

## SPEAKER:

## ALICIA McGIVERN:

Good morning everyone. I am head of education here at the Irish Film Institute. Along with Richard Fallon, we are delighted to welcome you today. It is a great event and we are delighted to have the chance to work with Caroline Carswell again due to her professionalism and dedication, which I am sure anyone who has encountered her will agree with.

I am conscious of making film accessible at personal level - as someone on the national cochlear implant waiting list, I am aware of the power of film to raise awareness of issues not usually visible to the public. Before handing over to Caroline to launch the event, I will give you a running order.

After Caroline opens the event, there will be a short pause while we dismantle equipment here and the screening will begin. After the screening, a short pause while we set up the equipment for captioning. After the question and answer session, which will be captioned, we then go to the mezzanine for refreshment. The fire exits are here and where you came up. The toilets are at the back of the foyer, where you gathered earlier. I will hand over to Caroline to open the event.

(Applause)

## CAROLINE CARSWELL:

Thank you for being here today. Some background to the film and our collaboration with Lisa Reznik, the producer. Four years ago, Lisa emailed me from New Jersey after seeing a blog post on the <u>Sound-Advice.ie website</u> and the relationship has grown since. Long story short, we screened 95 Decibels here in January 2014 after eligible children in Ireland gained access to bilateral cochlear implants on the HSE, which brings huge changes in public prospects regarding education and employment outcomes for this pediatric population.

Good to see Lisa and her family in Dublin again today, and necessary to remember the social issues we are addressing, are exactly the same both sides of the Atlantic. Enjoy the film!

(Applause)

(Film plays, 27:30 minutes' duration)

(Applause)

# RICHARD FALLON:

Just testing for the captioner.

## JOHN EARDLY:

Okay, we're ready to go. I think we all just experienced a very powerful film. A wonderful round of applause again to Lisa for all the work she has put in. As you can see from the programme, we want to welcome the organisations and all they've done for us. I also want to welcome Deirdre Donovan. I suppose you want to know who I am. I am John Eardly. from the Faculty of Law at Griffith College in Dublin. It seems they, from starting at 1996 onwards, developed a lot from that period of time to what we would call a diverse approach. Which basically means that we see ourselves in Ireland when we talk about education barriers in various ways.

We talk about education barriers in regards to religion here in Ireland. But we are also becoming more aware of other types of education barriers like the freedom of choice when a child is deaf. That's one of the things this film is identifying and It is very important to be aware of different perspectives, choices and access to individual rights in these discussions.

I think, in terms of developing this campaign about parent choice, it is very much in keeping with how that has developed as well as a human rights campaign. So just to start the ball rolling. The reason for this question and answer session is so you can find out your answers from the panel.

The first question I would like to ask is to Lisa herself. In terms of the film, when you first started making a film - what inspired you? And when you started, did you have an established idea for the film or did it evolve and change as you went through the process?

So, what inspired you, and how did the film process evolve as it did?

## LISA REZNIK MEYERS:

We decided that our main goal was to educate and possibly entertain a little bit. We try to add a little bit of humour. We wanted to talk about the generational differences and we also want to relate a story, showing that cochlear implants are a great option because hearing aids may not provide enough sound for our child to be able to learn to speak clearly.

It also raises public awareness about cochlear implants and builds inclusion. The film's been shown all over the world, so we're very happy to be working with Caroline and other people in Ireland. We have had screenings in other countries as well.

#### JOHN EARDLY:

There are also a number of very powerful moments, certainly in terms of battling barriers such as the insurance industry at the time. Could you speak about that a little, in terms of the effect it had on your family? And you mentioned that the situation had changed since. Have those barriers changed, in your experience of the battle to get health cover for this type of surgery?

## LISA REZNIK MEYERS:

We were quite worried. But our insurance system has changed since then and improved. Our daughter is now 20 and we have to be aware that it's just as important now as it was then. So that would be the audiology and the language therapy after a cochlear implant is activated.

## JOHN EARDLY:

Just moving down the line to our other three VIPs on the panel. [**To Miranda**]: If you were to explain to our other panelists here, what is the advantage or the effect that you feel this option [implants] has had after the decision your parents took - what was the effect it had on your life?

## **MIRANDA MEYERS:**

I've become a lot more independent [with cochlear implants]. I'm able to converse with almost everyone that speaks the English-language. Sometimes it's difficult, but I am usually fine. I would not be where I am today without my cochlear implants. I am able to communicate with anyone that I want to and experience things that all typical young adults experience.

#### JOHN EARDLY:

And our other two participants from Ireland - in terms of your own experience [with cochlear implants], how have you found the situation in Ireland on a day-to-day basis? For example, in school, how do you find that experience?

