

Making Sense: Navigating the politics and science of deafness and language

A special documentary by Connecticut Public Radio

Radio transcript

DAVID DESROCHES: Corrine Walter's pregnancy had been going perfectly. No complications, no surprises. Her son Jackson was born on July 1st, 2011. And she remembers everything.

CORINNE WALTERS: He was the first grandchild on both sides, I mean it was like your first child being born, so exciting.

DESROCHES: But she noticed something odd once Jackson arrived. He would just stare at the fluorescent hospital lights.

WALTERS: Deep inside I knew something was wrong.

DESROCHES: But, as a new mom, she questioned herself. Maybe that's just what some babies do?

WALTERS: Like he was probably minutes old, and, he was just staring at the light. And it sounds like nothing, but probably just my inner mom just said, that's weird, why are you staring at the light?

DESROCHES: She pushed the thought aside. Then Jackson failed the initial hearing screening at the hospital. But everyone told her it's common. It's just the amniotic fluid in his ears from the labor, it'll pass. She went back for another test, and he failed that one, too. A third test was scheduled a few weeks later.

DESROCHES: In the meantime, she was getting worried. Jackson wasn't responding to sounds.

WALTERS: Like smashing pans, knocking, things like, you know, when the dog would bark. I just took note of all sounds, and there was nothing...

DESROCHES: Jackson had to be asleep for the third test, called an auditory brainstem response. An audiologist placed electrodes onto her son's tiny head while he slept.

WALTERS: I'm holding him and he's connected to all these wires and they were like, 'alright you've got to get him to sleep, and it was just so stressful already. It's like your first baby, I don't know what I'm doing already and you want me to magically get him to sleep. It was so much work. We finally got him to sleep.

DESROCHES: The machine was connected to a computer that she watched as they tested her son. The monitor remained blank. Corinne can still picture the screen.

WALTERS: And then all of a sudden, probably like 40 minutes in, she's like, 'OK so on this screen, there's supposed to be stuff, there's supposed to be brain waves going'. And I'm like, 'OK,' I had no clue what that meant. And she's like, 'This whole time, there hasn't been any. So he's deaf'.

DESROCHES: Within minutes, a hospital worker handed her two pamphlets about her options. And that was it.

WALTERS: And we went on our way.

DESROCHES: I'm David DesRoches. This hour, we're going to talk to three families with deaf children. We'll explore how and why they made decisions for their children. And why the politics of decision-making for deaf children -- teaching them to speak or to sign -- are really complicated. Corinne Walters and her husband, Ryan, had to choose -- and they had to choose fast. How will Jackson communicate? Should they teach him sign language? Or should they teach him to speak? Both? Neither of them had never known a deaf person before their son was born.

DESROCHES [TO WALTERS]: So what was it like, just getting, you know, not being aware of the sort of science behind hearing loss, the science behind language, and having to get caught up so quick -- how did you guys deal with it?

WALTERS: Wine? I don't know how we dealt with it. Looking back, it's just such a blur. This all happened in less than a month. And it was just googling what cochlear implants are, we had never even heard of them. I never knew -- I thought you were either deaf or you could hear, I never knew there was such a broad spectrum in between.

DESROCHES: Their questions multiplied. What does all this mean? What's next? They soon learned that even the experts disagree. They were getting completely different messages. Only one thing was clear -- if Jackson didn't get any communication input as soon as possible, his brain could suffer. Corinne and Ryan needed time to think. But Jackson needed language immediately.

[END SCENE]

[SCENE: Rock climbing with the Posner family]

DESROCHES: Henry Posner grabs the climbing rope tight. He's there in case his climbing partner slips while scaling up this wall. There's also a climbing instructor.

INSTRUCTOR: Yup, there you go...

DESROCHES: Henry's deaf. So's his entire family. His right ear has a hearing aid, but it only picks up about half of the sounds it receives. His left ear picks up nothing. But he's keeping a close eye on his climbing partner. The other boy eventually reaches the top, and yells that he wants to come down.

BOY: Ok, I'm coming down.

INSTRUCTOR: Alright he wants to go down.

INSTRUCTOR 2: He's coming down.

DESROCHES: The instructors are repeating this, because it's hard for Henry to hear in the loud gym. And communication is vital when climbing, says one of Henry's coaches, Casey Walsh.

CASEY WALSH: You're always looking out for your partner, you're making sure that they're safe. So partner checks, and communication, are so key. So for him, just to be able to hear me, if I think he needs to stop and slow down or sit and rest, that's huge.

DESROCHES: The boy gets down safely. Mission accomplished. Henry smiles. It's a small win, but you can tell that it matters to him. Henry's sister, Faith, is proud of her little brother.

FAITH POSNER: Well, surprisingly, he's belaying at 6. I'm sure he'll tell you about that. But you're supposed to learn when you're 8. So, he was so cute, last week he was like, 'I'm gonna learn how to belay today, but I want the FM so I can hear when they want to come down'.

