

Interview with Near FM (Dublin's Northside radio station)

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Caroline Carswell from Irish Deaf Kids talks to Michael FitzGerald on Northside2Nite at Near Fm in north Dublin.

Michael I'm joined in the studio today by Caroline Carswell, the founder of Irish Deaf Kids. Now welcome to Near fm and welcome to the Northside.

Caroline Thanks, it's great to be here today.

Michael Caroline, before we start off today I want you to share with our listeners - you were born profoundly deaf. is that correct? It wasn't that you contracted an illness and lost your hearing, you were born deaf?

Caroline I was born deaf, yes and it was picked up at about 18 months. I got my hearing aids in both ears and started speech therapy and my speech therapist made it great fun so it wasn't like hard work.

Michael When we talk about that, neither of your parents were deaf - is that correct ?

Caroline Yes, there was no deafness in the family so it was a bit of a surprise but my parents did all the research both here and in the states about their options and they decided on the verbal approach with me, which was hearing aids and listening and speaking.

Michael And the case which we were talking about before we came on air is some friends of ours that both of the parents were deaf, but neither of the children are deaf. And so that got me thinking there's a whole world of communication that people have and how they learn to live with each other and communicate with each other, that the hearing community doesn't even hear about. Is that a fair way to look at the world and how you move about in it, Caroline? If you have parents that are not deaf, or equally if the parents are deaf and the kids aren't, they have to establish ways to communicate with each other.

Caroline Yes, they have to work harder and what most parents do they make the communication visual - that could be by teaching the alphabet in print and a few parents use sign language as well to learn words and meanings with their children then sometimes the parents are learning to communicate at the same time as the children. That requires more work but communication is so important it is worth making the most of it.

Michael I got to ask a hard question now. I have never heard of a case where parents rejected a child because of deafness - does that happen? All parents want their child to be perfect. No child is perfect. Are there cases where the child has been diagnosed maybe where parents say 'oh damaged goods, I don't want anything to do with that'. Have you heard of cases like that ?

Caroline Just a few, I am happy to say. Thankfully these days with technology and hearing aids it is easier to be deaf than it was before than say in the 40's, 50's, 60's when parents were more hard hit because you need to be able to hear with hearing aids to be able to speak because the aids process your speech. So back then the hearing aids weren't as available or as good as they are now, so communication would have been more manual then.

Michael Clearly we have much much better technology now. Has the knowledge base kicked in like education the way in which perhaps you would be able to overcome would be implants, hearing aids, lip-reading and there would be sign language. Has the technology improved from say when you were a child Caroline?

Caroline It has very much, yes. My first pair of hearing aids would each have been the size of a pack of cards with two cables in each ear and now I am very happy to say that they are tiny they are not quite in the ear canals in recent years unless you have more hearing loss but overall it is really great to have smaller hearing aids that are robust.

Michael So how old were you when you started wearing a hearing aid?

Caroline I was 18 months. These days kids are getting hearing aids from their second month upwards. We were talking to a contact the other day that provides a baby hearing aid for babies of 6 months upwards and as the child grows the hearing aid can grow with them.

Michael So when you starting wear a hearing aids, Caroline, I know when I first realised I needed glasses I was really self conscious and I had a pair of glasses for about four years before I would wear them all the time. Because you were so young was it something that was always there or were you very self conscious as a child?

Caroline Yes, I probably became aware of the hearing aids and other peoples' reaction from about 5 years age upwards and that actually is why we devised our children book, "A Birthday for Ben". The story is about a seven year old boy who has a hearing aid and the book helps to explain hearing aids and the concept of being deaf to children and adults of all ages.

Michael So were children horrible to you? Now I know kids don't mean to be but I remember I used to be called skinny, I used to be called specky four eyes, I used to be called carrot top were kids awful or are Southside children nicer than the ones I grew up with Caroline?

Caroline It is very interesting, I never actually believed it. It was more peoples ignorance that annoyed me asking, what is that in your ear? They were just curious and they did not know otherwise - maybe they associated deafness with senior years?

Michael When you were growing up then and wearing a hearing aid did it stop you doing sport I think if you were doing swimming you would take it out but did it stop you doing traditional sports you would have played at the high school like hockey?

