Inform Podcast
Episode 18: Fiona Murphy The Shape of Sound

Kirby Fenwick

Hello and welcome to Inform, a podcast where you'll be hearing from people with disabilities, as well as industry experts, on a range of topics.

I'm your host, Kirby Fenwick.

In this episode of Inform, we speak with Deaf essayist and poet, Fiona Murphy about her new book, The Shape of Sound.

Blending memoir with observations on the healthcare industry, The Shape of Sound is a story about the corrosive power of secrets, stigma and shame, and how deaf experiences and disability are shaped by economics, social policy, medicine and societal expectations.

Kirby Fenwick

Thank you so much for joining us on the Inform podcast, Fi. What is your new book, The Shape of Sound about?

Fi Murphy

The shape of sound is a memoir about my experiences with hearing loss. It's really about how I hid my hearing loss for almost 25 years. And it's kind of a coming-of-age story of coming into a Deaf identity and being open and proud of being Deaf.

Kirby Fenwick

You write throughout the book about 'passing as normal', following rigid rules like never asking anyone to speak up or repeat themselves, about 'hiding any difference or discomfort' at work. And also, about the effort involved in doing all that and about how exhausting it was to keep your deafness a secret. What was it like to write about those experiences but also, how do you reflect on them now?

Fi Murphy

I didn't realise how much effort I was continuously putting in to passing as hearing because it became quite an innate and reflexive way of being in the world. So, when I did finally sit down to write about being deaf, firstly, it was tremendously difficult even to think about it openly within myself. Because I had kept it that much of a secret and I had locked it away within myself that I didn't even like to think about it just in case I revealed it accidentally to someone in a conversation.

And when I finally got enough courage to start exploring deafness on the page, and in writing, and listing down everything that I, kind of all the rules that I had created. I was actually quite shocked with how much my thinking and behaviour was shaped by secrecy and wanting to keep my deafness as hidden as possible. And it was almost like an audit of going, Oh, I do this, and I never say pardon, or I never say can you repeat that and all these, like, really hardcore rules that I had created because I felt like it would give other people clues or hints about my hearing loss. And I was extremely strict about it. So, it was only in retrospect, that I was like, wow, this is immense. It's a lot of work that I've been doing to make other people's lives easier.

Kirby Fenwick

Where do you think that desire to—desire is probably the wrong word, but where do you think that need to keep your hearing loss a secret came from?

Fi Murphy

For the longest time, it didn't even really feel like a choice, it felt like the only option. Growing up, I didn't really see any deaf people on TV, or in media or in books. And when they were on the rare occasion present in popular culture, they were often the butt of jokes. And that was certainly something that I didn't want to be the butt of anyone's joke at all. And deaf people were really associated with the stigma of being deaf and dumb. And because I had so much trouble learning how to read, I felt incredibly limited with my intellect and ability to learn and understand. And I certainly didn't want anyone to know about that. So, it felt like the only way to kind of navigate the world safely and comfortably was to hide my hearing loss as much as possible.

Kirby Fenwick

It makes me think of that adage, which it’s almost a cliche now you can't be what you can't see.

Fi Murphy

Absolutely, I believe that to be 100% accurate and true. Without having positive representation for your experience in the world, you can't even imagine what it's like to live openly and proudly with an identity because it doesn't even look like it fits into what is accepted behaviour at all.

And in terms of Deaf representation, really, the only role model I had available to me was Helen Keller, who's an incredible deaf blind writer, creator, activist, but that set the standard so flipping high to be this like superhuman person is the only way to be deaf. And because I didn't know sign language, and I was really struggling to learn how to read and to write. I didn't think that I was anything like her at all. And that made me even more determined to keep my deafness a secret, because I assumed people would say you can't be deaf. But how can you be deaf? And unfortunately, that's something that did happen. Whenever I revealed my hearing loss, people questioned it.

Kirby Fenwick

I imagine that’s an incredibly frustrating experience, after being so open and vulnerable, to be questioned.

Fi Murphy

It's an incredibly confusing experience, because no matter what I say, some people just refuse to believe that I have any hearing loss at all. And often, it goes from the point of asking for access, because generally I only really bring up my hearing loss if I'm asking for access. And I'm disclosing it for a reason, to almost an interrogation of how did it happen? Why are you deaf? But you're so young, you don't look deaf? You don't sound deaf. You don't act deaf. And it's interesting how much people reveal their understanding of disability when you're asking for access.

And those conversations, unfortunately, are often difficult. And the work of educating others falls on the disabled person. And it's a really common experience for anyone with an invisible disability and the stigma of being a fraud and scamming the system and all these really horrible, horrible stereotypes of disability are still extremely prevalent in our society. And there's still a tremendous amount of discrimination, particularly in professional settings and workplaces.