DESROCHES: That FM system she mentioned? It's a microphone that the climbing coaches wear around their neck. They talk into it, and its signal feeds right into Henry's hearing aid, so he can hear what they're saying. It's especially helpful in noisy places, like this rock-climbing gym. The entire Posner family -- Rachel, her husband, Mick, and their two kids -- are all deaf. They use technology to help them hear, but, they're deaf.

DESROCHES: Faith and Henry used to play soccer, but communication was hard, says their mom, Rachel. So they found another sport. Even though Rachel's deaf, she grew up reading lips and speaking, which is how we're communicating today.

RACHEL POSNER: So this is a perfect sport for them, because they work independently but they learn how to be a team.

DESROCHES: The FM system isn't perfect, though. Like earlier in the day, one of the coaches left Henry with another instructor, but didn't pass along the FM microphone. Being deaf in the

hearing world requires A LOT of explaining, Rachel says. She understands that most people take it for granted that they can hear. So she tries to empathize.

POSNER: The guy is a really nice guy, it's not his fault, he's not thinking about it, because he can hear.

DESROCHES [TO RACHEL]: Is that common thing, when they forget to pass it?

POSNER: All the time, it happens all the time.

DESROCHES: They also use the FM system in school. Sometimes Faith's teacher uses the bathroom with her FM mic still on.

POSNER: When the teacher leaves the classroom, the FM goes with her; meaning Faith's ears, technically, go with her.

DESROCHES: Basically, when Faith's ears leave the class, they're going wherever the teacher's going. When it comes to the FM system, there's a long and steep learning curve for teachers and coaches. It's a lot like most things related to deafness -- the burden's on the person who needs support to make sure the support actually happens.

DESROCHES: When a deaf child is born, experts tell parents they have to choose between speaking and sign language. Families like the Posners, though -- they're trying to do it all. Rachel says her family wanted to do what works for them. They didn't want to fit someone's else's mold. But she also recognizes that people who sign might find their approach offensive.

POSNER: I know that I'd be crucified -- maybe some people would be like, 'That's great, that's just fabulous.' Other people would be like, 'F you, you're ruining the culture.' I'm not here to do anything to anybody, but to make my kids the best they can be.

DESROCHES: Rachel says she's a mom first, and a deaf person second. She's not here to ruin deaf culture. Her family just wants a normal life -- and what's normal for *them*, works for them. Her family uses what they call the Posner code, which is using sign language and spoken languages as needed, and sometimes at the same time.

POSNER: I do both because I feel it works for my family.

DESROCHES: So we've met the Posners, who sign and speak and use technology to help them hear. We've also met the Walters, who haven't yet made their decision. Now, we'll join the Gagnes for dinner. They do something else with their deaf toddler and two hearing kids.

[END SCENE]

[SCENE: Dinner with the Gagnes]

DESROCHES: It's a cold March evening, and Deanna Gagne joins her family for dinner. Pizza's on the table. Nobody's touched the Greek salad yet. At one point, Kurt, the father, motions for one of his sons to sit down. Kurt's deaf, and uses American Sign Language, or ASL, to communicate. Deanna also uses ASL, but she can speak and hear. She grew up with deaf parents, so ASL is actually her first language. She waves her hands to get Kurt's attention. They exchange signs and burst out laughing. Their youngest child, Logan, is also deaf. She's almost two, and is building her ASL vocabulary.

DEANNA GAGNE: Most of her sentences are like two words, which is like normal.

DESROCHES: Their two sons also know sign language, but, like their mom, they can also speak and hear. This family dynamic -- a deaf dad, a hearing mom, two hearing kids and one deaf toddler -- is not the norm.

GAGNE: Both of my parents are born deaf, so that's how I learned how to sign. And that's also probably part of the genes that contributed to having a deaf baby, which we didn't expect because our older two children can hear.

DESROCHES: Deanna is what's known as a CODA -- child of deaf adults. CODAs are often hearing, which puts them in a complicated position within their family. They often live in both the signing and speaking worlds. Deanna talks about walking a difficult line as a CODA -- a line that she walks today with her husband.

GAGNE: Some of the challenges that I faced as a child and you know, as a teen in growing up, is the fact that society viewed me, as the child, as better than my parents, who were deaf. Right? That people would do things like, you know, I'd go to a restaurant with my parents. And my father would put his credit card down to pay the bill, and the server would bring the bill and the credit card and place it in front of me.

DESROCHES: A similar thing happens when she's with Kurt.

GAGNE: Going somewhere and he's the one, you know, I'm interpreting for him. Because I do, sometimes, right, in instances when we're just out and about. And he's the one, let's say, we go into an automotive place and he's asking a particular question about, like, do you have this part, and then they hand this part to me, because I'm the one who spoke, right? It's like, 'No, like, you saw him signing, you know, you saw me interpreting for him, but yet you give it to me, it's different.

DESROCHES: That's classic ableism -- the idea that people with different abilities are somehow lesser than people with typical abilities. It's a mentality that Deanna's trying to prevent with her two hearing children.

