

TEASE  
FRIENDLY GENES  
BREAKING THE SHELL  
EACH SOUND IS A PRESENT  
FINDING HER VOICE  
TEASE

ALAN ALDA The kids at this picnic are growing up in a world that's very different from the one most of us experience.

ALAN ALDA (NARRATION)

ALAN ALDA I'm Alan Alda. Join me as Scientific American Frontiers enters the worlds of children who are "Growing Up Different."

FRIENDLY GENES

ALAN ALDA As kids, we're all of us convinced that we're different from the other kids. And of course, we are. A lot of our time as kids is trying to figure out what everybody else is doing and thinking and why, and you know, it's tough. Perhaps the toughest part of being a kid. And it takes years and years, sometimes a lifetime of practice. But for some kids, this struggle to understand the world is even tougher. That's because the difference that they're born with is so profound, that the world is more baffling than usual. In this program, we spend some time with children who are growing up different and with some of the researchers who are trying to understand why they see the world the way they do. We'll see how the insights that these researchers are achieving are not only helping the kids who are different make sense of the rest of us, but they're also helping the rest of us understand what it means to be human.

ALAN ALDA (NARRATION) We're at a picnic in La Jolla, California. At first glance the kids here are like most kids -- certainly they're high-spirited enough. But they are all linked by possessing a rare genetic disorder called Williams Syndrome.

ALAN ALDA Hello. Are you Scott? How are you?

SCOTT I'm Scott. Alan Alda. So nice to see you.

ALAN ALDA Nice to meet you.

SCOTT You were the best in MASH, I'll tell ya that. You were the best doctor in MASH I've ever seen.

ALAN ALDA (NARRATION) Scott and Steve are 39-year old identical twins, both with Williams Syndrome...

ALAN Is this Ursula?

SCOTT Yes.

STEVEN Yes.

ALAN ALDA How are you?

ALAN ALDA (NARRATION) ...while Ursula Bellugi is one of Scott and Steve's greatest fans.

URSULA Yes, this is a special occasion.

ALAN ALDA Yes. Who's this?

ALAN ALDA (NARRATION) Ursula is one of a growing number of scientists fascinated by the extraordinary contradictions of Williams Syndrome.

BETSY Hi Mr. Alda. I'm Betsy and I'm very very glad that you're here and that you could spend some time with us here today. Thank you so much for coming.

ALAN ALDA Thank you. I'm glad to be here. Hi, we met a second ago. How are you?

JUSTIN Good.

ALAN ALDA What's your name?

JUSTIN I'm Justin.

ALAN ALDA Justin, glad to meet you.

ALAN ALDA (NARRATION) Only one in 25,000 children is born with Williams Syndrome. It's most characteristic physical feature is an appealing, elfin face. On a social occasion like this, kids with Williams Syndrome are in their element.

ALAN ALDA Hi. We didn't meet.

KIRSTEN Hi, I'm Kirsten.

ALAN ALDA How do you do? Great to meet you. I'm Alan. Great to meet you.

SHANNON I'm Shannon.

ALAN How are you, Shannon?

SHANNON I've been wanting to meet you a really long time.

ALAN ALDA Something that's so clear, meeting these kids here today, is how affectionate they are. That seems to be a typical personality attribute of these kids. Am I right about that?

URSULA Yes. I would say it's affectionate. It's interested in people. It's highly sociable. It's gravitating toward people. That's their thing in life. So...it's...I think affectionate and sociable.

SCOTT Growing up different with Williams Syndrome you find that you have a lot of good times and some bad times. And the main thing is that there are people that will take good care of you. But me and my brother, we didn't find out until much later that we had Williams Syndrome.

STEVE Hi everybody.

CLOWN Would you like to help us stir this up? Okay, come on over Mr. Alda.

ALAN ALDA Hi.

ALAN ALDA (NARRATION) When Scott and Steve were diagnosed back in the early 1980s, they were among only 60 identified cases of Williams Syndrome in the country. It was then that Ursula Bellugi began her studies here at the Salk Institute. The first goal of her research team was to build up a better picture of the strengths and weaknesses of people with Williams -- whose social skills mask an often profound mental retardation

NASIM BAVAR I'm going to ask you some questions that I'd like you to answer. Justin, can you tell me how many months there are in a year?

JUSTIN There's 24 months in a year.

NASIM BAVAR Okay, good job. How old is the oldest woman on Earth?

JUSTIN I don't know. Probably fifty. I don't know.

NASIM BAVAR How much does a compact car cost?

JUSTIN A compact car?

ALAN ALDA (NARRATION) Cars, by the way, are a favorite topic of Justin's.

JUSTIN I'd say, like \$24,000. \$24,000 actually.

NASIM BAVAR What's the average salary per year for a doctor?

JUSTIN Um...I would say eight to forty-five. I'd say eight dollars and forty-five cents.

NASIM BAVAR Per year?

JUSTIN Yes. Per year.

TERESA DOYLE How many blocks do you have, Barry?

BARRY One, two, three, four, five, six, seven, eight.

TERESA DOYLE You know what? You need another block.

BARRY Nine.