Kirby Fenwick

I want to talk to you about Deaf culture and disability pride. In the book, you write about choosing to identify as Deaf, but also about how fraught a decision that was for you. How did you come to embrace that identity and Deaf culture more broadly?

Fi Murphy

It was really through Twitter, of all places. I really grappled with how to identify. I didn't know if I was half-hearing or half-deaf or not enough to be either hearing or deaf. And it was very confusing to know if it was cultural appropriation to openly identify as being capital D Deaf, Deaf as in seeing deafness as a cultural identity rather than a diagnosis.

So, I spent a long time grappling between how to label myself in a way that was respectful to the Deaf culture, but also in a way that I felt comfortable with as well. And because I wasn't fluent in sign language, and I hadn't grown up amongst other deaf people, I spent a long time trying to figure out, was I allowed to call myself deaf? Or did I have to keep calling myself half-hearing or half-deaf.

And it was really through Twitter, that I found other people with hearing loss who were having the same issues and struggles, and it was so many conversations with other deaf people that I realised that this is my identity. And it's something that because it's been oppressed for so many hundreds of years, that of course, I'm not fluent in sign language because I didn't have access to it through school at all. And that's really a reflection of social policy rather than kind of an individual failing on my own behalf.

And it's been so exciting to kind of come into a community where it's normal and fine and completely accepted to not have full hearing. And it feels really joyous to be kind of accepted wholly and completely.

Kirby Fenwick

What has engaging with the Deaf community brought into your world?

Fi Murphy

It's opened up so many opportunities. For the longest time, I thought hearing loss meant a chipping away and a lessening and lessening and kind of almost like a depletion of joy and fun and opportunities and kind of almost a narrowing of my world. But through Deaf culture and learning sign language, it's opened so much up, and it feels expansive, and exciting and incredibly joyous to be a part of a community and to have people understand the same kind of frustrations and obstacles that exist in society. And it becomes a point of humour that we all kind of engage in, and we can comfort one another, but we can also laugh about how ridiculous it is that there's so many ongoing misconceptions of what it is to have hearing loss in society.

Kirby Fenwick

And what about disability pride. What does it mean to you to be proud?

Fi Murphy

I initially identified as disabled long before I identified as deaf. And I feel like that's really important and a huge part of my identity. I'm really proud to be openly disabled. I think there's so much that I've gained from talking to other people with disabilities and becoming their friends. And whilst those experiences are not my own, because they're adjacent to my experience, I've learned so much about what it means to not only survive in the world in a disabled body, but what it means to thrive. And to feel fearless and unabashed in asking for access and to be included and to be treated as an equal. It's our human right to be considered equal and engaged in what happens in society.

And it's about learning skills as well. Because for so long I didn't have any deaf or disabled friends, I didn't know how to ask for access in a way that wasn't diminishing myself. I didn't know the phrases to use. I didn't even know that access was a thing. For so many years. I didn't realise I could ask other people: Can I please sit in this spot? Can you please use captions in the video? I had no idea that it was possible to ask for information to be delivered in a way that was less taxing for me to participate in conversations and learning environments.

Fi Murphy

And I think that's something that I've come to really appreciate and admire and have integrated into my own way of being in the world is from the disability community, whenever we have a meet up or we engage socially or professionally, we always, at the beginning of every meeting, we ask: What are your access requirements? Is everyone in the best position and set up to access all the information. And we stop and we check, and we make it part of our interactions together.

And it's really not that hard. And it really becomes second nature, once you realise what access means. And often it is as simple as changing positions or the layout of a room or the lighting of a room or delivering information in a specific way, that these aren't necessarily high-cost things, they just take time and attention and thought to ensure that all people have as much access as possible.

And everyone has different access requirements as well, that I think that by asking the question, you're allowing the other person to dictate the terms of what they need. I think a lot of people who have little to no experience with disability feel that it's a rude question to ask someone what are your access requirements? When really, it's an invitation to engage with another person and it's not rude at all. It's possibly the kindest thing to ask someone of do you have any access requirements? What can I do to make this situation easier and more comfortable for you?

Kirby Fenwick

Let’s talk about Auslan. I’m really excited to take to you about Auslan. In The Shape of Sound you write about taking classes and then doing on-on-one sessions. What has the experience of learning Auslan been like?

Fi Murphy

Completely eye opening and mind expanding. I had no idea that Auslan is a whole language that had nothing, it has nothing to do with English. It's a language in its own right with syntax and grammar and tenses. And this integration of the entire face and hands and elbows and shoulders, and practically all parts of the body.