GAGNE: The unique dynamic in the fact that we are a deaf and hearing couple, but I'm also the mom, right? So moms become default anyway, right? Like many kids will still go to their moms no matter what. So in order to try and balance that, I often tell my children, 'Go ask your dad, you know? Why don't you ask dad?' Not necessarily because I think that they're choosing me because I speak, but because I really want to almost overemphasize that interaction with him, so that it doesn't become about the English versus ASL.

DESROCHES [TO GAGNE]: That's a very classic parent move. Go ask your dad.

GAGNE: It is, it is.

DESROCHES: In this case it's more meaningful.

GAGNE: Right, well, I'm being a little bit more intentional with it, yeah [LAUGHS]

DESROCHES: Kurt says he doesn't want special treatment. Just equal treatment. Here he is speaking through an interpreter.

KURT GAGNE: I just want people to, like, open their minds a little bit and understand a little bit better, and give folks a chance. Because given a chance, they'll see that people who are deaf and hard of hearing work just as hard as everybody else and do just as good a job, so what I'm looking for is an attitude shift.

[END SCENE]

DESROCHES: So a quick recap -- and you can see why this can be overwhelming for parents. The Gagnes are signing with their deaf daughter. She'll also learn English, but probably only the written version. The Posners are doing a mix of signing and speaking, with some hearing technology. Now, let's check back in with the Walters, who we met in the hospital.

DESROCHES: You might remember that when Jackson was born, the hospital gave his parents two pamphlets and sent them on their way? Well, one of them was for the American School for the Deaf, which focuses on teaching ASL. They called the school and talked about what it could offer Jackson. They also called CREC Soundbridge, which takes the speaking-only approach.

WALTERS: Soundbridge is -- if you're going to do this, you're not going to sign. This is an oral -- that's your decision, you're going oral. And American School for the Deaf, is basically, we'll just sign.

DESROCHES: But the different service providers gave them conflicting advice. Some people told them not to sign with Jackson, that he'll never learn to talk. Others told them to sign with Jackson as much as possible so he'd have full access to language.

WALTERS: Looking back it was such an impulsive decision that we were, probably had not even nearly enough information on to make a decision at that point. But with all that pressure, and you have doctors telling you this, that this is something you have to choose now, so. It was really confusing.

DESROCHES: Very few things made sense. Everything was new. The only thing Corinne and Ryan were sure of? They wanted a normal life for Jackson. Coming up after the break, we'll find out what they learned. I'm David DesRoches. This is Making Sense -- a Connecticut Public Radio special. Stay with us.

[END PART ONE]

[SCENE: Birth-to-three playgroup at the American School for the Deaf]

DESROCHES: This is Making Sense, a documentary about deafness by Connecticut Public Radio. I'm David DesRoches.

BECKY PETERS: Good job Logan! Do we want to make a lamb?

CHILD: Yeah!

PETERS: Want to go sit down at our table and we'll go make a lamb?

DESROCHES: It's playtime for infants and toddlers at the American School for the Deaf, in West Hartford. If you have a deaf infant, it's the only place in Connecticut that will teach your kid sign language. It's available through the state's Birth-to-Three program. Becky Peters runs this playgroup.

PETERS: So we have a very small group today. Usually we have about eight kids, but we're down to four or five today.

DESROCHES: The walls are filled with finger-paintings and other works of abstract art. There's a book about colors on one table, and a tupperware container filled with shredded paper on another.

PETERS: It's very come and go as they please, It's very flexible to meet the parents needs.

DESROCHES: It's a mix of kids with different hearing abilities. All of them are getting some sign language exposure, Peters says.

PETERS: Right now we have got two hearing children, Jadrian and Bailey, and then we have Adenaya over there, who's hard of hearing, and Lori, she's got Miss Logan, who is completely

and profoundly deaf. So we've got a little bit of a mix of everything in here... So Jadrian, both Jadrian's parents are deaf... And Bailey's, both her parents are deaf.

DESROCHES: As many as 9 out of 10 deaf babies are born to hearing parents. And most of them have no idea how to raise a deaf child. So they visit places like the American School for Deaf, which is the oldest school for deaf children in the country.

PETERS: We teach them the vocabulary, if they sign it, great. But at least they're getting that exposure, they're getting the receptive language, they're getting the communication skills. They're learning how to follow directions... And we have a policy here at our school that we have to have communication accessibility, so we really have to be signing at all times, whether voice on or voice off. But that's the children's primary language at their school, at this school. Is communication through sign.

DESROCHES [TO PETERS]: That's the primary mode of communication.

PETERS: Yes.

DESROCHES: So with the bilingual aspect, how does that kind of work out? Like, so you're doing primarily signs, but if you also want some of them to speak...

PETERS: We kind of look at the individual child, we kind of bridge the ASL. For these guys I said, right now, these two can hear pretty well, obviously one is fully hearing. Do you want some more Adenaya? Ut oh. We spilled out... eh.