TERESA DOYLE Okay, make your blocks look just like mine.

BARRY This is the easiest one.

ALAN ALDA (NARRATION) Perhaps the most striking problem for people with Williams is performing visual-spatial tasks. They can get the details right, without seeing the overall picture.

TERESA DOYLE Do your blocks look just like mine?

BARRY Yes.

URSULA How about-draw me a bicycle. Do you want to do that?

SHANNON Certainly. I just drew my face. I made sure it was a ten-speed and it had brakes.

FRED ROSE I've got two lines at the top here.

BETSY U-huh.

FRED ROSE And there's an array of lines down below. I want you to pick out the two lines down here that are pointing in the same direction as those two at the top.

BETSY Three...and there is one.

ALAN ALDA (NARRATION) In contrast to Betsy's problems with lines, she has little trouble with a task matching faces.

FRED ROSE And I want you to pick out the three faces down here that are exactly like this one.

BETSY That one. OK. That one. That one.

ALAN ALDA (NARRATION) The most intriguing aspect of this face recognition skill was uncovered with the help of a little hat.

ALAN ALDA I think this is the sixth or seventh time I've had electrodes attached to my head.

DEBRA MILLS Do you want more?

ALAN ALDA I'm really getting into it.

ALAN ALDA (NARRATION) The hat houses an array of electrodes to pick up electrical signals from the brain.

DEBRA MILLS You'll be seeing a series of faces. You'll be seeing pairs of faces. You'll see one face and it'll go off, then you'll see a second face. And your job is to decide whether that second face is the same person or a different person from the first face.

ALAN ALDA (NARRATION) It turns out that when a non-Williams person like me first sees a face, there's a spike of activity over the right front of the brain -- where there's a region that specializes in face recognition. But when a Williams brain sees a face, this spike is absent. Instead there's a much bigger, slightly later surge of activity that seems to involve much more of the brain.

DEBRA MILLS It's like the brain is using as much brain tissue as it can to try to solve this problem. So it's organized in a different way.

ALAN ALDA (NARRATION) It's almost as if faces are so important to people with Williams Syndrome that their brains throw everything they can into recognizing them. The Williams Syndrome research project has little trouble finding eager volunteers.

SHANNON It's a lot of fun now. And I know I can help others that might have it. Williams Syndrome.

SCOTT And help the scientists and people who work so diligently for people with Williams Syndrome to find out why this occurs and further the studies.

ALAN ALDA And have you learned anything from these tests? Tracking your brain waves. Have you thought about the way you think?

SCOTT Yes and no. But mostly, mostly I enjoy life now. I used to not really enjoy things as much as I do now because I've been walking in my shoes with Williams Syndrome and it's been hard for me to find people to...people who are able to accept the situation and be able to accept people who are walking around different. Of course, I haven't had acupuncture in a long time!

ALAN ALDA (NARRATION) The biggest breakthrough into why people like Scott are different came when the genetic basis of Williams Syndrome was discovered.

JUSTIN'S MOM When we first came to the Salk, we knew nothing about Williams Syndrome. Nothing about what caused it.

URSULA Nobody knew anything.

JUSTIN'S MOM And nobody knew anything. In such a short time, I'll never forget the day Ursula laid down on the table in front of me. She put a picture of the gene, the chromosome with the gene marked on it and said "there it is, that's what caused it." And I just cried.

URSULA She wept.

JUSTIN'S MOM I just cried. In such a short time, for science to go from telling parents, "Your child has Williams Syndrome, that's all we know." To being able to say, "Here's the cause of it."

ALAN ALDA (NARRATION) The cause is literally visible under a microscope. When stained with a fluorescent dye, the chromosomes of a normal cell show a bright band in the middle of both copies of chromosome 7. In the cell of a person with Williams Syndrome, only one copy of the chromosome has this band. The missing chunk contains only about 25 genes. So scientists are hoping to be able

to trace not only the disabilities of people with Williams Syndrome but also some of their special strengths directly back to just a handful of genes.

ALAN ALDA I mean, are you going to find out there's a gene for compassion?

URSULA Let's call it sociability and...god damn it, we might.

ALAN ALDA You what?

URSULA We might. We might.

ALAN ALDA You might?

URSULA Yes.

ALAN ALDA You think you might actually be able to...?

URSULA Well, in this case.

ALAN ALDA That would be amazing.

URSULA Yeah, it would be, wouldn't it? I think that's sort of the hunt we're on. And I think that's a possibility.

ALAN ALDA So you're actually by studying carefully what the roots of Williams Syndrome are, you're actually finding out what the roots of qualities that all of us have are, huh?

URSULA That's absolutely...

ALAN ALDA I mean, you're beginning to track down how we are who we are.

URSULA I think that's put very very well and that is true and the added fascination that we've got is that we can understand so much more how the brain does it. And how you can get in unusual ways to these strong qualities.

ALAN ALDA Why is the keyboard here? Does somebody play? Do you play?

BETSY I play. All of us do. JORDAN We take turns.

ALAN ALDA (NARRATION) One quality that seems to be possessed by many people with Williams Syndrome is a talent for music.

