CODA film wins big at the Academy Awards

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With the success of Coda, a film about children of deaf adults, at the Oscar's, listeners give us their experience of growing up deaf in Ireland

Joe Duffy, RTÉ Radio 1:
Hello, good afternoon and you are very welcome to Liveline. It really is a terrible pity that that savage assault by Will Smith on Chris Rock at the Oscars last night has taken away from what is a very historic moment. And that is, the first time ever a primarily all deaf cast of a movie won, the movie itself, and indeed Troy Kotsur won best supporting actor, who's deaf as well. But it's the first time a movie with such a cast has scooped a best movie. And as I said last Monday, when I spoke about it, I thought it was an incredible movie and I thought it would go on to fantastic things. Now, we're going to talk to a number of people who've contacted us, I want to talk to Catherine White, first. Now, what I'm also saying to people, obviously we have difficulties in terms of technology, we don't have a signer at the moment here on Liveline, but we have got other technology including, if you can lip read and speak, even though you have got hearing difficulties, we can organise a Zoom call, if you want to contact us on 51551, or joe@rte.ie during the course of the programme, because we're very keen, we did it once before, I think about 18 years ago. And we asked members of the deaf community through their friends and indeed through themselves, I think we were using mobile phones at that stage to talk to us about what the issues were for them in Ireland. And a big one that came up was contacting the emergency services, dialling 999, is fine, 112 is fine but what happens if you can't hear the person, the garda, the paramedic, the fire fighter at the other end. Now that to some extent has been rectified because the Gardaí subsequently set up a system where you could register if you had hearing difficulties, you could register with the Gardaí and they would arrange a system where they could accept your texts. Now, let me start with. Catherine White, Catherine, good afternoon.

Catherine White:
Good afternoon.

Joe Duffy, RTÉ Radio 1:
You've seen CODA.

Catherine White:
I have indeed.

Joe Duffy, RTÉ Radio 1:
And you are CODA, you are a child of a deaf adult.

Catherine White:
Yes, I am.

Joe Duffy, RTÉ Radio 1:
Will you explain the movie to people, one, because it's on Apple which means a lot of people haven't seen it. I think it's on limited release at the Irish Film Institute in Dublin, will you explain the movie first of all, Catherine.

Catherine White:
Right. The storyline is about a hearing daughter who has deaf parents and a deaf brother and it just goes through the day-to-day life of the family dynamics, within themselves and then what it is that they face when they go out there into the community, that would be the shortened version of it.

Joe Duffy, RTÉ Radio 1:
And how does it work? How does it work on the big screen in terms of deaf people are communicating through sign language. And what we're looking at, those of us who are lucky enough to be able to hear but also be able to read, we're looking at subtitles, is it?

Catherine White:
Yes. Yes, obviously the movie was made in America, so they're using American sign language. Here in Ireland, we use Irish sign language and then in English it's British sign language. So, every country has got its own. So yes, there's a representation of sign language on the screen but it's American sign language, so deaf people and everybody else would be relying on the captioning.

Joe Duffy, RTÉ Radio 1:
Okay, now can you understand American sign language?

Catherine White:
I can understand it from a conversational point of view, but I'm registered qualified with Irish sign language and British sign language.

Joe Duffy, RTÉ Radio 1:
Will you explain to people, Catherine before we go anywhere, because obviously during the pandemic there was a number of issues raised for people who are deaf, one is masks, obviously and the difficulty of lip-reading. But two was every press conference in the South had one signer, obviously communicating with people who were deaf, but up the North they had two signers.

Catherine White:
That's right.

Joe Duffy, RTÉ Radio 1:
Why was that Catherine?

Catherine White:
In Northern Ireland, they've got two sign languages, Irish sign language and British sign language. And it's historical, this is a historical issue but it still remains the same, for anybody who is an Irish deaf Catholic they would be educated in Dublin, which would have

been the School for the Deaf in Cabra. And then if they were Protestant, this is going back in the day now, they would have gone over to England to be educated, then obviously once they'd grown up, completed their education they would have gone back to Northern Ireland again.

Joe Duffy, RTÉ Radio 1:
So…

Catherine White:
And so that's why you have the two sign languages.

Joe Duffy, RTÉ Radio 1:
And that's something I only came across when I, when Freya McClements wrote the book about the children who were killed in the troubles because one of the children that was killed, one of the children had learnt sign language to communicate with her deaf mother, she was a child of a deaf adult. But I didn't realise that Protestant children who were deaf and Catholic children who were deaf, who had both known sign language cannot communicate with each other through sign language, one uses – the Catholics use Irish sign language and the Protestants generally use British sign language.

Catherine White:
To be fair, they actually do. So, because they're interacting with each other all the time, they would have an understanding of each other, but they've also to develop their own dialect as well so you can have Irish sign language, British sign language but you can also have Northern Ireland signs. And so that would be the common denominator between the two but what that shows to me is that how very rich the language and the culture, is that that type of communication and culture can survive, so to me it's impressive.

Joe Duffy, RTÉ Radio 1:
So, Catherine, what did you think of CODA winning the Oscar for best movie and best supporting actor?

Catherine White:
Wasn't it three Oscars they won?

Joe Duffy, RTÉ Radio 1:
Yeah.

Catherine White:
I think it was best screen writing as well.

Joe Duffy, RTÉ Radio 1:
Yeah. Sian, yeah.

Catherine White:
First of all, first of all, it has got her name out there. We could not afford that kind of advertising as a voluntary organisation. So, the word CODA, is a name that describes people

who that, you know, people who are hearing but who have deaf parents. Because it's important to us that that distinction was made because yes, I can hear like you, yes, I can speak like you. But our experiences growing up is different and we wanted that difference to be acknowledged, but we want it acknowledged as positively rather than saying, 'Oh, what a pity, God love them, they have got deaf parents', we wanted to show, 'Well actually no, we got two languages, we've got two cultures and we want to acknowledge and respect our deaf parents, and the deaf community and the language that they have given us'.

Joe Duffy, RTÉ Radio 1:
And what was it like for you growing up? You were the hearing child as in the movie, it's Amelia Jones, the daughter of the singer Aled Jones, who a lot of people in Ireland would know from his appearances here, she's brilliant in the movie, and an incredible singer as well. As is her own Ferdia Walsh-Peelo who I mentioned last week as well, he's brilliant in the movie. But what was it like for you growing up as that young girl who was interpreting all the time for her parents?

