows, it's very tough to deal with teenagers as a teenager too. And then university again. I don't think it was anything that could be implemented at the adult stage or wasn't an option to me. Looking back, sometimes very good, very bad experiences, but I just wish I could go back and tell my younger self that it was ok to have a helper teacher, that I didn't need to feel embarrassed about it or feel different from anyone about it. I also wish that it was maybe a more seamless process that if I felt like I was being outcasted that we could have maybe met in the middle about it. But it also has to do with self advocacy and as a kid that can be really hard.

Karen

What I'm hearing from everybody is that you are the only person with a hearing loss in your class and you just wanna fit in, but you also need the help, so there's that back and forth I want this, they're helping me, but I don't wanna be different. That's a really tough place to be, but makes total sense. Maria, I don't know if you remember your brother back then.

Maria

So my brother didn't have an itinerant teacher. He actually was in a community class during the kindergarten and elementary school. So there was like maybe 10 people in his class and then it was very, very different from like what everybody's been saying about their experiences, because he was there for like learning difficulties and also for his hearing loss. So that he just had a very one-on-one or two on one experience with his like itinerant teachers. I'm assuming in the class and as well as just a teacher and the rest of the kids.

But at some point, I think our family was like, I think, like he's grown enough that he can integrate into, like, the regular classroom. So after lots of discussions with the teachers, principals, literally everybody involved in his care, they finally like, put him into a regular classroom. I believe he did have like a support person in the classroom 'cause, he would often come home and he's just like, yeah, class is fine, how is everything else? It's ok. So that's all we got out of him. But in terms of like the sibling side of things and like supporting him in his education. Mostly it was just sitting down and making sure that he's ok. Again, he was not talkative at all. So I guess for me was just trying to make sure that he's just doing ok.

Karen

It's hard to even express like what you're going through as a when you're young. It's very helpful for me to hear from you guys now that you're wiser, older and you can look back on your younger selves and see what it was that you were doing that was normal for your age, but also, you know. Maybe not so helpful for your own, you know, development. But, I want to talk about, you know, that feeling of needing some help and not wanting to be singled out as a as it relates to devices. So before we get into all the like technical parts of what you guys use and all the little 'cause, there is a lot of technology that gets used to help here, what about just simple things? You talked about seating. Did anyone have like tennis balls on the chairs in your classroom and and in the on the tables? Tell me a little bit about that.

Sofia

I had tennis balls every year and. So essentially, we would get a box of tennis balls and everyone would put a tennis ball on each leg of the chair and then on each leg of the desk. So that way when you're moving desks around, removing chairs back and forth, there's no sound. Personally I had a good experience with that because all of my classmates and friends loved it. We thought everyone thought it was so cool because we were the only class in the whole building with tennis balls on our chairs and they just thought it was really fun. And actually, I don't even think anybody knew it was for me. I don't even think to this day any of my friends have put together the dots that those tennis balls were for me. But I loved the tennis balls. I thought that was really helpful because the noise of people moving their chairs back and forth is very obnoxious, especially those plastic chairs in elementary school.

Maryam

Similar to Sophia's experience, a box of tennis balls just arrived, and we all put them on. And I think there was a lot of excitement in the class because it was something other than academic work. I found that they worked very well. We didn't put them on every desk. I think the ones that were against the wall like weren't gonna move anyway, but I do remember it made a significant difference, and in general it caused less disruption to the classroom for everyone too. I remember that being a really good experience.

Karen

Nimrat, I don't know if you had that. No. No tennis balls. Do you remember the classroom being noisy?

Nimrat

Well, my process was little bit different because in grade two I was in public school and then my school board had to transfer me to another school that's called HOH program. This particular program, called Hard of Hearing. So I was put in a classroom from Grade 3 and 4 where there was many other kids just like me. That time my self-esteem, everything was like really low to start because, like, why did I have to transfer from another school to a HOH program? But then I realized from grade 2 in my public school, I had a lot of trouble listening to teachers as well my confidence. My speaking was not matching the Grade 2 like the teaching level, which is why they had to transfer me and from during those two years, Grade 3 and 4, I had, like excelled their level and then they transferred me back to public school in grade 5. It was really like a rough patch for me because I I couldn't understand like why did I have to go to another classroom like a whole different school like it was out of my boundary, the school area, which was like pretty new for me.

Karen

That's a big transition, probably a lot of transportation time, right? Maybe you're on a bus for a while everyday or you would, you know, take in. And it's a new group of people. What do you remember about the differences between that class? Was there fewer children?