ALAN ALDA Why don't you make up a song for us? I think that will be great.

BETSY Okay. BARRY That's what I do. I do it like that. BETSY (singing) Alan

Alda, you're a very nice guy. You're kind and caring and I can't tell a lie. You're so interested in all that we do. It is so good to have a guy like you in this world. You are part of our family. You care about us as all of us can see. It's really great when you want to know about our favorite kinds of music or where we like to go when we're together. Thanks for coming, I'm glad that you are here. And since you are so interested in us, we hold you dear in our hearts and lives. Thanks for all you do. Thanks for caring for different people in this world. It's wonderful, just like you.

ALAN ALDA Great.

ALAN ALDA What do you hope to know? Where do you hope to get with this?

URSULA Alan, I'm going beyond my wildest dreams.

ALAN ALDA You've already gone beyond your wildest dreams.

URSULA By trying to link up an aspect of gene to brain development and higher cognitive functions. I don't hope for anything more than that.

BREAKING THE SHELL

ALAN ALDA (NARRATION) Tariq is two and a half years old. He was diagnosed with autism 6 months ago. His parents and I are sitting with him in a therapy room at the University of Washington in Seattle. Since Tariq was diagnosed he's been receiving regular therapy aimed at helping him break out of the mysterious and often impenetrable shell that seems to surround people with autism, cutting them off from the social world. DAD Two or three months ago you couldn't redirect him. You couldn't say, "Throw the ball to your sister. Now kick the ball to, you know, whatever. Now stop biting the dog or something like that."

ALAN ALDA How long every day do you work with him? DAD We're planning up to forty hours a week of home-based therapy.

MOM Right now we do about fifteen hours of one-on-one with a tutor, three hours here, and on top of that we do the occupational therapy and the physical therapy once a week for an hour. We do speech therapy for two hours. DAD And then he gets tired and he sort of withdraws from us a little bit and he does his own thing and he did his homework and he's darn well gonna be in his own world right now and that's it. Right? Sort of what he's doing right now. I think he's ticked off, he's tired.

ALAN ALDA (NARRATION) Autism is frighteningly common, affecting as many as one in every seven or eight hundred children born. Many but by no means all

of these children are mentally retarded. Some develop language, others never do.

ALAN ALDA There seems to be such a wide range of symptoms. Are they all along this autism spectrum because they have a common cause? Because they're related to the same part of the brain? Or what? What links them together?

GERALDINE DAWSON Well, the key feature that links them together is the difficulties in social relationships. So even the highest functional person may have an I.Q. above average and really good language may be out in the work world with a regular job. They would still have that very fundamental problem in relating to other people.

ALAN ALDA (NARRATION) Geraldine Dawson's own research is focused on just why autistic children find it hard to relate to other people. Six-year old Alex has autism -- and to win his cooperation the researchers have to employ patience, guile and fun rewards. ASSISTANT You got it! LESLIE Ready to put on this silly hat with all this hair on it, Alex?

ALAN ALDA (NARRATION) The hat is similar to the one we saw used in the Williams Syndrome research -- and like that study the plan here is to monitor the electrical activity of Alex's brain as he looks at faces.

ALAN ALDA Is each one of these EEG signals associated with a part of Alex's brain?

GERALDINE DAWSON Well, each one of these signals is one of those electrodes that you saw being put on his scalp.

ALAN ALDA (NARRATION) The signals from Alex's brain are recorded and processed as he looks at pictures of his mother's face or that of a stranger. In a normal child, the brain's response to the two would be very different. But Alex's brain responds to both his mother's face and that of the stranger as if they are the same. When it comes to faces, his brain is literally indifferent.

GERALDINE DAWSON In normal development, the brain is naturally wired to draw our attention to faces. And you think about a young baby, even a newborn will prefer to look at a face as compared to another complex object. So there's something wired into our brain that naturally draws our attention to the social world. So we think that tells us that that mechanism which naturally draws our attention is not working properly. If you're not paying attention to social information, how are you ever going to learn to develop socially?

BONNIE Whoa. Oh, nice looking at me now. And you're smiling....

ALAN ALDA (NARRATION) In Tariq's therapy sessions, Bonnie spends a lot of time trying to get him to look at her and respond, hoping to instill in Tariq through endless repetition a facility most children are born with.

GERALDINE DAWSON One of the things that we're understanding is that the parts of the brain that are probably involved in autism are ones that come online really early in life in the first and second year. So what we want to do is to pick up kids, really hopefully by birth, but right now we're at about 12 to 18 months. And we try to stimulate those brain systems while they're still developing and plastic, in hopes that the children will then kind of grow out of their autism or at least be less affected.

BONNIE Oh, you picked dot art. Good choice.

ALAN ALDA (NARRATION) So the earlier autism can be spotted the better. One early warning sign, which goes along with an indifference to faces, is the lack of a special form of eye contact.

GERALDINE DAWSON We tend to look at people at very specific moments. So, for example, when I want to communicate with you, I'll check in visually, and then I'll point to something, then check back. This is called joint attention. And it actually turns out to be the most significant diagnostic sign of autism. So it's not just the sheer amount of eye contact, but it's really how he combines eye contact with communication.