Catherine White:
This is a conversation that I have all the time. And what I always, what I always say to that is that it wasn't us, it wasn't our parents asking us to do the interpreting, it was the professionals that were interacting with the family that would ask us to interpret. And as the decades, I'm 57 now, so I've been dealing with this for decades. And I make a very clear point of saying the professionals should not be using children to interpret, for example, the doctor should not be asking the child to interpret a medical setting between a parent, it's private, one thing it's private…

Joe Duffy, RTÉ Radio 1:
And does that happen, Catherine?

Catherine White:
All the time. All the time, doctors, nurses, mental health professionals, the Gardaí, teachers, principals, you know, straight across the board, if there's any interaction. Now you know as a parent how much interaction you have with professionals, you know, how much you have to deal with on behalf of your children. Now imagine if your children were asked then to interpret, how would you feel about that? You wouldn't like it and it's inappropriate, because it's adult conversation being done through a child. Not appropriate.

Joe Duffy, RTÉ Radio 1:
And what is the alternative, the professionals would say, what is the alternative?

Catherine White:
Oh well you see this is, I know that I spoke with you last year, the reason why I got very excited about the Irish Sign Language Act, is because it now places a legal duty on the public bodies, you know, the public sector to use a registered qualified interpreter of which there is a register now in Ireland, as part of the Irish Sign Language Act. So, in the past it was based on goodwill, it was based on awareness, it was based on understanding whereas now it's like, 'No, you don't do that anymore, use an interpreter', but it's still not happening, children are still being asked.

Joe Duffy, RTÉ Radio 1:
So now, one of the official languages of the Irish State is, Irish, English and Irish Sign Language, isn't that correct?

Catherine White:
Yes. it's the third official language of Ireland.

Joe Duffy, RTÉ Radio 1:
And we are ahead of the UK because they're only debating it in the Houses of Parliament last week.

Catherine White:
That's right, we are ahead, on paper we are ahead of the game, on paper, we're ahead.

Joe Duffy, RTÉ Radio 1:
At what age, Catherine, were you asked to interpret, as a hearing child for your parents?

Catherine White:
You keep saying for my parents, I'm going to say, interpret for the professionals.

Joe Duffy, RTÉ Radio 1:
Okay. Well said, yes, well checked, yeah, well checked.

Catherine White:
Yeah, because I did not need to interpret for my parents, my parents did not want me to interpret for them but if somebody came to the door, if they had to talk to the teachers, they would be the ones, 'Will you say this to your mum and dad?' You can't as a child turn around and say, 'No, I will not', you will.

Joe Duffy, RTÉ Radio 1:
Yes.

Catherine White:
Because you know you're going to get reprimanded either by the parents or the professionals. So, it's easier to say, 'I will okay yeah', anyway.

Joe Duffy, RTÉ Radio 1:
Were you, as happened in the movie, were you sometimes asked to interpret for the professionals or in the movie, it was for the group of politicians at the top table?

Catherine White:
Oh yeah.

Joe Duffy, RTÉ Radio 1:
Were you sometimes asked to interpret difficult answers for the professionals?

Catherine White:
Of course, it's because - yeah well think about it, you're a child, as a child I wouldn't – I want you to put yourself back into your child – how much would you have understood about cancer, or a mortgage, or mental health issues, or mental health conditions, you know? As a child, would you know that? You wouldn't. That's what the expectation is. And I still, to this day don't understand how a professional thinks that's okay, to put the onus on a child to interpret adult conversations. One, it goes against the human rights of the child, it's placing an unfair burden on the child, when the only thing that the child wants to do is to please the adults around them. But also, they just want to be a child and you know, having to try and understand these very complicated concepts. Yeah, we grow up, I mean the one thing that I will say, you do grow up quicker. And I know that in relation to my own counterparts growing up, my conversations and my understanding of life was very different.

Joe Duffy, RTÉ Radio 1:
Wow. And so, did the movie, CODA, which has won best movie at the Oscars, did it ring through true for you?

Catherine White:
Yes, it does because - now the storyline in and of itself - you know when you're a native like being Irish you're native, you know what rings true, and you know what doesn't ring true. So, you know you adapt the storyline to suit the greatest audience, now I can pick through a couple of things. But the biggest thing is that, one, the name CODA is out there, the second thing, it shows that deaf people can do anything. And in this case, you know, the capacity to win an Oscar, once the willingness and openness and the understanding is there, anything is possible for the deaf community. The third thing is that it's showcasing, it's spotlighting, hearing children who have deaf parents, do have a different experience.

Joe Duffy, RTÉ Radio 1:
Like there's one scene in it where the daughter, I'm thinking of you, the hearing daughter, gets completely and totally frustrated, exhausted, fed up like any teenager or late-teenager and, 'No I'm not interpreting, I'm sick, sore and tired of doing it, I'm going to my room', did you ever go into a bout like that?

Catherine White:
This is going to sound dreadful but I was actually a good girl. I accommodated. Now, did I feel it? Of course, I did, you want to run out and play with your friends. And then you have to be called back to make a phone call because there's somebody at the door. Now I will have to say that my experiences were different in that all of our neighbours around my parents could all do what's called the [00:14:55.3 British?] alphabet. So, they used to have their own conversations with my parents and they would have a conversation for hours. So, I didn't have to do that part of it, it was only when we were out in the greater community like the schools, the shops, all of that. That's when that came into play. But growing up, it was the neighbours that did all the conversations and they would be the ones that would tell my parents that I came in the door at 1 o'clock because the gate was squeaking.

Joe Duffy, RTÉ Radio 1:
Okay, stay with us Catherine, because we're going to try something now. Jean Anne Doyle is on a Zoom or a Skype call to me, she can read my lips, Jean Anne, how are you and tell us what your hearing situation is please.

Jean Anne Doyle:
Hi Joe, I have a profound hearing loss in both ears from the young age of about three or four.

Joe Duffy, RTÉ Radio 1:
Okay.

Jean Anne Doyle:
And throughout my life it deteriorated. So, I've kind of had different stages of my hearing going down further. So, I used to wear hearing aids and now I wear a cochlear implant.

Joe Duffy, RTÉ Radio 1:
And what difference did they make to you Jean Anne?