Caroline Absolutely. Hearing aids need to be robust now.

Michael I'm going to ask you the difficult question, Caroline. When one gets to the age of 12, 13, 14, Caroline one starts to develop in a certain way and we all become self conscious whether it becomes looking at boys or girls was that a difficult period? Did you become more conscious look at me going around with a hearing aid and look at that blonde one over there, I'm putting on a hearing aid and she's putting on her lipstick - was that difficult?

Caroline My experience is actually very positive, maybe because I'm confident with wearing hearing aids. Having them all my life I was comfortable with them and telling people about them. In terms of dating I haven't found hearing aids to be a real issue.

Michael When you were at school. am I right in assuming you were probably sitting at the front of the class so you could see the teacher?

Caroline Yes I sat in the second row because the teachers were on a podium and front row you would have had a crick in your neck looking straight up at the teacher so my favorite place was in the second row which gave a bit more privacy to write notes in books with pencils.

Michael The other side of the coin and this is something I learnt from our friend Shane O'Reilly in his house they had lights so when the phone rang you didn't hear the phone, you saw a light when the door rang you saw a light. Was that the same in your house to the same extent?

Caroline Yes we did have an adopted doorbell it would make everybody jump when people were around because the house lights would darken.

Michael Did you have brothers and sisters?

Caroline Yes, they are both hearing.

Michael How did you get on with them - did they learn to communicate with you ?

Caroline We talk verbally, we have a great relationship - my brother was my sparring partner growing up and my sister is 9 years younger. She was a great help with the phone and dating - when the boys are calling, you don't want them to talk to your parents.

Michael So have mobile phones helped a great deal with that?

Caroline Yes that was before text. I am delighted with mobile phones actually because you have privacy and not someone listening in on your conversations.

Michael as all children and teenagers want, is that right?

Caroline yes, they want privacy

Michael So a couple of areas I would like to look into, Caroline.

Education. You were lucky, Caroline, you said to me you went to mainstream education you didn't go to the deaf school in Cabra where my aunt used to teach in the 50's. How important do you think that was? You weren't segregated from the rest any more than the guy that was short sighted you were in the same class. How important was that for you for your personal development?

Caroline Yes, it is huge being in mainstream school because I was with friends I had known since preschool age and primary school age when in secondary school and that is the reason I am so comfortable with interacting with people from different backgrounds.

Michael Is it that deaf children are now generally being educated in mainstream schools or is it a class thing in the sense that if you had the money we can send you to the high-school or Wesley or Belvedere? Or if you're a poor person and your child who has hearing issues will be sent to somewhere like Cabra or a specialist school I hate to use the term - what is the situation for the majority of deaf children, Caroline?

Caroline First of all there are over 3,300 children in mainstream education - they are visited by visiting teachers from the Department of Education so the teachers have this help and support.

Michael Would these be classified as special needs teachers ?

Caroline To an extent their work would be monitored, but not in a bad way - in the country it would have an impact on schooling for example if you were in Donegal you wouldn't have a unit for deaf children. So in Dublin you have the two deaf schools and in Limerick another one.

Michael Something that I was saying to you about my friend Robbie because he grew up in rural Ireland and had 2% sight they took him to a specialist school and he was educated with people with sight difficulties perhaps it might have been different for him if he grew up in a bigger population centre. Is that the same with people who are deaf in country areas and or on farms they are more likely to be separated from their family which is something I think everyone would regret?

Caroline It would be the parents choice really - we find parents usually evaluate their child's school options all the while making sure the children are keeping up. Of course sometimes, the child is moved around if they need more one to one teaching.

Michael The other side of the coin is that we hear about the economy and certain facilities under threat. How is deaf education handled in this economy - is there still a lot of support or is deaf education an area where we don't have as much money to spend now so you have to look after yourselves unfortunately. What is happening or is the news better for say deaf education ?

Caroline It is interesting the reduction in support hours this academic year, the 10% reduction. It means a child who had 4 hours of resource teaching goes to 3 1/2 hours which is not as bad as it sounds with the teacher and child getting more out of their contact time to improve efficiency.