ALAN ALDA (NARRATION) Two year old Kendall has great eye contact.

ALAN ALDA Right in the cup. You want to do it?

ALAN ALDA (NARRATION) She's a healthy, normal little girl who's here to help psychologist Andy Meltzoff give me a lesson in the importance of imitation.

ALAN ALDA Ah, good.

ANDREW MELTZOFF Kendall, watch this. I bet Alan doesn't even know what we can do with this. Watch this. Isn't that funny? Kendall want a turn?

ALAN ALDA Whoa. Very good.

ANDREW MELTZOFF Typically developing children are like sponges. Adult in front of them just behave and the baby watches wide-eyed and does what they do. They become little adults in the culture from watching the adult.

ALAN ALDA Good pop.

ANDREW MELTZOFF You want Uncle Alan to try that?

ALAN ALDA (NARRATION) Four-year old Mia is another great imitator.

ALAN ALDA You want to try it?

ANDREW MELTZOFF Now that's imitation.

ALAN ALDA Yeah.

ANDREW MELTZOFF That's imitation.

ALAN ALDA (NARRATION) Andy Meltzoff has done the same experiment with autistic children.

ANDREW MELTZOFF Now you remember this toy?

ALAN ALDA (NARRATION) This child seems social enough and intrigued by the cup -- but he isn't collapsing it as Kendall did.

ALAN ALDA If you just walked in on the room and you were looking for eye contact you'd think, oh, he's relating normally. But if you're looking for imitation, you won't get it.

ANDREW MELTZOFF Exactly. I think imitation is a higher art of activity than simply eye contact. So some children with autism can make eye contact. But what they seem to have a profound deficit in, is doing these simple imitation games which seems to be relating to another person from the inside at a deeper level. It's this drive to want to relate to you as a person. To be like you. They don't seem to have that impulse.

ALAN ALDA (NARRATION) Andy Meltzoff thinks this failure to imitate other people is yet another useful early warning sign of autism. But he also believes it may be at the root of many of the later problems people with autism struggle with -- a failure to see other people as beings like them.

GERALDINE DAWSON So one of the first things you do in any kind of early intervention program is teach a child how to imitate. And there's lots of different ways to do that. What you may have seen with Tariq is, she was imitating some of his behavior, just so he starts to look at the correspondence between what he's doing and what she's doing. So in this case the child doesn't have to think, "I

have to imitate you." But they start seeing the correspondence between their action and your action as you imitate them.

ALAN ALDA Now, here, who initiated this?

GERALDINE DAWSON It appears that what she's done here is she's brought out a toy that he's highly interested in and she's doing something that is very appealing to him.

ALAN ALDA She's blowing on it and he's trying to get it to turn by...now she's imitating him.

GERALDINE DAWSON That's right. Now she's imitated what he's doing.

ALAN ALDA So building up these interactions can develop the ability to interact in other ways, in other areas, at other times.

GERALDINE DAWSON That's true, although we do target what are sometimes called pivotal skills. These are fundamental skills, that if you learn them, they open up the door to all kinds of learning.

ALAN ALDA (NARRATION) Among the most important such skills is communication.

BONNIE Oh, you said cookie and you're looking at me?

ALAN ALDA (NARRATION) Tariq, like many other autistic children, is being taught to use a communication system in which pictures replace the spoken word.

BONNIE You told me juice? Yes, you want some juice?

ALAN ALDA (NARRATION) But while Tariq is benefiting from what's already known about autism, the University of Washington program is also investigating autism's many unknowns -- including what, if anything, is different about the autistic brain. One of the volunteers in this research effort is seven-year old Elizabeth. She's being prepared for a scan of her brain in an MRI machine.

ALAN ALDA I did this once and you're taking it so much better than I did.

STEVEN DAGER When you're in the magnet, when we talk to you, try not to move your head like this because then we'll lose kind of where your head is in the magnet.

ALAN ALDA (NARRATION) Elizabeth is the daughter of one of the scientists here.

RESEARCHER So we're slicing from back to front, here's the cerebellum...

ALAN ALDA (NARRATION) Her brain is one of the normal brains the researchers are comparing to the brains of autistic children.

ALAN ALDA Have you found anything so far that seems typical of the difference of the two?

STEVEN DAGER What we seem to be finding is that the kids with autism have bigger brains.

ALAN ALDA Bigger brains?

STEVEN DAGER They have bigger cerebrums than both normally developing children and kids with developmental delays.

ALAN ALDA So, that seems...

STEVEN DAGER Peculiar.

ALAN ALDA Odd, yeah.

STEVEN DAGER Bigger's not necessarily better.

ALAN ALDA Right.

STEVEN DAGER Clearly they have bigger brains but their brains aren't working as well.

ALAN ALDA (NARRATION) To find out why autistic brains don't work as well, Steve Dager and his colleagues are also peering deep inside them, looking for differences in important brain structures. And they've discovered another puzzle - a region called the amygdala is bigger than you'd expect, even given a bigger brain.

ALAN ALDA What is the amygdala normally associated with?