DESROCHES: Ut oh. [Laughing]

PETERS: That's OK, this is part of our life. So I'll speak to them. I'll speak to them directly. And then when we do story time, I'll put the signs in, or I'll have another person who signs the story while I'm reading it. And that's how we do the bilingual approach.

DESROCHES [NARRATING]: Parents of newborn deaf babies often visit classes like this, to see what's out there. And while they're figuring all this stuff out, they're constantly bombarded with conflicting ideas about what's best. Then there's this idea of normalcy. What is normal? Of course, everyone has their own answer to that question. But for a lot of parents, that answer changes, once they have a deaf child.

Parents also learn about the centuries-old tension between the speaking and signing communities. It's a tension Jeff Bravin knows well.

[END SCENE]

DESROCHES: Bravin sits at a circular table inside his office at the American School for the Deaf in West Hartford. Rosy-cheeked and quick with a smile, Bravin runs this school. He uses ASL to communicate, and he speaks using a female interpreter.

I mean you would never know I was a deaf person if we emailed back and forth, if that's how we chose to communicate. You would never know I was deaf... I function as any normal person.

DESROCHES: This idea of normalcy -- that a person can be both deaf and normal -- is one that parents of deaf newborns often struggle with. That's because most deaf babies are born to hearing parents, who communicate by speaking and hearing. So they're often quick to judge someone whose hearing abilities... don't exist. What follows is that they see deaf people as abnormal, or less than, or sometimes even unintelligent. Here's Bravin again through an interpreter.

BRAVIN: Every parent wants one thing -- they want my child to be normal, that's what they want. That's what every parent wants. It doesn't matter, hearing, deaf, it makes no difference. When that child is born, they just are hoping that their child would be normal, if not, I'll do anything and everything to fix my child, this is very normal for any parent ...

DESROCHES: Elizabeth Cole also understands the tension between the two schools of thought. But unlike Bravin, she promotes the spoken language path for deaf kids. Cole was the director of CREC Soundbridge, a spoken- language program that we'll visit later. She's since retired. She says the bottom line is this: no matter what choice parents make -- speaking or signing -- it's going to be hard.

COLE: It's not such a simple thing, because when parents are making decisions, what you really start off talking about [is] babies. If you choose spoken language than one of the things you need to do is keep the equipment on and talk to the child a lot, about a lot of stuff, all the time, and it's very tiring and it's not an easy process. But if you choose sign language, then you need to get really fluent in sign language very fast, because you want to immerse your child in an appropriate, correct language model.

DESROCHES: That equipment she mentioned? She's talking about hearing aids and cochlear implants, which are devices that convert sound waves into electrical impulses. Cole's right -- it takes a long time for an adult to learn a new language. Even if you study 20 hours a week, it could still take over *two years* to become fluent. But Jeff Bravin says the deeper problem is one of perceptions. Oral programs, he says, try to sell their philosophy on the idea that they can make your deaf child normal. Here's Bravin through his interpreter again.

BRAVIN: That's their belief, and that's OK... My belief is that every child here is normal because they have full language access right here. And I can prove it. I'm living proof.

DESROCHES: Cole counters that we live in a speaking world, so kids will have more opportunities if they learn to talk and listen.

COLE: The vast majority of children really do have the potential to learn spoken language through listening.

DESROCHES: Both Bravin and Cole say they respect a parent's right to choose their child's communication mode. But when it comes to which program they think is best? Their allegiances are clear -- as is their mutual skepticism of the other's approach.

[BREAK]

DESROCHES: Something happened over two decades ago that shook the signing deaf community to its core.

TV SPOT: Kelly was born deaf, even hearing aids were of no use. But now thanks to a surgical device called the cochlear implant, a whole new world has opened up to her.

DESROCHES: When cochlear implants were approved for use in children, signers worried that their language and their culture would slowly die. They thought that parents would choose speaking over signing if they believed their children would be able to hear.

MEDICAL SCHOOL AD: She dreamed of a career in medicine, but it's hard to listen to dreams when all you hear is silence.

DESROCHES: Not long after children began being implanted, research into deaf education matters plummeted, one study found. Fears got so bad that some people tried to define deafness as an ethnicity, so signers would have the same civil rights as ethnic groups. Others sought to establish a constitutional right to language to protect signing. Today, the rate of cochlear implant-use is growing, and the tech is advancing. But, it's certainly not perfect.

[SCENE: Cochlear implant mapping session at CREC Soundbridge]

ERICA NAIR: Mrs. White thinks it will be good to start with the right ear...

DESROCHES: Erika Nair is an audiologist at CREC Soundbridge, where we are today. Mrs. White is Meagan White, a teacher of the deaf in Greenwich.

NAIR: Jamie, while you're doing that, i'm going to read the information from your right processor, will you pass that to me?

JAMIE: Sure.

DESROCHES: Nine-year-old Jamie McGovern is here to get her cochlear implant tweaked. Her device works by sending different sound frequencies to her brain at different volumes, but sometimes the sounds are uneven, or too soft or loud. Here's Meagan White explaining what they're doing today.