Michael So is that putting more pressure on parents? Are the parents having to make up in attention or supervision of a child that would be the responsibility of teachers a couple of years ago?

Caroline From what I'm hearing in the grass roots, if a child is managing in mainstream and keeping up with their peers - that reduction is not causing huge issues. It depends on the individual child and how they receive info in class and the efficiency of the class teacher and resource teacher in that time.

Michael What sort of support and I'm thinking here in terms of financial support because hearing aids cost money, implants cost money even remedial teaching to a certain degree costs money whether it is sign, lip-reading - do they get help from the government to support deaf children?

Caroline In fact hearing aids are funded on the HSE until a child completes full time education, that means 23 years of age. If a child goes to university which more deaf children are doing that is fantastic as for cochlear implants they are available on the HSE as well the hospital is negotiation to retain the funding for those because they are so important.

Michael Do many deaf people go onto University education?

Caroline I believe it is about 15% at the moment but this year we had some very encouraging reports about somebody in veterinary medicine at UCD and two people who had 520 points and 495 points equally.

Michael So that would probably get them into study European history or something like that now. Trinity of course have a deaf centre, don't they - is that for deaf studies or is that.. I suppose what I'm asking is how are the universities set up to deal with deaf students because I know from experience originally Trinity in particular weren't set up to deal with people with chairs and they had to put in ramps and they didn't want to put in ramps and they didn't like putting in ramps because that affected the architecture. Clearly it's a different situation with deaf people but some of these lecture halls are very large so if you're not at the front and are doing like you are lip-reading it must be very difficult and if you don't have good hearing a you have to be very close to the speaker to pick it up. What feedback are you getting Caroline about how the Universities respond to the needs of deaf students?

Caroline There actually is a program in place in Trinity called deaf support in third level where they get the leaving certificate students together and educate them in the support available in all the universities and institutes of technology so the aim being that this student can go to their access officers and say they are entitled to a note taker or sign interpreter. As you said earlier if someone lip-reads they cannot take notes at the same time. That's where the note taking comes in.

Michael Communication is clearly really important and that's where I came in on this and if we want to we can come up with ways of communicating and I found that really exciting as I mentioned to you, I came across Arts and Disability Ireland and how they were doing captioning for plays and I never heard of that before and I'd seen captioning and I was like yeah, we have seen that and I am going to ask you in terms of socially I asked people in wheelchairs and blind the same thing when I was your age deaf people would have had great difficulty going to the cinema.

Michael What is the situation is it improved now even with a hearing aid? Can you go and get the full cinematic enjoyment? What is your experience in that regard?

Caroline There are some barriers which is crazy since digital films are coming in because the subtitle code can be embedded in the digital code - now it is the cinemas responsibility to switch that capability on.

Michael Are there many in Dublin?

Caroline There are some, I believe Galway is good in activating this code. We have asked the Swan cinema in Rathmines but they are a bit slow on the uptake as in in the bigger picture the Irish film Institute in town is a better option because they have foreign films with subtitles so audiences there don't object to subtitles.

Michael Ok yeah my generation grew up before dubbing and actually like subtitles. I would rather have subtitles than look at an Italian movie with American accents. I just hate that. I would rather read a subtitle going across the bottom of the screen I'm comfortable with that.

Michael Help me on this one. Music. Is music out on this? We have an example of Evelyn Glennie. Evelyn is a percussionist well known in classical music but is music absent from your life is the question I would ask you ?

Caroline That is a very general question - it really depends on the person and how receptive they are to vibrations in their environment and also on whether they have a hearing aid or cochlear implants. Sometimes it can be a revelation how much you can hear and enjoy music. I remember going to see The Phantom of the Opera in London and the clarity of the sound really opened my eyes because opera has a purer sound than classical music.

Michael I was thinking Caroline is probably into heavy metal. Some people like it for that reason. You get the vibration.

Michael So have you been to the Grand Canal Theatre ?

Caroline Not yet

Michael I recommend it to you because the sound quality there is the best I have heard in Ireland we will happily talk to the Swan Cinema and say why aren't you putting on movies that Caroline and our friends can see.