Jean Anne Doyle:
A huge difference, absolutely life-changing, before the cochlear implant, I could only see people one to one, I was lip reading, probably 90% of a conversation. My social circles would just get smaller because I was losing my hearing. So, I was losing a lot of speech. After the implant, I was able to get promoted at work, to management. I could hear birds for the first time and different sounds like, [00:16:52.0] or the light switch. I was able to hear phone calls, never heard on the phone before then really, I mean I would answer the phone to maybe a close friend or my parents and that would be it, because I could memorise how they sound, yeah and then I could hear the radio, so you'll be interested to know that, yeah. I met the Queen, I was able to hear her voice, she's very soft-spoken.

Joe Duffy, RTÉ Radio 1:
And Jean Anne, the process of going from being deaf to getting some of your hearing back, what was that like?

Jean Anne Doyle:
The process is a slow process. And how it works is, when I had the cochlear implant fitted, I had a month of silence, so that my ear would heal. And then the device then gets activated, so it gets switched on. So, some people might have seen YouTube videos babies hearing for the first time and everyone's bawling around them. And so, for me it was a little bit different, wasn't exactly crying like that but what my very first sounds were, bells. And then those bells became robotic, the voice became robotic, then I put two and two together and realised it was actually my audiologist speaking to me. So, the journey of hearing, from when it's switched on takes up to about two years. So, within the first few weeks, you hear just basically it's like walking around Disneyland, hearing Minnie and Mickey Mouse voices, then that becomes more human sounding. What is actually happening in terms of the brain and the processing is, the implant is – so basically, I hear through my brain, so the cochlear implant is a device that's put in to stimulate the hearing nerve. And so the sounds over time

become more human as time goes on and learning background sounds then onto learning things like music and radio, took a lot longer. Because it's much more complicated whereas background sounds is like you know, if you just make a tapping noise, it's just one frequency as opposed to you know, listening to – I don't know music of a rock group on radio, then it's much more complicated. So, the brain has to learn to put all that together and memorise it and that's why it takes time.

Joe Duffy, RTÉ Radio 1:
How did you manage during the pandemic? How did the deaf community manage during the pandemic, especially with masks?

Jean Anne Doyle:
For me personally, I did struggle at the beginning. But then I, with the problem-solving skills, quickly had to learn that you know I can either pretend I'm hearing or just ask people to lower their mask. So, I just got in the habit of doing that and I think it can be hard, someone with a hearing loss or someone with complete deafness to say that, you know. It depends on your confidence, it depends on your experience to say what your needs are but also a two-way thing, you know if you go into a shop and order something, the person behind the counter, if they're looking at someone like myself. They would never know that I had a hearing problem, my hair is down, covering my ears, I speak like I don't have a speech impediment. And so, when I ask them to repeat or 'I'm deaf', you know there's quite confused looks and then they understand what they need to do and then I tell them to lower their mask, yeah so that's just something I had to get used to.

Joe Duffy, RTÉ Radio 1:
What are the mistakes that hearing people make when they're communicating with people like you, when you were deaf?

Jean Anne Doyle:
Some of the things, for example, someone shouting. So, there is a common myth that you know the shouter you loud – the louder you shout, sorry, it's - that's how someone's going to hear. But the problem behind that and I think it helps people understand why that's an issue is because when you shout and the deaf person is lip reading, it distorts the mouth patterns. So, you can't really lipread. So, it's best to just repeat again in the same, you know the same volume and not to speak too slowly so not to say, 'What – can – I -do – to – help - you?' You know all those pauses in between; it makes it harder to lipread as well. So, it's just repeating. The other problems, covering the mouth, so like with you, we're on a video call, if you started to cover your mouth, I have to tell you to not do that. So, that I can see what you're saying. And having the light behind you, darkens your face, so it's best to have the light in front. Lots of - when we think about it, it's lots of kind of little bits of common sense, I am not saying that people are lacking it, it's just sometimes it takes a conversation to let people know that actually, this would help me or that would help me. Rather than just expecting everybody to know, because it is a two-way thing between someone with a hearing loss and someone without a hearing problem. So, we kind of have to come somewhere in the middle. The other issues, because someone with a deafness like myself, if someone came and tapped me hard on the shoulder, or just struck my shoulder, or touched me to get my attention. That is quite alarming for someone with a hearing loss because if

you think about it, we have – touch is one of our senses. If we lose our sight or we lose our hearing, the sense of touch is heightened, so it feels much stronger, so better to come around in front of them, wave to get their attention if you're at a distance. And also, when I go back to Ireland, I live in the UK now, so when I go back home, there's a tendency, no offence to anyone Irish but there's a tendency for male Irish to mumble. So, I'm always you know telling friends and family members they need to speak up, but also speak clearly and raise their face, because there's a tendency to lower their face as well, which you know, all these small little things, but they make a huge difference. And the most obvious thing is being in a quiet place when you're talking to someone with a hearing loss to reduce the background noise, so it helps them lipread a bit easier.

Joe Duffy, RTÉ Radio 1:
And as you know a lot of people in Ireland have hearing loss as they get older which is becoming, people are addressing it through hearing aids. Jean Anne, what do you do if you need, I know you're living in the UK, what do you do if you need to contact the emergency services?

Jean Anne Doyle:
So, me personally, in the past when I didn't use the phone, I would have gone to a friend or a family member or someone nearby. Luckily, I've not had an emergency when I was younger. I do know about an emergency text number, which I believe is 999 but nowadays with the cochlear implant I'm fortunately able to make a phone call so that's what I would do, I would make a call myself. Usually I would, whenever I make a phone call I do sometimes say, 'By the way I'm hard of hearing, just so that you're aware', and then carry on.

Joe Duffy, RTÉ Radio 1:
Okay. Stay with us Jean Anne and Catherine. Catherine, I know in the U.K. you can text the police or the fire services, what do you do in an emergency here in Ireland?

Catherine White:
It was like you were saying earlier, is that deaf people register with the Gardaí and […] service.

Joe Duffy, RTÉ Radio 1:
Say again, I'm sorry your line broke.

Catherine White:
They register with the 112 service yeah.

Joe Duffy, RTÉ Radio 1:
Okay and what, they dial, they can't hear.