STEVEN DAGER Emotionality or emotional response. So the question obviously is, if these kids have a paucity of emotional response, or have a problem with emotional reciprocity, why would their amygdalas be bigger?

ALAN ALDA Yeah.

STEVEN DAGER And I don't know. That's what we're trying to better understand. We're trying to better understand as we study them over time. So these kids are coming back now when their ages six to seven and we're looking at the change over time as a dynamic way of understanding brain development.

ALAN ALDA (NARRATION) Brain imaging is clearly one of the new frontiers in autism research.

ALAN ALDA Elizabeth, you did great. That was great.

ALAN ALDA (NARRATION) But while Elizabeth's contribution to autism research will no doubt pay off one day, for now the main hope for children like Tariq lies in the dedication of therapists like Bonnie Smith -- and hours of patient chipping away at the walls his autism has erected. Tragically, for many children growing up with autism, not even this is enough.

ALAN ALDA What do you think of the prospects for this little boy?

GERALDINE DAWSON Oh, I'm very hopeful that this boy will go on to develop language and to do quite well. As I said, at this age it's extremely hard to tell. That's another focus of our research is to try to look at -are there early indicators that tell us which child's going to go on and do extremely well and other children could have exactly the same intervention and make very slow progress. There must be something biologically different about those two kids. But no, I'm very hopeful that he'll go on to develop language and friendships. I have very positive prospects for him.

EACH SOUND IS A PRESENT

ALAN ALDA (NARRATION) Seven-year-old Kelly Flynn lives with her family near Northampton Massachusetts. One of her favorite walks is through the woods to a nearby river.

KELLY FLYNN I love the river.

MARY FLYNN Why?

KELLY FLYNN Because it is beautiful.

MARY FLYNN Yeah. Can you hear it?

KELLY FLYNN A little.

MARY FLYNN What about when you get your cochlear implant?

KELLY FLYNN When I get cochlear implant, I will hear the best.

ALAN ALDA (NARRATION) Kelly has been profoundly deaf since she was two. What little hearing she has -- boosted by a conventional hearing aid -- is worsening. She has no trouble communicating by sign -- but for years she's wanted to talk.

MARY FLYNN Do you like to sign or do you like to talk?

KELLY FLYNN I like to talk. That's why I want cochlear implant. To hear better.

MARY FLYNN To hear better. Why do you want to hear more?

KELLY FLYNN Because I would love to hear more. Because when you call me, I will hear.

ALAN ALDA (NARRATION) Tomorrow is the day Kelly has been waiting for for months.

MARY FLYNN You're gonna go in, in the room, in one minute. Mommy has to change her clothes, and then I will go in there with you. Okay?

GARY FLYNN It's just the beginning, but it's an exciting beginning. And in a way, the beginning of her hearing in a whole new way which is very exciting. And she's the most excited about it.

MARY FLYNN Good girl, Kel. You're so brave.

ALAN ALDA (NARRATION) The surgery that's about to begin on Kelly will permanently implant a tiny set of electrodes deep within her inner ear.

MARY FLYNN Thank you.

ALAN ALDA (NARRATION) In a normal ear, sound vibrations are translated into nerve impulses by millions of tiny hair cells lining the inner wall of the snail-shaped cochlea. Kelly went deaf when an infection destroyed these delicate hairs. A cochlear implant substitutes an array of tiny electrodes -- 22 in Kelly's case -- for the hairs of the hair cells, directly stimulating the cells to send their messages to the brain. Kelly's surgery is being done at Boston's Children's Hospital by Dr Margaret Kenna.

MARGARET KENNA What I'm doing now is drilling actually into the cochlear. And the bone of the cochlear is very hard bone -- harder than the rest of the bone in the rest of the body. And as you go towards the center of the cochlear it gets very white. So now we have a hole in the cochlear. Do you see it?

ALAN ALDA Oh yeah, I see it very clearly. Every time I realize that there's is a seven- year old girl under that draping it has an effect on me. Do you keep that out of your mind or how do you handle it?

MARGARET KENNA Well, you have it sort of in the back of your mind. I think just to stay focused on the job at hand. But also I think if it was my child, I couldn't do this. Someone else would have to do it. I couldn't do it.

ALAN ALDA (NARRATION) The electrode array being slipped into Kelly's cochlea is attached to a receiver that is also implanted under the scalp. Both the electrodes and the receiver are connected in turn to an antenna and a magnet. The entire implanted system is visible in an X-ray taken while Kelly is still in the operating room.

MARGARET KENNA This is the antenna right here. This is the magnet. This is the receiver stimulator right here. And this is the wires, the electrodes in the cochlear. If you look even closely, you can almost count each individual electrode.

ALAN ALDA (NARRATION) It will take about two weeks for Kelly to recover from her surgery.

MARILYN NEAULT Hi. Are you ready?

KELLY FLYNN Yes.

MARILYN NEAULT Good. What are we doing today?

KELLY FLYNN My cochlear implant will turn on.

MARILYN NEAULT We're turning on your cochlear implant. Alright.

ALAN ALDA (NARRATION) A wireless transmitter sticks to the magnet under Kelly's scalp.