Michael Now moving along Caroline you can lip-read other people use sign. Is it purely historic that you learned to lip first or whats the situation? Is there a general rule in the deaf community that we sign or do they prefer to lip because that mainstreams community more.

Caroline It goes both ways, what I find is a lot of deaf people I meet who sign are able to lip-read or are open to writing things down. Generally lip-reading has been an asset to everyday life. You can go everywhere and understand. I really recommend backpacking for deaf students because you meet a huge variety of people from different countries and that broadens your understanding.

Michael Something that I came across a few months ago and it is something I am interested in seeing the issues behind it. Irish sign language now it is not in gaeilge it is in english is that correct? It is a means of communication using signs but it is using the english language is that Irish sign language Caroline.

Caroline Yes Irish Sign Language is unique to Ireland in that it has its own syntax and grammar and names are spelt with one hand whereas in the UK the sign is different. It is just where the signs evolved in Ireland - you have different signs in Donegal and Cork they have different dialects even in Belfast, and in NI there is NI sign language.

Michael Like the Irish language. I did an interview with senator Cait Keane and she was hoping to get the government to recognise Irish Sign Language because I gather people wanted to do exam in Irish Sign Language and be educated in sign language that was important. As part of the good friday agreement i understand sign is recognised in NI but not here.

How important is it that Irish Sign Language is given recognition?

Caroline It is very important to the signing deaf community because there are about 1000 signers in this country who grew up with sign as their first language. In fact the Irish deaf society campaigns for that recognition. At the moment they have a photo exhibition with celebrities signing letters with different signs. I believe that exhibition is going on national tour soon.

Michael The other issue when I was growing up and I was self conscious because of my hair and people used to call you this and that and the other carrot top and all sort of things and my mother used to say when I came in crying because people were slagging me off don't worry, Jesus had red hair. Are there role models for the deaf that you can recommend to young kids and say there's that person...

Caroline Yes we have to remember that deafness is a different experience for everybody. There would be a few different role models. One would be Evelyn Glennie who you mentioned. Another would be deaf rapper Sign Mark he is from Finland I believe. He travels around and his concerts are very popular. In the states you have Marlee Matlin.

Michael Marlee Matlin was the original really, Marlee won an Oscar for Children of a Lesser God. When we see Marlee not as a deaf person but in a mainstream movie where she just happens to be deaf, how important is that you don't see many deaf people on television?

There is a very interesting storyline developing in Eastenders one of the little boys in that has had a hearing aid from a very young age and he is also doing boxing now. That must be very encouraging if you are a child who is sitting at home with a hearing aid and you hear someone that must be very encouraging.

Caroline It is yes in fact my parents made sure I knew other kids with hearing aids in primary school there were three other children with hearing aids and in secondary school I kept in touch with them. We find as well in Irish Deaf Kids that parents of older children are really encouraging to parents of younger child because the parents of the younger children can see what it would be like when their children get to say 9 or 10 years of age.

Michael

Going back to the Shane O'Reilly story I mean when everybody is going out and we are looking to meet people. Ignorant people might think I better not go out with that person because I might fall for them and I might have a child with them and the child might be deaf. For example in Shane O'Reilly's case both his parents are deaf neither of the children are there is no linkage just because you are with a deaf partner that either of the children would be deaf.

Is that a reasonable explanation Caroline?

Caroline I haven't found it to be the case, no.

Michael And have you ever come across prejudice and as you have been growing up and becoming a young woman have you ever come across people that were prejudicial against deaf people in say African people might or gay people might or have you been lucky to avoid the more ignorant in society?

Caroline Yes I think most deaf people meet everyday ignorance maybe when they first meet those people those people may not know anything about deafness they may cover their mouth when speaking to that person or they might shout that doesn't help because sometimes we can lip-read but overall I haven't personally come across any discrimination whether it happens in the background it's hard to know.

Michael You drove out here today, is it difficult for instance I don't drive a car, I ride a motor bike. is it difficult to drive a car as a deaf person or do you just steer straight ahead

Caroline In fact it is one areas where deaf people have an advantage because there is scientific evidence to prove that our vision is more developed. We have 180 degree vision if your eyes are good and it will help because you can see that wing mirror and the other wing mirror.