#### **ODHRAN SEXTON:**

I cannot really say that I have felt much change. It would have been a lot more difficult for me growing up in school. First off, with all the teachers and many of my friends, they would have had to have learned sign language just to be able to communicate with me. That would have made a lot of unnecessary complications rather than just getting the implant and learning how to speak. I found that it has been a lot easier for me and I am fairly happy with it the way it is now.

#### JOHN EARDLY:

Do you have other friends and support groups that you can connect with that support you in your expenses?

## **ODHRAN SEXTON:**

I take part in athletics within and outside of the school. It has given me a variety of friends that I am able to make inside and outside of school. I enjoy doing it. Without the cochlear implant I would not be able to do it as well.

#### JOHN EARDLY:

In terms of Ireland, we are at the start of it, in terms of the battle. In terms of role models, you rarely see people on the screen or television that are speaking deaf, is that important to young teenagers when they are growing up? Do you think this gives them confidence?

#### ODHRAN SEXTON:

I think as long as they are benefiting from it [an implant], it's great for them to see that it isn't such a bad route to go along. Even if it does not work out quite as much as they see on TV it's still an improvement.

#### JOHN EARDLY:

Absolutely.

#### CAROLINE CARSWELL:

My friends that I am in touch with today, are all from the sports teams at mainstream school and college, like Odhran says. Sport genuinely breaks any barriers with hearing and builds lasting friendships.

If you are a parent and a teacher comes to you with concerns, please listen. It could be greatly beneficial to a child in a classroom.

#### JOHN EARDLY:

At this stage, I'll like to ask if any one has a question to ask the panel?

#### SPEAKER:

Is it OK to take a photo of you? I would like to know that if a child is born with a hearing difficulty, is there a waiting list - how long is a waiting list, and how do you find yourself in this situation?

#### LAURA GRANT:

Hello, I am Laura Grant and I'm speaking from a parent's perspective. Can I have a show of hands who is a parent in this room?

In my experience, there was a wait. It was a bit of trial and error, for the expense in my family's case. We went to our GP, our general practitioner, almost immediately. And hearing loss had become apparent. We were put on an 11-month waiting list for audiology. So we decided to try privately, and then in that period, that 11-month wait, we had a cochlear implant because we pushed through the system. That is not available for everybody. We're based in Dublin. I think things are getting better. There is hearing testing for newborns [since 2013].

Things have gotten an awful lot better, there are a number of representatives for hearing care in this room. They continue to do great things in the HSE. There are huge stresses on the health system here. Unfortunately hearing loss is an invisible issue for a lot of people. It is not, it is not seen to be as serious as it is. In my experience there were obstacles put in my way in terms of accessing parent options, things were made easier recently, but there were definitely obstacles at the time.

#### JOHN EARDLY:

Any other comments or questions?

## **QUESTION FROM FLOOR:**

Yes, a question for Lisa and Miranda. For the prospect that you were not being covered by the insurance, I was wondering now, does the insurance cover now seem to be better? We do not have insurance in the States, like the system in the Republic of Ireland. Is it better now?

## LISA REZNIK:

it could happen.

#### **MIRANDA MEYERS:**

I find that getting the first implant is covered but the second implant is not covered by Medicaid. If you don't qualify and cannot afford to get a second cochlear implant, you are at a loss [in terms of accessing the possible benefits].

#### LISA REZNIK:

The mother who played audiologist Susanna did not have insurance coverage. She was in Croatia. She got an implant by paying for it herself because Croatia does not have a system in place as Ireland does.

#### JOHN EARDLY:

Ongoing costs. COMMENT FROM FLOOR:

It is a lot for the family.

#### JOHN EARDLY:

There is not much more you can do. Thank you.

## **QUESTION FROM FLOOR:**

When did they start doing implants in America?

#### LISA REZNIK:

1990? It was a long process. It was first approved for adults. When Miranda was identified as deaf, we did not have newborn screening in our state until 2013. It started after Miranda was born, which was 1996. There was nothing in place as soon as it should have been then in your country. What is the organisation that advocates for newborn hearing testing in this country? It is important.

#### **QUESTION FROM FLOOR:**

Talking about mainstreaming, did Miranda have any hurdles to overcome or was it a smooth process like a regular child?

#### **MIRANDA MEYERS:**

A question for me? I do not remember kindergarten. But when I went in there, things seemed to be fine then what I remember at elementary school, grammar school, I think everything was fine, right? Yes. It has been a while. My problems started in middle school years, 12 to 14 years old.

**MIRANDA MEYERS:** It was because that that point, you start switching classrooms and each teacher has their own subject they teach. I would have to carry the FM system to each classroom. It made me stick out a bit because I had to give it to the teacher at the start of each class and get it back at the end of the class. I had to pick up the microphone at the start of school every day. I stuck out more in middle school because of that.

In high school, things started to be easier for me because I got older. I knew what worked for me and what didn't. My first year of high school, I stopped using the FM system. It was very beneficial for me. For a lot of people, the microphone helps me a lot. For me, I wanted to hear everyone in the classroom and not just the teacher like with the FM.