MARILYN NEAULT Can you see it?

ALAN ALDA (NARRATION) From now on, this is how sounds will get to her brain -- from the microphone behind her ear, via a computer that will process the sound

into the signals sent to her cochlea. Right now, Kelly's microphone isn't on. These beeps are being fed into her cochlea directly. The cochlea normally responds to high frequency sounds at one end, low frequencies at the other. The electrodes in the implant mimic this process. Kelly has been asked to put a ring on the stick whenever she detects a sound.

GARY FLYNN She told her friend that when she came back maybe she'd be able to call her on the telephone. She's already exploring it in her mind. She's imagining the things she might be able to do. And her hearing, it's a gift now. It's not just being something you're born with. It's something very special to her. It's like Christmas. Each sound is a present.

ALAN ALDA (NARRATION) So far today, Kelly has only heard the beeps generated by Marilyn's computer. But now comes the moment Kelly has been waiting for. Her microphone is switched on. Now sounds from the room are able to enter her head.

MARY FLYNN Do you like the way that sounds? Is it really really loud? Is it really loud? Or is it perfect?

KELLY FLYNN It's perfect.

ALAN ALDA (NARRATION) Kelly gets her own little computer to process the sounds picked up by the microphone behind her ear into the signals sent to her cochlea.

MARILYN NEAULT I'll just put it there. And let the hair fall down over it.

ALAN ALDA (NARRATION) It's the sophistication of this processing -- especially for the sounds of speech -- that has in the last few years started to open up the hearing world to profoundly deaf children.

ALAN ALDA Hello. Hi. Hi.

ALAN ALDA (NARRATION) To find out how -- and what lies ahead for Kelly -- we're visiting a classroom for hearing impaired children -- where my job is to read a story.

ALAN ALDA "It isn't fair that my brother Anthony has two dollars and three quarters and one dime and seven nickels and eighteen pennies."

ALAN ALDA (NARRATION) The room is equipped with a sound system so that the voice of teachers -- or guests -- is kept at a constant level. Some of the

children here have conventional hearing aids. Several -- including six-year-old Timmy -- have cochlear implants.

ALAN ALDA Timmy, do you like money?

TIMMY I like lots and lots of money.

ALAN ALDA Lots and lots of money?

ALAN ALDA (NARRATION) Those of us without cochlear implants can never know exactly how they sound to children like Timmy, but here's a guess.

ALAN ALDA "So they brought lox because my father likes to eat lox, and they brought plants because my mother likes to grow plants."

SPEECH THERAPIST Tim!

ALAN ALDA (NARRATION) Timmy had his cochlear implant when he was just two years old -- and ever since, he's been working hard.

SPEECH THERAPIST Timothy? I want you to be thinking about your nice "k" sound okay? Okay? And Mr. Alda will probably think about his nice "k" sound, too. We will all think about that.

ALAN ALDA What are we supposed to do in this game?

TIMMY Umm...Get a match.

ALAN ALDA Make a match?

ALAN ALDA (NARRATION) When he was nine months old, a bout of meningitis effectively destroyed Timmy's hearing.

TIMMY Crack the egg.

SPEECH THERAPIST Nice job. Let's do it one more time, Bud. Let's here the "ck" at the end. Watch me.

TIMMY Crack the egg.

SPEECH THERAPIST Nice job.

ALAN ALDA (NARRATION) At a time when most children are absorbing the sounds of speech, Timmy lived in a nearly silent world. He's been playing catch-up ever since, not only learning to interpret speech, but to speak himself.

ALAN ALDA Ha! Not a match.

TIMMY Not a match.

ALAN ALDA (NARRATION) Accompanied by his mother, Tim has also spent many hours here, in the audiology lab at Children's Hospital in Boston.

MARILYN NEAULT Don't look at me, OK?

ALAN ALDA (NARRATION) Today he's in for a routine testing of his cochlear implant... and a tune-up if necessary. He's played sounds at different loudness levels and pitch.

MARILYN NEAULT I am determining how soft a sound Timmy can hear with his speech processor in his implant at different pitches or frequencies. And I want to make sure that he can hear all the different frequencies at a soft enough level for him to hear the different sounds in speech. The "s", the "f" and the unvoiced "th". "Sss," "fff," "th" and also "p" and "k". The sounds that you make when you're whispering are the trickiest to pick up and a deaf child with hearing aids would not hear those. With a cochlear implant you can detect and even learn to discriminate among those sounds. Hey Tim. Marilyn on the radio again.

ALAN ALDA (NARRATION) In a quiet room like this, Tim's ability to hear and speak is remarkable.

MARILYN NEAULT You just say the same word after me, okay? Alright? Are you ready? Toothbrush.

TIMMY Toothbrush.

MARILYN NEAULT Butterfly.

TIMMY Butterfly.

MARILYN NEAULT Water.

TIMMY Water.

MARILYN NEAULT Ball.

TIMMY Ball.

MARILYN NEAULT Pencil

TIMMY Pencil.