Michael When i do a driving test I have to wear my glasses it is part of the conditions on my li-
cense is there specific conditions for people that are deaf?

Caroline My driving test was some years ago so I don't know about the current rules but I do have a great story of a colleague who was doing a driving test and he found the tester had a beard which made lip-reading very difficult so he explained to the tester that because of the beard he would find it more difficult to lip-read and he might be asking for the questions to be repeated instead. This is really interesting. The instructor parked the car, he said wait a minute and he went back into the office and he reappeared five minutes later having trimmed his beard.

Michael So when you get a taxi would you have to sit in the front seat so you could talk to the driver and give him directions ?

Caroline Yes it is very important as a deaf person to be clear about your communication needs and that is an area where you have to get it right. You have to be like an elevator pitch and you have to get it across in 5 seconds.

Michael Theres no real reason why children who are deaf should have an enormously different life to those who got hearing - I'm just talking in normal children's activities like playing.

What would be the type of activities that deaf children do. Do they like say doing drama or would they be just as likely to do sport. We often ignorantly hear the view that deaf people are isolated and they are solitary and readers. I would have thought that something like drama deaf children would be just like everybody else doing it. Is there a outlet of deaf children doing drama in dublin ?

Caroline It can vary from person to person it depends on your personality obviously whether you want to perform if you have a hearing aid or an implant it would be much easier for you to pick up what is being said around you. So I am not saying mainstream drama is an issue because some people manage other others like you say might prefer to go to an exclusively deaf group. But it is great to have both the options.

Michael You founded Irish Deaf Kids how long has that been going Caroline?

Caroline It was founded 4 years ago we are delighted with how it has grown since because it started as a blog and we got the grant and funding over the last 4 years.

Michael Who's that from the Department of Education?

Caroline Not the Department of Education specifically but some from the HSE and some from Dublin Bus and from private companies like Three and Irish Life. It took a lot of work and a lot of writing of funding applications but we now have information sessions and workshops and seminars for outreach and book readings like today just to get the message out that it is a mainstream organisation and that inclusion is very important to us.

Michael Well done, well done, As you say it started as a blog, so what is its role now is it all embracing, it is a collective organisation for the deaf community or is it specifically orientated towards children or do you have something else for parents?

Caroline Our stakeholders are from different backgrounds. We have parents, we have children, we have educators, we have technology people, we have researchers, we have policy makers, students really across the spectrum because that is what mainstream society is about.

Michael It's a community.

Caroline Our focus is education. We focus to that because there are other deaf groups with different focuses so we thought it was important to have the niche and to do it well having come from that background myself.

Michael Well that's what we are hoping to be able to encourage and to assist the deaf community with but your doing a reading *A Birthday for Ben* its a child's story it is going to be a reading for children. What is the book about just to share with us because you will be doing it again?

Caroline The book is about a boy who is 7 and he has a hearing aid and his party is coming up and he tells his parents he doesn't want a party because he is afraid that his friends who are deaf and hearing won't be able to enjoy the party games.

Michael That's a very natural reaction isn't it?

Caroline Yes the book is actually educating everybody about the appearances of a child who is deaf and how they might see the world.

Michael And who wrote the book ?

Caroline It was written by Kate Gaynor from Special Stories. We had the idea of a book and we needed a publisher to do it so we talked with Kate and through another contact I met an artist who is deaf and she did the illustrations very visually in a way another artist might not have done.

Michael You were saying earlier that ITV have filmed it is it available or can people find it on the internet somewhere ?

Caroline Yes the ITV animation is on signedstories.com - you have to search for the book title but it is up there and some of the images from the original book have been animated for that film so we are very excited about that.

Michael And how did the children react to it - do they see themselves ?

Caroline Yes we have had some really touching feedback from families and adults who wish this book was around when they were children and we also have aunties and uncles who are deaf and they need to introduce hearing aids and sign language, hearing aids and sign language to their nephews and nieces so they do it through the book.