Catherine White:
They register… no, they register the details and then once the Gardaí have their details then they can send a text message to 112, because the Gardaí will already know who the person is calling, yeah. But there's also the Irish Remote Interpreting Service, it's called IRIS and that

means that a deaf person can make a video call through an interpreter and then through the interpreter a deaf person can make any kind of phone call that they want. But it's pre-booked service and what they're wanting to happen is that that service becomes an on-demand service, so that they can pick up the phone just like you and I can pick up the phone at will whenever we want, yeah. So, there's progress to be made.

Joe Duffy, RTÉ Radio 1:
At any one time, how many people in Ireland are deaf, is it 5,000, 10,000?

Catherine White:
Well, the census is on. So, we're hoping that deaf people will put down, Irish sign language as their first and preferred language but also for the family members to state that they also have Irish sign language because we need that kind of data, in order to know what kind of services that need to be provided for. So, the guestimate is that there are 5,000 deaf people that use Irish sign language, with 40,000 being family members, professionals that work within the deaf community.

Joe Duffy, RTÉ Radio 1:
Okay, stay with us, Catherine and Jean Anne, I'm looking at you now, as you can see on the screen, if you could stay with us too, I'd really appreciate that. And we'll be back after this break, joe@rte.ie, we're talking about the conversation generated by last night's Oscars, not that awful, awful assault, but the issue of children of deaf adults and the deaf community and the issues they face and the lessons we can all learn due to the fact that this movie won the best movie at the Oscars, joe@rte.ie.

[Ad Break]

Joe Duffy, RTÉ Radio 1:
We're talking to people about the success of this movie, Children of Deaf Adults, Vivienne Curran, Vivienne.

Vivienne Curran:
Hi.

Joe Duffy, RTÉ Radio 1:
What's your situation?

Vivienne Curran:
Joe, oh I'm so excited. They've been tremendous speakers both people that you're after interviewing.

Joe Duffy, RTÉ Radio 1:
Catherine and Jean Anne.

Vivienne Curran:
Absolutely fantastic and I always, always feel so sorry for children, they don't get enough praise, of deaf parents. I think most of them I've met are just tremendous people, so it's a day for praising today.

Joe Duffy, RTÉ Radio 1:
And you are a MODA, you're the mother.

Vivienne Curran:
I'm the mother, I'm the super-granny actually.

Joe Duffy, RTÉ Radio 1:
Okay, well tell us.

Vivienne Curran:
No, my son is 56. And I'm so proud of him, I just can't explain and all the deaf. I'm always fascinated with them and always fighting for them and giving out about what they're not getting in life. It's such a hidden handicap. And I try to explain this to so many people in life but even family, you know, it's hard to be reared with a deaf brother or a deaf sister, and all the great parents and people of deaf children, just to give them more hope today. I'm so excited over this award, I didn't see the movie yet, but I know the greatness that's in them, and people don't really realise how the courage they have, and how they are offended by horrible people like in all walks of life but there's some great people out there today.

Joe Duffy, RTÉ Radio 1:
And Vivienne, when did you realise that your son was deaf?

Vivienne Curran:
Oh yeah, I diagnosed him myself, he was six months and everybody kept saying, 'No, no there's nothing…', he was very, very tiny at birth but I had – they went back on my history and I had German Measles. So, he was overactive and he's profoundly deaf. So, it's tremendous to hear partially deaf people being able to speak like that today and the advantage today but we're so backward here still. My son is a great traveller, he's been travelling, he went over to my sister in Cambridge at 15 and her husband was just tremendous with him. And he never stopped travelling, he just adores travelling, they know him so well in that airport, on trains. And his grandfather was a locomotive in Connolly Station and this is where the interest, but unfortunately, he really couldn't have a job around the situation with the trains because of the deafness, how deaf he is.

Joe Duffy, RTÉ Radio 1:
And that arises in the movie as well, CODA because the family need the daughter, the adult, the hearing daughter, so to speak, they need her with them all the time on a fishing trawler for safety reasons…

Vivienne Curran:
Yeah, but you don't really because they're really so equipped themselves, this guy has been, he's travelled all by himself and I just wanted, Joe, I hope I'm not taking up time.

Joe Duffy, RTÉ Radio 1:
You are fine.

Vivienne Curran:
But I just feel I'm so low at the moment and so old now, I just feel I just would love to thank all the wonderful people for the kindness to Mark. There's one couple, Paddy Dever and Teresa got him the first job. And I just cannot thank, I'm just thinking, I had so much time to think about life. My husband died 22 years ago, but I don't know, I had a great time in this situation. I suppose good comes out of everything - just to think about my life but thanking, people forget to thank the right people in life. And the best person and I was out at her grave yesterday, was my mother. She was just one of those mothers, if she could have taken the stars out of the sky for him and you know, I just feel very emotional, and I'm so interested. But when I heard about that award and I just was so happy because it's so hard, they're so perfect that people really never understand the loneliness that's with it, but this guy of mine is just, he could have been a movie star, if he had of had the chance.

Joe Duffy, RTÉ Radio 1:
Okay, stay with us Vivienne because I want to go back.

Vivienne Curran:
Oh yeah certainly…

Joe Duffy, RTÉ Radio 1:
I want to go back to Jean Anne and update her because she can't hear you at the minute.

Vivienne Curran:
Oh right.

Joe Duffy, RTÉ Radio 1:
So, I just want to tell Jean Anne that we have Vivienne on the other line and she's the mother of a deaf adult. Now, what she did mention there, she mentioned lots of things and she thanked so many people that have helped her son Mark, who's now in his 50s. But Jean Anne, Vivienne spoke there about loneliness, what was it like for you growing up?