ALAN ALDA (NARRATION) Remember, this is a boy who was completely deaf when he got his implant four years ago, at the age of two

MARILYN NEAULT With early diagnosis of hearing loss, early introduction of language, early implantation and proper therapy and nurturing of language, this outcome is becoming far more commonplace than it used to be. He is typical of a good outcome but there are many many of them. I think some people feel that there are two or three children ever who have achieved this degree of speech reception and speech perception and spoken language competence. And that's not true. There are many many children of this nature. Okay, this is the last thing. I'll say a whole sentence and you say the same thing after me, OK? OK, don't look at me remember. Ready? I'm hungry.

TIMMY I'm hungry.

MARILYN NEAULT Turn off the TV.

TIMMY Turn off the TV.

MARILYN NEAULT The fruit was on the ground.

TIMMY The fruit was on the ground.

ALAN ALDA (NARRATION) Once highly controversial within the deaf community, cochlear implants are now finding wider acceptance -- in part because of the striking success of children like Timmy.

MARILYN NEAULT Excellent! That was wonderful.

ALAN ALDA (NARRATION) That opposition to cochlear implants was based in part on how they might damage a deaf culture based around sign language. But Tim's first language was sign. And his parents expect sign to remain invaluable in the future.

TIMMY'S MOM If he has the implant off, he can't hear anything at all. So if he's in the bathtub or he's at the beach, or he can't go on slides or on trampolines, etc., it's so nice to have another language. So yes, we probably will always continue.

And he likes it. We'll sign to him and he'll speak back to us. So it's really funny...In church...

TIMMY'S DAD It's really useful in church. We can actually yell at our child if we need to in church and nobody will know what's going on, so...

TIMMY'S MOM Right now Timmy doesn't think he's any different than anyone else walking around and in time, he's gonna know there are some differences. But I think, from the roots that we've given him, he's gonna be able to do whatever needs. And the best thing that you could do is just give him so much confidence right now, just like you would with any small child. Just so that later on, as he realizes he is a bit different, he can go back and dig on those roots.

ALAN ALDA (NARRATION) For Kelly Flynn, the long journey into the world of sound and of speech is only just beginning. But already walks near her home have taken on a new dimension. Finally Kelly can hear her river.

#### FINDING HER VOICE

ALAN ALDA (NARRATION) Our final story is about a young woman who, like Kelly Flynn, has always wanted to speak. In her case, it was cerebral palsy that robbed her of a voice of her own. But as we've seen as we've followed Kara Johansen over the years, her inability to speak hasn't stopped her from talking. I first met Kara when she was twelve. Her mother, Pam, spoke aloud what Kara had to say by reading the letters Kara looked at on a plastic alphabet board.

PAM JOHANSEN A, N, D- and K- and S, O. And someone - someone says it.

ALAN ALDA (NARRATION) I appreciated Pam Johansen's skill at translating for Kara even better when I tried it myself.

ALAN ALDA What was the play about? S, E, W. No? X - Sex? No? - Well, it was the letter I saw.

ALAN ALDA (NARRATION) Kara's family and close friends were almost as skilled as Pam Johansen at using the board. The communication it allowed was central to the bond that exists between Kara and her sister, Melinda.

MELINDA JOHANSEN Kara and I are really close and we have been that way every since she was little. And a lot of times people categorize her- she can't do this, she can't go on a roller-coaster, she can't off a diving board. And that has never been a barrier between us, because she has done all of that and that is what keeps us together most of the time - because we have overcome so much together. I don't want to do this!

ALAN ALDA (NARRATION) But when Kara was fourteen, Melinda started boarding school - and sisterly chats became much more difficult.

MELINDA JOHANSEN It's hard for us to communicate. It has to be over the phone and there needs to be a person communicating with Kara just to be able to tell me what she is saying. If there was a way that I could talk to her directly, it would be perfect.

ALAN ALDA (NARRATION) No-one better appreciated Kara's need to talk directly than the person who had always been her principal voice - her mother.

PAM JOHANSEN Kara loves Melinda and Melinda loves Kara. And Kara would love to privately talk to her sister without any other person, without an adult -- without a mother -- to censor what was being said. And she would love to communicate with Melinda on her own, very privately, and talk their secret stuff that they have to share.

ALAN ALDA (NARRATION) In 1994 an attempt was made to give Kara a voice of her own by fitting her with a device that would track the gaze of her eyes. But Kara made no secret of her opinion of its practicality.

PAM JOHANSEN It's T, O, O -- it's too -- B, U, L, K -- it's too bulky?

ALAN ALDA (NARRATION) But the eye-tracker did allow the researchers -- at Boston's Children's Hospital -- to confirm that Kara's gaze was steady enough to control some sort of communication device.

PAM JOHANSEN It's sliding down over her eyes.

ALAN ALDA (NARRATION) Over the spring and summer of 1994, Kara and Pam Johansen made many visits to Children's. Work on the new system was going slowly. And Pam Johansen was acutely aware that Kara's need for independent communication was becoming more urgent.

PAM JOHANSEN O.K. Make a third wish.