Michael You and I and I think this is quite an interesting one this is the first time we have met each other. How important are social networks ? You and I came across each other through Facebook. How important are social networks to the deaf community? Does it reduce that sense of isolation and clearly it is an effect means of communication. You're a big user of it yourself which is great to see

Caroline Like i said we use Facebook and Twitter to communicate without hearing in the case of videos when there is audio present we make sure there is subtitles. For people who don't hear so well social media is very important because hearing doesn't matter. Most of the communication would be visual and text based. We find for the deaf community who sign they make sign videos and they can quickly share those across Facebook and Twitter and we recommend captioning for people who don't sign.

Michael You recommend captioning ?

Caroline Yes on all videos on the web it should be easier to do and it should be more routine because there's nothing worse than having a beautiful video and you can't hear some of the sound you can't quite hearing some of the words that can be said it can be quite frustrating. Irish Deaf Kids is talking to people working to make web videos easier to captioning. We also had people together at a seminar last monday to talk about that topic for example to get signers in the deaf community to caption their videos to make those videos accessible to the mainstream community

Michael So we both saw Shane's play 'Follow' when I went to see it at the recent Fringe I'd say over half the audience were deaf. How important is it that the hearing community recognise not only that there is a market out there but there is a demand for plays, drama, television, theatre and not exclusively orientated but has a primary orientation towards the deaf community. Clearly it was well received people enjoyed. It was awarded 'The Spirit of the Fringe' which is great because Shane is a lovely guy as well and to me that was a recognition not so much of a play but a community. Was that seen in the community that way as well Caroline?

Caroline We know the signing deaf community is very strong and that really is a fantastic resource for people in the community in terms of accessing theatre, television or lets say video some people would like more sign to be used in these productions and in fairness the Abbey Theatre produces at least one signed performance and captioning. So the Abbey and Arts Disability Ireland are working to make their products accessible to those who sign and to the people who prefer captions so in numbers terms there are probably around 35,000 people in Ireland who know some sign. One thousand of those would be native signers with sign language as their first language in the bigger picture you would have around 700,000 people with hearing issues going from senior hearing loss to primarily deaf people - that is the size of the market for captioning and sign language.

Michael We have got a gentleman staying with us at the moment he is late 60 early 70 as with many people his hearing goes. His hearing is considerably reduced so if I stand behind him I say answer the phone he cannot hear it. Someone like that is in denial that his hearing is going how much can someone like that learn from the community who have experience with hearing loss and accept it because to me he is denial about his hearing loss.

But just how to deal with reduced sound to me there is a great bridge to be built there that would be an area where the deaf community would be in the driving seat in effect how do you feel about that, Caroline, there could be a role for the deaf community in helping people particularly whose hearing is going but don't want to admit that their hearing is going and don't want to wear hearing aids or say I'm too old to learn sign language or I'm too old to learn lip-reading. Do you think the deaf community could play a role in that way, Caroline.

Caroline I think hearing aids have an image problem like you say and in fact the statistics show the senior people take 10-15 years to seek assistance and that is a long time to be missing out on everyday communication so I think that they will benefit as they say they have contacts and learn how the hearing aid benefits their everyday communication and with family and friends sometimes the person who is losing their hearing is asking everyone around them to repeat maybe 2 or 3 times and everyone feels the pressure because of that so there could be a case for deaf people to encourage. I know sometimes at parties people have a quiet word with me they say so and so is not hearing - would you be able to talk about hearing aids and how great they are these days. I am getting more and more of these requests.

Michael They value your experience then Caroline. Last but by no means least today, we have a reading of a Birthday for Ben. Any other things coming up with Irish Deaf Kids that we want to share without listeners before we go ?

Caroline We have two events before Christmas in November and December, we will put details on the site as they are finalised so keep an eye on the calendar page because that is where they will be listed and then we have another event in the spring so there is a steady stream.

Michael Well you make sure you let me know and we will make sure other people get to know - Caroline it is the first time we have ever met and I am almost certain it is not going to be the last.

It is great to communicate and I hope that here in Near fm we can play a role helping the deaf community and to help yourselves. So, Caroline Carswell and all our friends in Irish Deaf Kids and all our friends in the signing deaf community it has been a pleasure in talking to you today.