Jean Anne Doyle:
I think, it's different for everyone. In my case when I was younger, I had probably a moderate hearing loss. So, I was able to hear to some extent with hearing aids. I think in terms of, I suppose the times of my life where I felt more sort of isolated or feeling lonely, would have been the time just before having a cochlear implant because hearing aids were sort of like running out petrol, shall we say, they were only giving me so much. And I was getting more deaf. And then when that happened, that's sort of when that kicked in and it does have an impact on your mental health and wellbeing. But you know having support of family and friends around you makes a massive difference, and having alternative ways to cope when you're going through that period. Other people do shut down, it can be very isolating, some people, a lot of people actually and it's quite a big issue, if you lose your hearing later in life from people that I know, and people from my work where you become

deafened. And it's very, very easy to slip into feeling isolated because suddenly you are not keeping up with the family gatherings, you know you're not hearing what's on the TV but you're too, maybe a little bit too proud to put on the subtitles in front of other people. So, there's lots of issues even just going to a restaurant, with maybe three or four people is so easy. If you cannot lipread and suddenly you have to learn to lipread. I mean I have been lipreading since the age of five, but if you have 50 years of your life with normal hearing and suddenly you have to find ways to cope with a hearing loss, and learn to lipread and use body language to help you communicate it is really, really difficult. So, it's very easy to kind of take the back seat. And it's literally the back seat you know, you slip in behind the group or people that you meet up. And it's just - it's very, very, it can cause a lot of stress and anxiety. So, for people around - anyone with a hearing loss who is trying to come to terms with it, they can make a huge difference. I used to have this problem myself, when my hearing aids weren't working or I just couldn't really hear in a noisy environment. I still struggle but thankfully through you know, being brought up independently by my parents I've found ways around it, but people around you can really help.

Joe Duffy, RTÉ Radio 1:
Okay, thanks Jean Anne, Jean Anne I'm going to talk to, I'm looking at the screen. So, I'm not talking because I want you to know that the next caller is Rachel. And Rachel is going to tell us about her siblings who are deaf, Rachel good afternoon.

Rachel:
Hello and thank you for having me on, hello.

Joe Duffy, RTÉ Radio 1:
Tell us your situation.

Rachel:
Well, I don't know if there's an acronym for what I am but I'm the hearing sibling of two deaf siblings, I tried to think what that would be, but yeah.

Joe Duffy, RTÉ Radio 1:
Are they younger or older?

Rachel:
One older and one younger and because I came in the middle my parents assumed I think, like with Vivienne, that it had been a case of German Measles. And so, they had me that fortified their conviction and my brother came along, it became evident that it was genetic, it was a connexin gene hearing loss, so they stopped at that point.

Joe Duffy, RTÉ Radio 1:
So, the points you want to raise are, I see one, go ahead.

Rachel:
I have a lot of respect for all of the speakers you've had on. And Catherine, talking about her experiences as a child of deaf parents, and Jean Anne and the cochlear implants and then Vivienne from the perspective of the parent, which is a very tough one particularly when

you come into old age and you're going to be leaving their child alone in the world. I just wondered if I could say the following which is that all profoundly deaf people speak Irish Sign Language, both of my siblings were brought up under the traditional of oralism because we lived in Sligo and they would have had to go to board in Cabra in Dublin. And my mother had seen the children going up in Connelly Station and didn't want that for them. So, she gave up her job and taught them by a method that she had developed herself as a language teacher. So, as a result they fall between two stools in a way, because they are deaf but they're not members of what we might understand as the deaf community, which would be a signing community. And both of them have high powered digital hearing aids but my brother is now what they call post-aid in his 40s, which means that he's just coming up for a cochlear implant. And I think the point that I wanted to make more than anything else - because I'm not speaking on behalf of the deaf community, I'm speaking on behalf of a very particular set of family circumstances, is the financial impact of disability. And there was a report, you might know about it, I think, Heather Humphreys launched it last year, about the cost of disability. And it was estimated, I imagine it's a lowball because it takes all disabilities into account and averages it out, but it estimates the cost of disability as being at about I think €11,000 was the upward limit per annum presumably per person. So, for a family with two parents moving into old age, one with dementia, the other one, you know, they're older. For me it means that there's quite a considerable financial burden as the person who in many ways is their carer, and I suppose I'd like to make a political statement if I can and that is that, you know, these things could be remedied, you know, hearing aids and cochlear implants and helpful people – to whom we are very, very grateful are all very well and good and using texting has transformed their lives. But I've written to various politicians over many, many years to ask if certain taxes could be there to help people who are deaf. Even to affray the cost of hearing aid batteries, if they could be on a par with the tax credit for blind people for instance. A tax credit for deaf people. And the other thing is that, I mean there are certain things that would also help particularly you know, if you're growing up as a deaf person, you're reliant financially in many ways if you can't work. Like I think the son of Vivienne she was saying it was too difficult to work and he belongs to a certain generation that couldn't avail of early cochlear implant intervention. And those people are quite a lost generation. I really think that it would help parents coming into old age if there were no inheritance tax for people who are profoundly deaf, that they could in some ways have tax credits that would assist them with the sheer cost. There are two things that are really difficult I think, in a family that is disabled. I don't think any one person is disabled, it's not a quality of personhood, it's a quality of your situation. In a family with a disability - time and money are huge issues. Also, having to fight for everything individually, you'll have heard of Andrew Geary for example in Cork who's fighting to have an appropriate assistant in class with his son Callum. All of this constant fighting for subtitles to be switched on for subtitling of internet content, for telephone lines to be accessible to people who are deaf, the fighting never stops. It's exhausting and the financial impact is huge. And then there's no category for somebody like me. I can't avail of a carer's allowance even though I'm always in care-mode and that has an impact career wise. If the category of carer were more clearly defined, it doesn't have to be somebody who lives in the home with somebody who's physically incapacitated, but it's that category where we're better recognised. I can't avail of a tax credit for the care that I give. I'm sorry to make it such a political issue, but they're very simple things and I really, you know, hope with the

refreshing of the Labour Party under Ivana Bacik that these will be pursued more vigorously by politicians.

Joe Duffy, RTÉ Radio 1:
Rachel, the issue you raise, which is a fascinating one about inheritance tax for – we've covered it … sorry, we've had calls about it on the programme, say for example adults, elderly adults as you pointed out, who have adult children with disabilities they worry profoundly.

Rachel:
Of course, yeah.

Joe Duffy, RTÉ Radio 1:
As you do, about what will happen.

Rachel:
Yeah, who will look after them and where will they live and can they afford it?

Joe Duffy, RTÉ Radio 1:
Surely inheritance tax should not apply to them either, isn't that the argument that.

Rachel:
Of course, yeah.

Joe Duffy, RTÉ Radio 1:
Yeah, that is a fascinating point.