ALAN ALDA (NARRATION) Pam Johansen had begun to lose her own battle with cancer. She died in October 1994. A few months later, a new system was ready to be tested. This time a custom-fitted helmet held Kara's head still while the eye-tracking system was mounted separately. From it an infrared beam shone at her eye -- which was tracked with the help of two crosshairs - one centered on her pupil, the other on the reflection of the infrared beam. By comparing the position of the two crosshairs, a computer could tell precisely

where her eye was pointed. The system was calibrated by having Kara look at numbered squares on a screen. When her eye fixed on a square, it lit up. The plan was to replace the numbered squares with letters of the alphabet so she could spell out words that could be spoken aloud by a voice synthesizer. RICKY RAZDAN If you don't think it's right there, just look around that area until it highlights.

ALAN ALDA (NARRATION) Or so that she could trigger pre-recorded phrases.

VOICE It's great to see you again.

ALAN ALDA What a nice reception! Hi Kara! It's great to see you again too!

ALAN ALDA (NARRATION) Kara had prepared several phrases in anticipation of my visit - including a reminder of the first time we met.

VOICE I haven't done any more plays about sex!

ALAN ALDA Having you been spending a lot of time trying to get this machine to work right?

VOICE Yes.

ALAN ALDA That's wonderful. O.K. if I try this?

VOICE Yes.

ALAN ALDA (NARRATION) I got to try out the test version of what was intended to become an alphabet board like the one her mother taught her to use. But this one would be linked to a word processor that would allow her to write, as well as a voice synthesizer that could read aloud what she had written.

VOICE Hello Dr Watson.

ALAN ALDA (NARRATION) In January 1995, almost a year after work on the eye tracking system began, Melinda Johansen - away at her boarding school in Maine - received a telephone call from her sister.

MELINDA JOHANSEN Hello. Hello?

VOICE Hi Melinda. It's Kara.

MELINDA JOHANSEN Hi Kara.

VOICE I'm using the I-Scan computer system for this phone conversation.

MELINDA JOHANSEN That's good. Do you like it?

VOICE Yes.

MELINDA JOHANSEN Did you have fun in school today?

VOICE No.

MELINDA JOHANSEN Why not because it was Friday and you had to go?

VOICE When you play basketball, did you win?

MELINDA JOHANSEN Of course not, we never win. I scored eight points. And the other eight points, I assisted. Kara, how is school going?

VOICE Good, but very stressful.

MELINDA JOHANSEN Excited about coming up next weekend?

VOICE Yes.

MELINDA JOHANSEN Good. I'm really excited about you coming up too. O.K., kiddo, I got to go.

ALAN ALDA (NARRATION) This was the first time Melinda and Kara had ever talked by phone without someone else -- usually her mother -- speaking for Kara.

MELINDA JOHANSEN I will see you next weekend when you come up. O.K.?

ALAN ALDA (NARRATION) Of course, this conversation was hardly private or spontaneous. But in spelling out her final message, Kara was taking the first step toward the independent voice her mother had so wished for her.

VOICE I love you, Melinda.

MELINDA JOHANSEN I love you. Bye-bye.

ALAN ALDA (NARRATION) By the summer of 2001, both Kara's and Melinda's lives had changed. Melinda is now married and a teacher. Kara lives at the Massachusetts Hospital School on weekdays and with Melinda and her husband on weekends. And a few days ago, Kara got a new communication system to try out.

ALAN ALDA Kara, hi, how are you?

KARA JOHANSEN Hi Hawkeye.

ALAN ALDA Great to see you...

KARA JOHANSEN What's up?

ALAN ALDA I'm sorry would you say that again?

ALAN ALDA (NARRATION) This device no longer tries to track her gaze.

KARA JOHANSEN What's up?

ALAN ALDA (NARRATION) Instead it allows her to use her head.

ALAN ALDA Now this little dot you have on your forehead. This thing is reading where you look, huh?

ALAN ALDA (NARRATION) Mounted on top of her computer is a camera that tracks the dot on her forehead and uses this information to control the position of the cursor on the screen.

ALAN ALDA It's almost like watching a mouse cursor, but your head is the mouse.

KARA JOHANSEN Yes.

ALAN ALDA Right. When we first talked, you were interested in writing. Have you been writing?

ALAN ALDA (NARRATION) The system is far simpler than the one Kara first found her voice with six years ago. And it's commercially available -- no longer a cumbersome experimental device.

KARA JOHANSEN I still am very interested.

ALAN ALDA Do you have to work hard all the time on communicating, learning different ways to communicate? Does it seem like hard work to you or is it part of your life, you just take it in stride?

KARA JOHANSEN Just do it and it's hard but I just remember how my mother told me never give up.

ALAN ALDA Boy that's terrific. That's terrific. You know, there's nothing you can't do. That's what my mother told me, and it got me into a lot of trouble because I believed it. The funny thing is you really can do probably anything you want to do. I mean you have this ability to stick to it like this. And you take so much pleasure out of life. That's the secret I think. .

ALAN ALDA (NARRATION) With her sister Melinda still at her side, and with the help of enthusiastic volunteers and a dedicated staff at her school, Kara daily demonstrates the spirit and determination of all the kids we've seen in this program who are growing up different.

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