WHITE: So what Erika's gonna do, is produce some beeps from the computer and Jamie practices counting them out so that she's able to report back how many she's hearing.

DESROCHES: They're essentially mapping out the sounds. They're sending beeps at various frequencies into Jamie's implant, and seeing which frequencies need to be raised or lowered.

NAIR [TO WHITE]: That went down a little, so I'm gonna go back up.

DESROCHES: Cochlear implants are usually used only if a hearing aid doesn't work. Here's an approximation of what words sounds like to a cochlear implant user, thanks to Arizona State University. You'll first hear the sound input, then you'll hear what it sounds like.

VOICE: Don't live beyond your means.

SIMULATED COCHLEAR IMPLANT VOICE: Don't live beyond your means.

VOICE 2: That was an unexpected outcome.

SIMULATED COCHLEAR IMPLANT VOICE 2: That was an unexpected outcome.

DESROCHES: These mapping sessions happen as often as needed, to make sure everything works. In Jamie's case, sounds have been really loud lately, and she's been taking the outer part of the implant off to silence it.

JAMIE: It's just because everything was so loud a lot, and, including the water in Michigan, and the boats.

LEAH THORNTON: It's true, we were in places that had different sounds, different kinds of white noise...

DESROCHES: Jamie's mom, Leah Thornton.

THORNTON: Lots of traffic and train traffic at my mom's. So a lot of controlling her auditory input by pulling down.

DESROCHES: So today, audiologist Erika Nair is trying to fix it so Jamie doesn't get overwhelmed by sounds.

NAIR: Cause you're just checking -- Is this device working the way I want it to or the way that it should be?... Two? OK. Meagan, i'm gonna move to another pitch.

[END SCENE]

DESROCHES: Remember Corinne and Ryan Walters? They've been exploring the signing approach and the oral method for their son, Jackson. And then they also visited a cochlear implant mapping session like the one we just heard. They wanted to know what's involved over the long-term, if they decided to implant their son. They also met other parents and kids with implants.

WALTERS: They weren't all poster children, some of them were not speaking well.

DESROCHES: They continued to be pulled in every direction. But meeting others like them, was huge.

WALTERS: You have these directors of these schools trying to sell you their school, and they're going to tell you why this is good and this is bad. But talking to the parents and seeing the kids who had already gone through it all definitely helped me the most.

DESROCHES: The kids who find the most success with cochlear implants are usually implanted very young, and get constant support at home. But sometimes, kids with cochlear implants struggle, and it's hard to know why. To find out more about these struggles, I went back to CREC Soundbridge to visit a classroom during summer school.

[SCENE: CREC Soundbridge summer school]

DESROCHES [TO CLASS]: I'm with a local radio station and we are working on a story about education programs for deaf and hard of hearing students around Connecticut.

ELIZABETH COLE: Did you hear what he said?

STUDENT: No.

DESROCHES: The students are 12, 13 and 14. That adult's voice is Elizabeth Cole, Soundbridge's director at the time. We heard from her earlier.

COLE: You want to tell him what we learned today?

STUDENT: We learned about, um, um, the states, the United States, and, we talked about like 38 states, now we have like, how many 13 more [unintelligible].

COLE: Twelve more.

DESROCHES: Learning about the 50 states is usually something for younger kids. But these students are pretty far behind. They each need to speak into a microphone to be heard by the others. It broadcasts each voice through an FM signal directly to the the other students' cochlear implants and hearing aids. There's only one microphone, so they have to share.

COLE: Why don't you tell them what you presented today, you presented a full state today,

STUDENT: Three...

COLE: Yeah, number three, which one was it, do you remember which state you presented?

STUDENT: Oh yes, I do...

COLE: New Jersey. Yeah. What about New Jersey was special to you?

STUDENT: New Jersey have...

DESROCHES: Speaking into the mic, the student explains what he likes about the Garden State. The other students fidget as they listen -- he's hard to understand. He talks for about a minute before Cole jumps in.

COLE: Atlantic City, that's a hard one.

DESROCHES: Cole and the teachers do a lot of clarifying. They make sure each student is speaking into the microphone. They are always making sure the students hear what was said. In a later interview, Cole points out that these students are not typical cochlear implant users. They have additional disabilities that make it hard for them to acquire spoken language. But I ask her if they can't access language, how can they learn other things?

COLE: It means they need longer, longer time, and longer exposure. I mean, by the time they're 18, they may still need to have like a fifth-year program, or whatever... Many of them test out at really high levels on, uh, nonverbal skills. So there's been no negative effect there. But many of the IQ tests are so heavily-based on verbal skills, that they wouldn't test as well as somebody else, and there's a big discrepancy there. But what we try to do it build up that language base so that there isn't as much of a discrepancy.

DESROCHES: Cole said that most kids who struggle with spoken language might have started out signing, but their parents decided later to teach them to talk and listen.