Rachel:
And thank you Joe, so much for having this on. I think that it's an issue that often becomes a silent issue, because many people who are profoundly deaf are not able to speak on the airwaves, in particular. I'm talking about not an inability, but just because an oral/aural medium and I think it's very, very important and just thank you very much. Could I say one last thing on loneliness as well and isolation. That living as a family with disabilities is incredibly isolating, particularly if you aren't in the deaf community through lack of sign language. And I'm sure there are many people out there, I hope there are but certainly we didn't have any contact with any other deaf families growing up. And no State support whatsoever. And my father had to beg for a primary school to take my sister in because the teachers at the time assumed you either went to Cabra or you didn't go to school, and they were convinced that my sister wouldn't be able to use the bathroom, that's how primitive things were. And we came across a Catholic nun called, Sr Anthony who immediately said, of course, they would have her in, and I went to school with my sister even though I was younger, I sat beside her in school to tell her what was happening in class. So, I was her ears from the get-go, from I think the age of three, so yeah it can be a very isolating experience, and very different experiences I think you have found from the various people you've spoken to and just thank you very much.

Joe Duffy, RTÉ Radio 1:
And Rachel, how do your siblings communicate with you, with each other, with others?

Rachel:
Lipreading, when they're communicating with me. And I have a very clear voice because I was brought speaking to them and for them, so they lipread and something, I forgot her name, is it Kelly Anne? Sorry.

Joe Duffy, RTÉ Radio 1:
No, Jean Anne.

Rachel:
Jean Anne, forgive me, sorry Jean Anne was saying, the exhaustion that people feel when they're lipreading, it's such an exhausting thing to do to try and figure out what people are saying. And I'd appeal to all Irish men to speak more clearly, they notoriously, they really don't move their lips, yeah.

Joe Duffy, RTÉ Radio 1:
Okay. Jean Anne, just the last point that Vivienne was making there, was reminding us, which is the point you made. One, how exhausting lipreading can be and two, another appeal to Irish men, to stop bloody mumbling, stop mumbling. Okay stay with – I know Rachael, I hope you can stay with us.

Rachel:
I have to go.

Joe Duffy, RTÉ Radio 1:
Okay, hopefully we'll talk to you again, back after this break, joe@rte.ie.

[Ad Break]

Joe Duffy, RTÉ Radio 1:
Joe@rte.ie we're talking about the victory last night at the Oscars of the movie called CODA, which is Children of Deaf Adults, it's a drama, the vast majority of the actors in it are deaf and they're brilliant, brilliant actors and have won the Oscar, won three Oscars, best screen play, best movie, which is the supreme award and best supporting actor, for one of the actors who happens to be deaf and plays the character that way, brilliantly, Troy Kotsur, now Darren is in Portarlington, Darren you were listening to Vivienne.

Darren:
I was indeed, Joe, how are you? Good afternoon.

Joe Duffy, RTÉ Radio 1:
Good. Darren, you know Mark.

Darren:
Yeah, I worked with Mark, 20 odd years ago now but Vivienne speaking of feeling lonely and that and she mentioned Pat Dever. So, Pat Dever would have been our company director at the time along with our manager Luke Finnegan and they would have looked after Mark very well in the warehouse environment.

Joe Duffy, RTÉ Radio 1:
And were you aware of Mark's fascination with travel, Darren?

Darren:
Oh absolutely, he'd come in every Monday morning, be dying to tell you in the canteen about the locomotives and trains, and where he was planning to go on his holidays. And if I remember correctly, he was a member of the Aer Lingus Club, so he was always showing you how many points he'd have or what it would be worth to him for his travelling you know.

Joe Duffy, RTÉ Radio 1:
And how did you communicate in the workplace Darren?

Darren:
Well, lipreading mostly.

Joe Duffy, RTÉ Radio 1:
Okay.

Darren:
I just remember one time, Liverpool were playing in the Lansdowne. And I think Vivienne dropped Mark off to us and by the end of the match we had him shouting for Liverpool, quite clearly through lipreading, you know.

Joe Duffy, RTÉ Radio 1:
Okay, and did all the workforce rally round, Darren?

Darren:
Oh absolutely. Oh absolutely.

Joe Duffy, RTÉ Radio 1:
Yeah, okay.

Darren:
Always gave Mark time and that, you know.

Joe Duffy, RTÉ Radio 1:
And he's a fascination. Jean Anne, can I come back to you just for a second, I'll ask Vivienne the same question and indeed Catherine, has technology helped? I'm thinking iPads, phones, touch screens, texting, Jean Anne, has technology made a difference?

Jean Anne Doyle:
Absolutely. To our education I would have used a lot of assistive technology. So, listening devices, I've used support workers in my lectures, so they come along and they type notes up for me. So, that I can just focus on lipreading in the lecture and then I read the notes afterwards, because I wasn't able to do both at the same time. Over time it just gets better and better. I don't rely on technology in terms of phones completely, but obviously the implant being technical itself again if it wasn't for technology, I wouldn't be able to hear you, as we're doing now. But I used texts a lot, emails, with work I use Zoom to call my clients, my team, I still use speech to text reporters for my training sessions. So, as you can see a lot of technology over the years and it's definitely helped with where I am today, be able to do the job that I'm doing.

Joe Duffy, RTÉ Radio 1:
Okay, stay with us Jean Anne. Catherine, is Catherine White still there, Vivienne, Catherine has technology made a difference in your area of work?

Catherine White:
Yes, it has. If you look at the pandemic as an example, a lot of the in-person work was impossible. So, everything was transferred over to the online platforms such as Zoom. Which means that my work as a sign language interpreter was made more publicly you know, more readily available so if any organisation wanted to book an interpreter, they could do so online without the added you know, travel and time and everything else that goes with that. I do want to hop in on a couple of points that were made. One, there was an early point about health and safety. Now I'm not here talking on behalf of deaf people but just as my own experience in the deaf community, health and safety is actually a myth, there is no research that has shown that deaf people are unsafe. It is an assumption, there is no proof that they are unsafe. For example, deaf people drive, they're more alert because they're not distracted by the radio and they're not distracted by telephone calls. So, it's hearing people that are more at risk than deaf people when it comes to driving, health and safety and I really do need to emphasise that, it's not proven that that really does need to be made clear. In terms of the experiences of being isolating and so on - yes, there is that spectrum, yes it does exist. But the issue – it's not an issue, the experiences that I had growing up with my deaf parents and my aunt, my uncle, my five first cousins and my two second cousins is that they had a huge deaf community network all over Ireland and they would go and visit each other for all of the celebrations, they would come together, they would you know, as with any community would do, they would be out there supporting each other. And that I do acknowledge what the others have had to say in terms of their own experiences, but I will have to go back and talk about the positive aspects of having sign language, is that you don't have to struggle with lipreading all day, every day and the others are right, it is exhausting, mentally and physically exhausting, having to watch a whole number of people and their different patterns, with sign language that's not an issue.