I had other accommodations helping me out, like preferential seating. I always sat at the front. The chairs under the desks used to make noises that even the hearing people did not like. There was tennis balls on the chair legs, so it was helpful for me.

As I became older, it was easier for me and my family and everyone else to get what I needed, because I knew what I needed and what helped me. I could be more vocal about it and it was easier. I got confident because I knew it helped me and that is what I needed to succeed in school.

#### **QUESTION FROM FLOOR:**

Have you had any exposure to sign language?... (inaudible)

#### **MIRANDA MEYERS**

Did you hear that?

#### LISA REZNIK:

We are in favour of choices. When you use sign language you rely on other people around you to know sign language to communicate. It is complicated. I do not have expertise in American sign language or Irish sign language.

#### MIRANDA MEYERS:

Did you hear the question? Can you repeat?

#### JOHN EARDLY:

The role of sign language. The various choices available. How do you recognise or understand or appreciate sign language as an alternative or option?

#### **MIRANDA MEYERS:**

Do you guys want to answer? (indicating to Odhran and Maedhbh)

#### **ODHRAN SEXTON:**

I do not have experience using sign language. I have been speaking as long as I can remember. With people born before cochlear implants are an option, sign languages

are a big part of their life. I know there have been allowances made with specialist schools where people can go to where everyone speaks sign language. It makes life easier for these people.

#### **MIRANDA MEYERS:**

I am not against sign language at all. It is a beautiful language. I go to Rochester Institute of technology, and in that school, it has the Institute for the deaf, and a lot of students there rely on ASL. I never learned any, and when I got there, I started signing a little bit. I like being part of the community and it is important to be able to talk when you are eating because you can just use your hands.

It is good to know a little bit in case something goes wrong. I know how do finger spell. I learned more ASL at school. I am not against that. It doesn't translate across countries, which is difficult. You have ISL, then you have ASL, even though both countries speak English. I appreciate speaking and being part of the wider world.

## SPEAKER:

The experience I have with sign language was a speech pathologist using sign language with people with strokes. It has good results in return of speech, and I do not know if it is the same here? I wanted to share this.

**ADRIAN BRADLEY:** I am also a speech pathologist and I thank you for coming here. Using sign with people with strokes, I have not come across that in Ireland. To use that as a medium for therapy, particularly visual aspects, my question is your experience of speech-language therapy as a child and getting cochlear implants, did you find it useful?

Once you get the cochlear implant, the environment is enriched with language. Do you think it was beneficial for you?

## LISA REZNIK MEYERS:

When we met with the specialist, he agreed to be in the film because he was a student of Susanna, who plays the audiologist, and she is from Croatia. Speech and language therapy is vitally important and it is covered by New York City as a state. It is also covered in New Jersey. Miranda, who got her cochlear implant at age 2, had to make up for when she didn't have one.

#### **MAEDHBH SEXTON:**

All I have ever known is through my cochlear implant. I do not really know what it is like to hear. I have never experienced it. Speaking helped me, because I had the same language as everyone else in my classroom or youth group.

#### **MIRANDA MEYERS:**

Speech and language therapy is very important too. Without it, I would not speak as well as I can. You also need auditory therapy so you can listen and learn to speak. It is a process to learn how to listen and use cochlear implants in order to process

sounds as a hearing person would. I know that now, getting my second implant. It is important to practice and go to auditory verbal therapy to get everything working together.

You want to be able to speak and be able to hear. Not just when you are speaking, but when everyone is speaking. So you can learn everything. If I did not hear how other people were talking, I would not know how to talk as well as I do.

## JOHN EARDLY:

One more question. Unfortunately, we are a little out of time, but we can continue the conversation afterwards. A question up here [from the floor].

## **QUESTION FROM FLOOR:**

My partner is hard of hearing and we do not have experience of a cochlear implant. Congratulations with the film. It is really well done. A question for people with hearing issues. How do other people around you, say in your class when you were a child, how did they react? Were there problems with how they saw you?

#### **ODHRAN SEXTON:**

My biggest problem was, they kept asking me what's the thing on my ear. I would explain what it is and they would move on.

#### SPEAKER:

Well done on the movie, really.

#### JOHN EARDLY:

We started a wonderful conversation today and the purpose of a movie like this is about social awareness and raising awareness. In terms of the wonderful speakers we have, their bravery and groundbreaking experiences and all of the experiences we have shared today.

What I would like to do is continue the conversation leaving here and continue the conversation as we go out from here and remembering this is that the cost of all we are doing now. It is not one size fits all. It is about diversity and human rights development and it is great. I see it in other groups campaigning for rights. There isn't anything like a film to join people. Let us thank them for making a wonderful movie.

(Applause)