COLE: They often also have additional disabilities of all kinds. So, would those kids be better learning sign language than English? Who's, you know... It's parent decision, I can't decide for them what thing they ought to be doing.

DESROCHES: But where do those other disabilities come from? They could be the result of not having access to language, or they might be something else -- something genetic, for example. The hard part is that it's really hard to know. Cole says it's difficult to figure out when something isn't working. Like, if a student is not making enough progress with spoken language and should switch to sign language. Or vice versa.

COLE: I can't say, OK, age 3, we decide definitely one way or the other. Because sometimes the children are a bit behind, but with more time they can catch up and be on age level at age three.

DESROCHES: But that's what school districts often tell parents of kids with disabilities -- give it some time, your kid will catch up. But sometimes that time, that delay, actually hurts the child.

COLE: And sometimes it doesn't.

DESROCHES: So how do you know?

COLE: Who knows! There's no magic on this, you know.

DESROCHES: Even though the class we visited was full of students who seemed years behind, Cole says most of her students are doing OK.

COLE: Ninety-three, or five percent of our kids, are doing well enough that all they need is relatively minor support. And they're doing well enough in the sense that they're within a grade level of their grade peers, and they have friends, they're involved in their communities and so on. So it's the minority that you're really focusing on with these kids, well, what if they don't make it, kind of thing. And there are kids like that, there are.

[END SCENE]

DESROCHES: Jeff Bravin, head of the American School for the Deaf, knows this scenario, too. A teenager comes to his school. The teen has almost no language skills. In fact, by Bravin's own account, nearly two-thirds of his high school students come to him after years of failing in traditional schools, which mostly focus on speaking and listening. Soundbridge's Cole says the same thing except she says her kids are delayed from speaking because they've been focused on signing. So if experts can't agree on the best approach, how are parents supposed to figure it out. When we come back from our break - we'll find out what Corrine and Ryan Walters decided for their child. Stay with us.

[END PART TWO]

DESROCHES: This is Making Sense, a documentary about deafness by Connecticut Public Radio. I'm David DesRoches. Corrine and Ryan Walters had to sift through conflicting information about what would be best for their son after they learned he was deaf.

WALTERS: It was such a learning experience. And so fast, and so confusing, and so scary. I thank god for Google, because I don't know how people did it before...

DESROCHES: And eventually -- after spending time at the American School for the deaf and CREC Soundbridge, after a lot of time searching google [and reading parent forums], they made a decision.

WALTERS: Our thinking back then was: If we have the chance to do cochlear implants and at some point he can hear something, and he chooses later in life, 'I'm deaf, I want to sign,' he can just take them off and he can sign.

DESROCHES: Jackson would get cochlear implants and learn to speak. Corinne and Ryan enrolled him at CREC Soundbridge. But they wouldn't be able to talk to their son for an entire year while waiting for the implants.

WALTERS: So, in my head, I'm like, 'I have to wait a year with this kid having no language,' and that was stressful to me, so...

DESROCHES: She chose to ignore Soundbridge's recommendation and signed with her son. Contrary to what she was told, Jackson's signing didn't make it harder for him to learn to talk.

WALTERS: I'm glad I still signed, even though they said not to...

DESROCHES: Which can be helpful for their daily routine.

WALTERS: He knows enough sign language where without his ears on, we can have a conversation.

DESROCHES: The ears she mentioned is the part of the device that's worn outside the actual ear, and can be taken off. Corinne and Ryan now have two sons. Their youngest, Chase, is also deaf. Genetic testing showed that both Ryan and Corinne carry a recessive gene for deafness. As for their sons' ears -- it's a constant and expensive process of processor upgrades, battery changes, and audiologist appointments. But for families like the Walters -- the ultimate challenge is balancing the hearing and deaf worlds.

WALTERS: Yes, they're deaf and we want them to know that and we want them to have Deaf culture knowledge and we want them to know a little sign language just in case, god forbid, something ever happened... But they're hearing and they're living in a hearing world just fine with these.

DESROCHES: She also knows she's lucky. In fact, if you step back and think about what deafness looks like globally -- *all* the families in this story are lucky. Cochlear implants are expensive. Often it's only the well-insured or wealthy who can afford them. So, it's a privilege. But it's also a privilege to have the time to learn sign language as an adult, which parents have to do if they want their kid to sign. Globally, most of the world's deaf population lacks any structured language -- visual or oral. It's estimated that 80 percent of the world's deaf population -- some 56 million people -- has no formal access to education or language.

DESROCHES: In short, deafness is a complex and charged topic globally, and locally. There's no silver bullet answer that will make everyone happy. People can't even agree on what the actual problems are, or if deafness is a medical condition, a culture, or something else completely. The one thing most people in this field agree on? It takes a lot of work to raise a deaf child. Jeff Bravin from the American School for the Deaf says the key is strong parent support. Here he is speaking through an interpreter.