Joe Duffy, RTÉ Radio 1:
Okay, I want to bring in Sylvia Nolan, Sylvia, you're manager of the deaf village in Ireland. Go ahead, Sylvia.

Sylvia Nolan:
Yes, I have a moderate hearing loss myself. And I went to the School for the Deaf, because in those days they didn't have the support that they have now in the schools. So, my parents really had no choice but to send me to a deaf school. So, I've been with the deaf community all my life, over 30 years. And I'm now managing the centre of Deaf Village Ireland. And we're open 10 years actually this year. And I just wanted to say that you know, we're a very distinctive happy community, it is a very strong ISL sign language community. But and we cater for everybody around Ireland, for example now this month, at the end of this month we have a CODA Day here in the DVI to celebrate CODA. And so, families outside of Dublin and in Dublin will be coming to Deaf Village Ireland and we celebrate all occasions. And it's the same with, I know some of your members mentioned about the isolation which absolutely does exist, but when you're involved in our community, like we set up a Christmas Day dinner here in Deaf Village Ireland. And it's basically it's not for people that can't have you know, can't afford a Christmas dinner or anything like that, it's just really to support people because you know, a lot of people, deaf people say even within their own families there would be communication barriers. And it's just for them to feel part of a community and to be able to communicate and have that support you know, here in Deaf Village Ireland. And that we've been doing that now for the last three years but obviously with the pandemic we couldn't have it for the last two and we hope to have it this year as well. So, it's all about you know inclusion and involving the deaf community to try and make them feel you know, that they're included in socially. And they are a very happy community and I know sometimes you know people from the outside would see sign language, when people are using sign language, they may be uncomfortable to approach people that are signing, but it is actually a beautiful language and we'd always try and welcome people into the centre here as well and just even given them out alphabet cards or you know to encourage, to try to engage with our community, because they're always very welcome and the deaf community you know, there is that isolation out there but when they get together here, it's a very unique community.

Joe Duffy, RTÉ Radio 1:
Okay, I just want to mention to Jean Anne because Jean Anne, the only lips she can see are mine, on the screen, Jean Anne, Sylvia who is manager of the Deaf Village in Ireland, which is in Cabra, in Dublin as far as I know. She is again, is talking about isolation and that difficulty but she also mentioned and I want to ask you this question Jean Anne, that people, hearing people can learn sign language, did anyone in your family grouping that did not need to learn sign language learn sign language to help you?

Jean Anne Doyle:
No, not at all really, because I think my most of my life because I went into mainstream schools and college and then work, it was pretty much there was no sign language required in my circle, because I could hear and lipread together. If I had grown up completely deaf and not used a cochlear implant, possibly I would have learnt sign language, might have gone to a deaf school and then family and friends would have learnt it. I think one of the barriers unless it's mentioned already in the conversations with learning sign language is the cost of it, it's actually really, really expensive to learn. Which is quite unfortunate really because if everyone you know had just the basic conversation in sign language, I think communication across the counter, you know, at the post office or in a café, 'What would

you like to order?' Simple things could really go a long way and I think one of my kind of visions would be to have everyone just on level one, so that we can help communicate with those in the deaf community. And then those that aren't within the deaf community because if it's not already been mentioned there are people that associate themselves with being in the deaf community. In my own experience I'm not part of the deaf community, I just am someone with a hearing impairment, that's how I identify myself. You have different categories of people with deafness, and there's a little bit of an assumption that everyone fits into a category, when actually all the categories are just labels that come from health professionals. But then it creates a little bit of a stigma of, 'Which one are you?' So, basic advice is, if you don't know how to communicate with someone in order to help have that conversation going, just ask. So, it's one thing I always say to people you know, if you're ever in doubt, any disability, just ask the person, if they don't hear you first time, they don't communicate, write it out on a piece of paper, text them, you know, or just make, maybe you show them on the menu. So, simple little things and then there will be a way, so it's just all about finding a way of communication, isn't it, that works between two people.

Joe Duffy, RTÉ Radio 1:
Okay, thank you Jean Anne and we'll be back after this break, joe@rte.ie.

[Ad Break]

Joe Duffy, RTÉ Radio 1:
We are talking about what it's like to be deaf in Ireland, obviously there are impediments in doing it on the radio, but I think we're overcoming some of them at least through Zoom here in the studio and various other methods. Triona Keane, Triona, good afternoon.

Triona Keane:
Hi Joe, how are you?

Joe Duffy, RTÉ Radio 1:
Good thanks, tell us your situation.

Triona Keane:
Yeah, and thanks for having me on. Yeah so, I suppose I have grown up with I suppose hearing impairment, I suppose I'd lots of ear infections in my ears growing up, that I suppose that eventually led to me kind of becoming I suppose moderately deaf. So, eventually then when I was 17, I got a hearing aid then at that stage and they were great.

Joe Duffy, RTÉ Radio 1:
And they made a difference.

Triona Keane:
Absolutely. Yeah absolutely, like yeah, I just said to your researcher yeah it really was like getting a new lease of life at that stage. I suppose the difference in the sounds I could hear kind of and I suppose how clear people speech became kind of and yeah it was brilliant, yeah, it really was.

Joe Duffy, RTÉ Radio 1:
And Triona do you lipread?

Triona Keane:
I'm not I suppose trained or I haven't done anything to try and lipread, but I think but a lot of people say to me that I do subconsciously actually lipread and I think I do yeah, without kind of realising it yeah, like I do definitely, yeah.

Joe Duffy, RTÉ Radio 1:
So, you want whoever's talking to you to reiterate what Jean Anne said, you want whoever's talking to you to speak clearly and to you, in front of you as well.