Nimrat

Very different. So as a normal classroom in like, elementary middle school, we have 28 or 32 depending how big a school is, but HOH program, there was only like 5 kids and it was an outdoor classroom, but there weren't any desks. It was like carpet, and it's like a white board with few chairs around it. So in the classroom there was four corners and each four corners there's four different learning activities. Basically, and every two hours you have to change the station and that did not help me because personally I like to learn on one spot and stick to learning to like you know for a few hours but like that one they change every few hours. I'm like my mind was like getting confused like am I focusing on this? Then switch to the other whole new course, but could be arts or writing or like math or like listening or speaking course right. It was a little bit confusing for me.

Karen

Sounds like there's lots of different kinds of teaching, and these classes were trying to do things in a different way, so interesting that you went from a mainstream class to the special class and then back again. Other than the tennis balls, let's talk about the FM systems. The other technologies that you guys were using back in elementary school. May, do you wanna tell me a little bit about an FM system that you used and what you thought of it?

May

I tried the FM system in Grade 5. From what I can remember, it's this little device that you can wear and I think I wore it in one of my ears. And my homeroom teacher, she would wear this necklace that looked like a like a pen and basically, in the classroom when she wears that necklace and turns it on, it's almost like this microphone inside my ear so I can hear her really clearly. And I tried that for a couple of weeks and I decided not to use it. There was several reasons that I thought it was really inconvenient. In terms of the hearing improvement, I just didn't think it was helpful enough for me to want to continue using it, and partially because there was a lot of background noise when my teacher forgot to turn it off. Or, you know, or she didn't wear it. And I just think that, perhaps in an elementary school setting where you just have one teacher, it's helpful maybe for small children. But long term, I didn't think it was a sustainable strategy to help my hearing experience. I just

didn't really like the fact that I had to rely on someone else to maintain or like to to get the hearing experience I I wanted. So that was the major reason why like both my family and I tried like throughout my childhood, we kind of put more emphasis on developing natural ways to adapt to new and different settings rather than relying too much on technology. So I think, my experience growing up without any heavy reliance on technology has allowed me to kind of be able to adapt to different settings busy. The FM experience in Grade 5 was. Wasn't. It was like the first time my family and I decided, like, let's try something, but unfortunately it wasn't really helpful. My teacher, she was really kind and she even told me, you know, if you want to try a device, I want you to try it in my classroom and I'll do it with you. But like, sometimes she forgot to turn it on or she forgot to wear it or she forgot to turn it off. In some ways I also felt if I were to ask every teacher in the future to do this, it would feel like a burden for myself because I try my best to be independent and not have to ask others for favors and all that just to accommodate myself.

Karen

I hear you. You know, this idea that you wanna be independent, you wanna have some control. I just wanna follow up what you said is you found different ways to navigate that were maybe better than what the FM was offering. What do you think worked better than the FM?

May

Well, for me because I hear normally on my left side, the easiest and most effective way for me to kind of maximize my learning experience in the classroom was to just ask the teacher directly if they could assign me a spot that was on the edge and at the front, so my hearing ear was in the direction of the teacher's voice, but that also made it challenging in cases where my table mate was on my right side and even though they're right beside me, because I can't hear at all in my right ear, it's still really hard to hear them. And I think over time, I've become like pretty good at interpreting and inferring what they said based on, you know, lip reading and other external cues that can like make me make sense of what they said.

Maryam

May, I just want to say, I can totally relate to even though we may have different degrees of hearing loss. The whole idea of wanting to maintain your privacy was huge to me, and I feel like with the FM system I just couldn't get that. So when I was a kid, I first went through a trial of trying on hearing aids before I got the implant on my left side and then ended up not wearing anything for the right ear for a long time. And, already the hearing aids were not good for me. They screeched a lot and I just couldn't get sound distinguished distinction

that well. The FM system, same problem as you were saying. Sometimes the teacher would forget to turn it on or forget to turn it off if they went away to have a private discussion with the student or they went to the bathroom or were on the lunch break and I would just feel so uncomfortable being privy to a private conversation. So sometimes I would just turn off my device cause I just felt morally wrong about it, or I would have to somehow go track down the teacher if I know they just stepped outside the hall to be like, can you just please turn off? I ultimately chose not to use it for the rest of my education. But interestingly, I can see it making a comeback now that I'm in I guess professional school, where I can see the benefit of it. I don't know if the technology compares. It's also been like 10 years since, but I have been interested in trying it again, cause I think there's always room for improvement.