BRAVIN: Any child -- hearing or deaf, doesn't matter -- will succeed only if the parents are involved. Many hearing children do not function well in a public school. The answer is simple: their parents weren't involved. The same is true for deaf children... Academic language doesn't only come from school instruction, it comes from parent involvement as well, and there are many children -- because parents are not involved in children's lives or in their instruction -- the children fail. I've seen children, even struggling in school, but because the parents are so involved and so invested the child does well. The bottom line is how much the parents are involved in their children's upbringing and educational career.

DESROCHES: Basically, parents need to be all in when it comes to raising their deaf child. Even if they were language experts, like Diane Lilo-Martin, from the University of Connecticut, they wouldn't have all the right answers. Lilo-Martin says there's a lot we don't know about language development. For example, we don't know how much time it takes a child to learn sign language and spoken language at the same time.

DIANE LILLO-MARTIN: It's actually a very complicated question. When people have studied this question with bilinguals who are using two spoken languages, there's some evidence about how much time is needed in each language. But we don't know the first thing about the answer to that question yet for people who are becoming bimodal bilinguals. We don't know how much time they need on each language.

DESROCHES: Bimodal bilinguals. Those are people who speak two languages in two different modalities. -- like ASL is one language modality, and speaking and listening is another. Lilo Martin says one thing is clear. A child needs constant input to learn any language, and constant input from two languages if they want their kid to be bilingual.

LILLO-MARTIN: It's different of course for the deaf children, because even with the hearing technology their access to spoken language is not natural, they need to have training in order to learn the spoken language. And it's quite possible that their access to the sign language will be different because their parents don't know sign language, and the way that they get access to it is through others as well as their parents learning it at the same time.

DESROCHES: Deanna and Kurt Gagne were faced with the same decision as the Walters when their daughter Logan was born. But *their* experiences led them down a *different* path. Speaking through an interpreter, Kurt says he struggled growing up as a deaf child, and wanted something better for his daughter.

KURT GAGNE: When I was young, my parents didn't realize that I didn't hear until I was about 18 months old. But as soon as they realized that, they had me placed in a school for the deaf where I learned American Sign Language, and I was there until I was about 11 years old, at which point I transitioned to a public school with interpreters. Again that was about finding a education that suited me.

DESROCHES: I asked him what it was like when he found out his daughter was deaf. Kurt pauses, thinking about the question.

GAGNE: So, I mean, mixed feelings, to some extent, because, um. For one, I didn't want her to have a negative experience in school the way I did when I was younger. That was my major concern.

DEANA GAGNE: There's a point of pride too, like, wow you know. I have somebody like me, right?

DESROCHES: When Kurt was born, it wasn't required for newborns to be screened for hearing loss like it is today. In Kurt's case, his parents didn't figure out he was deaf until a neighbor had come over and was playing with him on the floor. He clapped and made other sounds, but Kurt didn't respond. His mom's first reaction was typical - that something was *wrong*. It's a common response because most people can hear, so, *not* being able to hear -- being deaf -- is *abnormal*. Or, something that should be fixed. But when Kurt's youngest child was born deaf, he and his wife Deanna saw things differently. Sure, *something* was wrong, but... it wasn't with Logan.

DEANNA GAGNE: For me, her deafness is not a barrier for her. What's a barrier for her are people. And the people around us, and the way that people would view her, is the part that, was, that I grieved over. Because she's a beautiful baby, and she's very smart, and I can tell, she's already paying attention to her world, and to people, and to signs. And so there's no concern in any of those realms. It's about the way people react when they learn that she's deaf.

DESROCHES: On the one hand, Logan will share a language connection with her father and two of her grandparents. But like other deaf people, she'll also likely spend a lot of time in the hearing world, which sends her the message that her deafness is a disability that should be cured. One thing's certain for Kurt and Deanna. Logan won't be getting cochlear implants. At least not until she decides that for herself. Here's Kurt through an interpreter.

KURT GAGNE: When she's older and she goes to school and she sees other kids with hearing aids, if she comes home one day and says, 'You know, I'd really like to get hearing aids, because everybody else has them. I'm curious what sound is like, I'd like to see how that goes.' You know, we'll address it at that point. And if that's what she wants to do, that's gonna be fine with us.

DESROCHES: So much attention is paid to making the big communication decision early, that it's easy to forget this is an ongoing process. Kids develop differently, and parents shouldn't be afraid to adapt if something's not working. It's what parent-advocate Lisa Kovacs stresses to parents with newborn deaf babies -- don't be afraid to change.

KOVACS: We found when my son was approaching age three and his language was significantly delayed, that this was not a good fit for him. And honestly we waited too long, if only I would have known what we know today.

DESROCHES: Lisa now works for an organization called Hands and Voices. They support families with deaf and hard of hearing children, regardless of which communication mode they choose.

KOVACS: And so we changed course, and we tried something different. All I can say it's how he was wired, and it was a great fit for him.

DESROCHES: She told that story once at a training session, and another parent laughed.

KOVACS: Her experience was completely the opposite. And they ended up with what worked for their child is what we initially tried. So it just goes to show the uniqueness of every family and child.