Triona Keane:
Yes, yeah. Just simply because I definitely find as soon as people turn their, someone turns their head kind of away from me, I suppose just immediately I suppose I just start to struggle. I suppose that's kind of I suppose that's where I come from, I suppose with my particular hearing impairment I suppose, I just kind of start to struggle to hear then at that point. It's just – I suppose I just find it easier to kind of to hear when I'm facing someone like, if I'm kind of like sitting down with someone or something like that, I'll often, I won't even, well aside from COVID times, of course but I won't go to sit beside them, I'll often actually sit across from them, so that I am facing them, yeah.

Joe Duffy, RTÉ Radio 1:
Okay, thank you Triona, that's Triona Keane. Kathleen Nolan is in Beaumont in Dublin. Kathleen your situation please.

Kathleen Nolan:
Hiya Joe. Lovely to have me on. Yeah, I'm just talking about my son, he's 43 now.

Joe Duffy, RTÉ Radio 1:
Okay.

Kathleen Nolan:
I never leant the sign language which I was raging I didn't but he done very well.

Joe Duffy, RTÉ Radio 1:
When did you realise he was deaf, Kathleen?

Kathleen Nolan:
I realised when he was in the cot Joe and he was only about say about 10 months old and he'd never turn around only if he saw a light on the wall that he'd know I was there. So, he got his hearing aids at a year old.

Joe Duffy, RTÉ Radio 1:
And did they make a difference?

Kathleen Nolan:
Not really, he used to throw his, the things in his ears in the fire. I used to be crying, you know as a baby, but like I taught him how to speak in a funny – even though he's deaf I taught him to say, thank you and it took hours for him, just to say thank you because he wanted me to speak for him.

Joe Duffy, RTÉ Radio 1:
And how did you teach him?

Kathleen Nolan:
Like say if I was cleaning out the fire, I'd be rolling up the papers years ago and he'd be helping me as a kid, he wasn't in school at the time. And I'd turn around to him and I'd say, 'Say thank you', and he would just shake his head and I'd say, 'You're not getting it, say thank you', and eventually, I have it on a tape when he was a kid, so I taught him how to speak, even though he's profoundly deaf. So he went to ordinary school until he was about 10, then he went to Cabra.

Joe Duffy, RTÉ Radio 1:
The School for the Deaf.

Kathleen Nolan:
Then from Cabra he done his Leaving and he went to Sandymount and the girl in Sandymount said, 'Wesley, this is not for you, you're profoundly deaf but you have everything in you', so she got him into Bolton Street to study construction management. And he said, when he got a certificate but he said, 'Mam', even though he's not able to hear he said, 'Mam, I'm going to be up on that alcove in my gowns.' So, he went off to university in Wolverhampton and he represented Ireland first in water polo for the deaf in Ireland, and that was in Beijing, and from there he came home, then he went off to Wolverhampton to study and he, it took him four years and he was the only deaf lad in that university and he got his degree.

Joe Duffy, RTÉ Radio 1:
Wow, fantastic.

Kathleen Nolan:
From Wolverhampton, so then he was a career guidance for the deaf in London and he used go all around London and it was a lot on him because he has three kids and he has a partner in Rochester and Samantha Cameron invited him to 10 Downing Street.

Joe Duffy, RTÉ Radio 1:
David Cameron's wife.

Kathleen Nolan:
And I said, 'God, Wesley, I said go out and buy yourself a good suit, don't let me down', which he did and then he went in, and she just wanted to know what kind of work did he do for the deaf. And he had an interpreter with him because he said in England they had better interpreters than Ireland, so I went through cancer and he was going to – he said, 'I'm going

to swim the English Channel in three years'. So, it took him three years to train in swimming pools, in Dover beach. So, in 2014 he swam from Dover to [Walnot], 16 hours 35 minutes it took him. And he raised it for the deaf, he was going to do it for cancer and he said, 'Look mam', he said, 'the cancer society is always getting sponsored, you know, getting money, but he said the deaf in Ireland', he said, 'they're forgotten about'. So, he raised €11,000 Joe, in 2014 and he came over to the Deaf Village and he put up his story. And we all went, the whole family and they represented him with a beautiful Waterford crystal saying, Wesley fair play - but he wanted the, you see the Irish sign language was never recognised, which I never knew, Joe.

Joe Duffy, RTÉ Radio 1:
And it is now.

Kathleen Nolan:
And it is now and Michael D Higgins had signed that thing.

Joe Duffy, RTÉ Radio 1:
Into law, yeah.

Kathleen Nolan:
The day after he gave that cheque to the Deaf Village.

Joe Duffy, RTÉ Radio 1:
Brilliant.

Kathleen Nolan:
So, he done something good even though he's profoundly deaf, he achieved a lot in life.

Joe Duffy, RTÉ Radio 1:
And where did that come from? His parents and yourself, Kathleen.

Kathleen Nolan:
Yeah, and I was right beside you Joe, in Glasnevin.

Joe Duffy, RTÉ Radio 1:
Okay.

Kathleen Nolan:
But anyway, well that's his story. I never learnt, as mother and father we never learnt the sign language because we were told not to in Cabra.

Joe Duffy, RTÉ Radio 1:
Okay. Stay with us Kathleen I've one more break to take.

[Ad Break]

Joe Duffy, RTÉ Radio 1:
Just before, I'm told we will be continuing this tomorrow such is the volume of calls but Jean Anne - Jean Anne Doyle, who I'm talking to on Skype and she's primarily hearing me through or communicating with me through reading my lips. What was the experience of the programme like for you Jean Anne, because I am conscious that you are not able to hear all the other callers?

Jean Anne Doyle:
Yes, yeah so, I obviously didn't hear what they were saying, but it's really great that you could recap some of the speakers and what they were saying. So, I was able to kind of then comment. I was having a think about you know, maybe going forward in terms of accessibility, for radio stations in general. It's something that I always talked about but never actually kind of just got in touch and said, 'Maybe we could do this or that', the programmes if recorded, they go on the website if they have subtitles.

Joe Duffy, RTÉ Radio 1:
Subtitles, yeah.

Jean Anne Doyle:
So, if anyone wanted to listen to the show and I think a lot of people with hearing problems or deafness would love to do. That would be great for people that have a hearing loss, however, maybe a BSL - ISL or BSL video alongside the recording clip for the show specific to this matter would be really great because then you have those who use sign language and those who need to use the subtitles.

Joe Duffy, RTÉ Radio 1:
Okay, thank you indeed Jean Anne Doyle and all our other callers, Fergus Sweeney produced, Ray Darcy is next.

ENDS