Nimrat

I don't like FM because they're really loud. Even my teacher try to lower the volume and it really didn't help. It just hurts my ear even more because a lot of static noise days. But like I usually stay in a front of the seat during the elementary and high school and middle school. So therefore, I wouldn't have a lot of problem because of my classroom was kind of smaller, so like my learning it was more direct to the teacher. So, like I didn't really require FM, but knowing now I'm in university in a big lecture hall like I sometimes wish, oh, I wish I have that now, because that would be so beneficial for me to hear in a big 500, 600 lecture, I mean students, in the class.

Karen

One of the things I worry about with FMS is that, although you have to hear the teacher in the classroom. You know in a lecture hall, it really is about the professor and there's nobody else, so it's a really good example of how an FM would work, or if you were watching television or something where it was one sound source, but in a classroom there's so many other things and interactions with other classmates and so forth. So Sophia, do you have any thoughts about why you did and didn't like the FM?

Sofia

I can relate to Maryam, to Nimrat, to May about all of it. I have a lot of experience with FMs because against my will I was forced to use them for the entirety of my elementary school. I went through a couple different systems, some worse than others. Earliest one that I remember, it was actually a speaker system. It was a speaker with a microphone, and so the microphone, so it's amplifying for everybody, so in that context, the teacher would be at the front of the class with the mic and then the speaker was always located near my desk and then every time a student would have a question, my teacher would give the microphone to the student. It was kind of like in that way everybody was hearing everybody

because everybody had a microphone. I didn't really like that because it was weird that there was a microphone and everything was so loud, so if you were down the hall of the of the school, you could hear everything happening in in my classroom and we got complaints from classrooms next door because they're hearing everything. So ultimately we had to switch because it was disrupting other classrooms. The next one that I had was the one where I'm wearing a system and the teacher's wearing a system and we both have to have it on in order for it to work. The biggest problem I had with that one was very similar to what Nimrat said about the static is that the connection like if she would go to a certain part of the room like it would get really staticky it would be kind of like, shhh-shhh shhh-shhh, and I would get really annoyed, but luckily I didn't have to turn off my CI to get rid of it. I could just turn off the FM system like I if I just click off button on my personal FM system it automatically cuts the connection which I thought was good. An FM system really did not feel necessary if I was located in the right position in the class as long as, so I'm completely deaf on my left side and I wear a cochlear implant on my right side. So as long as I was always on the left at the very edge left edge of the classroom, so that my hearing, my cochlear implant was in the direction of everybody else and the teacher, I usually felt pretty fine. I never really ask people to repeat themselves. I always found that just responding em-hmm or ok usually got me by pretty well without having to ask people to repeat themselves. I mean, everybody knew that I was deaf. For me it was always very visible, that I was wearing something. I definitely think sitting in the front of a room is much more effective than an FM system, but I do see the potential of an FM system in a university setting. I thought it was so cool what Maryam said that she can just put a little microphone. I think that that works really well.

Maria

In my class last year in oral rehabilitation, our professor, he was a CI user and a hearing aid user. So we had to use videos FM in his class. We use a remote microphone, so he wore like the mic around his neck and then. I think every now and then there was like, I think two or three microphones across all of our tables. And for context, he was like 30 audiology students in the room. There's not too many people, so every time somebody has a question, we just speak into the mic and he's able to pick it up on his his hearing aid side, he's able to pick it up and hear us completely fine.

Karen

The way that we need help as we get to adulthood is a little different than what you need help with when you're a child.

Sofia

What helps me is if you're talking to me, say my name first because that way my brain knows to pay attention to that specific person. It sounds so simple, but it really makes such a difference.

Karen

You guys this has been another amazing eye opening conversation for me. There's so many things that you have shared that I didn't think about before and it's really helpful to hear what did and didn't work for you as you went through school. So I really would like in our next conversation to get a little bit more into the high school years and how you transition from high school to now. Thank you so much guys and I can't wait to talk to you again soon.

[MUSIC]

Karen

Thank you for listening to this episode of the Here Hear Podcast Season 4. I hope you enjoyed this conversation. I want to give a shout out again to the here here podcast team. Nimrat Chani, Mei Wang, Maryam Othman, Sofia Olaizola, Maria Khan, Annika Gasee, as well as my colleagues that are involved. Laura Carinci, an audiologist here at the hospital for Sick Children, Dr. Sharon Cushing and Dr. Blake Papson also. I hope you enjoy this music which was performed and composed by Dr. Blake Popson. Thanks for listening.