DESROCHES: Lisa says some families pick speaking or signing and stick with it, because it works. The key, she says, is evaluating your child's progress and remembering that language is only one aspect of your child's wellbeing.

KOVACS: My son's almost 19 years old. And he's so much more than what language or modality he chooses now. When I think of Anthony -- he's engaged, he's happy, he's a contributing member of his family and the community that we live in. This is the goal, you know? He's engaged in his community, he's got friends, he's doing everything that we dreamed that he would do. So the path of getting there may look different from family to family, and child to child,

but our shared vision for all deaf or hard of hearing children should be that they are gonna reach their potential, and that they're leading happy and fulfilled lives no matter what that language or communication mode is that they choose to focus on.

DESROCHES: Like the Walters and the Gagnes, Rachel and Mick Posner were also faced with choices when their kids were born with hearing losses. They both grew up deaf in hearing families -- Mick's from Long Island and learned to sign, and Rachel grew up in Connecticut speaking. So their different experiences helped shape their decision to use *both* modes of communication with their children Faith and Henry.

DESROCHES: Growing up in Waterbury, Rachel's family chose for her to live in the hearing world. It took a lot of effort but she was for the most part content. But inevitably she was confronted by a different world. In 11th grade, she'd taken a job at a roller skating rink running the food counter. The music was always loud, so her lip-reading skills came in handy. She was working her usual shift when a customer saw Rachel's hearing aid, and immediately started signing.

RACHEL POSNER: All I could see was her hands flying, and I was like, 'whoa, whoa, I don't know any sign... But that made me feel bad, because it woke up a part of me, like, 'wait a minute, I should know sign', you know what I mean?

DESROCHES: Her senior year of high school, she left her friends at public school and enrolled at the American School for the Deaf so she could learn ASL. She threw herself into deaf culture, but she wasn't fully accepted. She found herself not belonging in either world - too oral to be deaf and too deaf to be oral. She eventually ended up at Gallaudet University, known as the world's first college for the deaf. That's where she met her husband, Mick. Together they have two bilingual deaf children. Faith has a hearing aid in both ears and Henry has one. They can both speak and sign. Rachel says she wants her children to have exposure to both worlds, and both cultures. It's about having a balance. But her daughter, Faith, has struggled with that balance. One time she was in a store signing with her mom and she saw a classmate from school and became embarrassed.

POSNER: I asked Faith, I said, 'What's the problem?' And she said, 'I have my hearing life at school and my deaf life at home, and I don't like to mix them both.'

DESROCHES: It upset Rachel. She wanted her daughter to take pride in her deafness, and own it. Rachel later called Faith's teacher-of-the-deaf -- the person assigned to help deaf or hard of hearing students in public schools. Rachel asked if Faith could lead the class in a sign language lesson. Faith's birthday party was coming up and the whole class had been invited, along with people from the Deaf community. Rachel wanted the class to be familiar with the language, and the culture. So Faith taught her class some ASL, and soon enough the birthday comes along, and everyone showed up. Here's Faith talking about the theme of the party, which was based on an emoji that, well, just listen...

POSNER: Ok you can tell him.

FAITH POSNER: When she went to bring me like these brownie cupcakes, my birthday party was emoji, so she brought, like, poop cupcakes.

RACHEL: Of course you had to mention that.

FAITH: Yes, of course I did, that was a big detail.

RACHEL: Ok, go ahead.

FAITH: When it was time to sing happy birthday, they started signing!

RACHEL: I'm like, Happy Birthd... everybody was signing. I'm like, 'This is awesome! This is so great!

DESROCHES [TO FAITH]: When they signed happy birthday to you, what did it feel like?

FAITH: Oh my God, it was like the best day ever. Cuz they were all just like signing awesomely. It was just so weird, because like a week before I taught them how to sign. And they must have been practicing at home or something, because they were like, pros.

DESROCHES: So you don't get embarrassed by sign language any more, you think?

FAITH: No, no I don't. That kind of like just taught me, that all I have to do is just like, let people know, and that it'll be really cool, and the effects of that little experiment worked out really, really well.

RACHEL: If you own it, then nobody can discredit you.

DESROCHES: That was two years ago. The experience opened Faith's eyes. Since then, she's been teaching her classmates ASL, and inviting her hearing friends to the deaf club at school, where they learn about her world and her culture. Rachel says that Faith accepts her deafness, and has genuine confidence. Why? Because she chooses how she wants to communicate.

DESROCHES: Making Sense is a special production by Connecticut Public Radio. Gwen Everett helped with production and research. Special thanks to Jeff Cohen, Catie Talarski, John Dankosky, Harriet Jones, Diane Orson, and Ryan Caron King. Go to [wnpr-dot-org slash Making Sense](http://wnpr-dot-org/slash/Making%20Sense) to see videos of interviews in ASL, as well as more information and links. Do you have a story to share about the choices you made for your family? Find us on Facebook and Twitter and leave us a message. I'm David DesRoches, thanks for listening.