Like many people, I had grown up not realising that Auslan was a language, and that there's hundreds of sign languages around the world. When I started taking classes, I was astounded by how challenging it is to learn from a physical level of getting the hand shapes correct to being able to interpret and understand what other people were signing as well, that individuals have accents and different ways of expressing themselves. It was fascinating and exciting.

And it made me really start to understand how much Auslan has been repressed by social policy. And for so long, it's been treated as the last resort for people with hearing loss, that it made me incredibly upset that it was a language that I didn't have access to from a much younger age. It's incredibly difficult learning a language as an adult, let alone a language that uses completely different mechanisms to communicate clearly and fully.

Kirby Fenwick

Speaking of that social oppression, you mention in the book a 2019 report from the World Health Organisation that speaks to this resistance to sign language. Do you think that is shifting or changing, is there a greater acceptance or embracing of sign language?

Fi Murphy

I think there's, sign language is becoming more and more popular with changes with the NDIS and people with NDIS funding are able to select Auslan as part of their package, which I think is a really fantastic and tremendous. And it's not only for people with hearing loss, but it's also available for people with other disabilities. And I think that really highlights how incredible the sign language is.

I do think that people still assume that Auslan isn't a whole language and we still have a long way to go with sign language and in particular Auslan aren't recognised as official languages of Australia. And it's still treated as kind of, as kind of a substandard version of English. People still don't realise that Auslan is its own language that isn't derived from English at all.

It is really exciting that Auslan is being included in a lot of press conferences. But often it is included when it's a natural disaster or something like the pandemic, it's still hasn't been integrated in kind of entertainment, and kind of pop culture and things like what's happening in the UK and America where interpreters are much more present on a day-to-day basis in the media.

Kirby Fenwick

I wonder whether the fact that there have been as many interpreters onstage present for those press conferences that you mentioned, I wonder if that helps with that kind of visibility of the language?

Fi Murphy

Absolutely, it's had a huge impact. And I know for myself that seeing interpreters on the screen really changed my internal dialogue and my sense of self. I became a lot more prouder and open about talking about deafness, it was almost kind of an avenue into having conversations with people about hearing loss.

Kirby Fenwick

In The Shape of Sound, you write about reading academic papers and research and finding stories of other Deaf people in them and finding some companionships in those stories, a sense of kin. What did reading those stories mean to you?

Fi Murphy

When I started writing about deafness and hearing loss, I really was unsure about where to begin. And because of my background in health science, training as a physio therapist, I had gained a lot of skills of research. So, I kind of fell back on those skills when I was a little bit lost in writing this memoir, and I spent a huge amount of time going through medical journals trying to understand how other people view deafness and what it means to be deaf, and the impact it has on the brain and the body, and communication. And these were really challenging articles to read because often deafness was described as a tremendous deficit that has a raft of negative impacts on the body. And that, of course, made me feel incredibly low and upset.

And it was only when I shifted my research from being kind of scientific, scientific medical journals to more sort of social studies and kind of social history that I started to discover all these interviews with deaf people. And it was like I was coming into a community of people that I knew, even though they're de-identified in all the journal articles, it felt like I was entering this kind of world of, where people understood what it meant to be deaf and it wasn't all negative. There are some really great moments of recognition and humour, of being astounded of what it was like to learn how other people hear and navigate the world and I got so much comfort finding these deaf voices and it really brought it home to me of how these voices aren't present in films or in newspapers or in books that it took going deep into kind of journal articles to find and discover other people with similar life experiences to me.

Kirby Fenwick

And, I guess also, in many ways, your book is now a story like that for others?

Fi Murphy

I hope so. And I'm really excited that disability literature is gaining a tremendous amount of momentum in Australia with more and more stories about disabled bodies being published year after year. And I have so much optimism and hope and just pure joy of books and stories being released from disabled perspectives. I, I honestly think it's some of the most exciting work that's happening in Australia at the moment.

Kirby Fenwick

I wanted to ask you about that, because there’s been some really excellent books about disability or written from disability perspectives published in the last couple of years. Earlier this year we had Growing Up Disabled in Australia, which you are also in, what does that broader and deeper conversation mean to you? And what does it also mean to be a part of it?

Fi Murphy

It's absolutely thrilling to be a part of the disability arts community. I've got some incredibly dear friends who are writers and artists who also bring their disability perspective to their work. I do think we still have a long way to go in kind of broadening out the perspective more.

Growing Up Disabled in Australia showed that there are still so many voices and perspectives that haven't been heard. And I'm really excited by the reception that that book has received and that it's crossed over into the mainstream, and it's selling out, and it's into its second print run, and people are really, really excited about these stories. And I hope that this momentum continues, because I think we've only just begun this incredible conversation of what it means to be disabled or to have chronic illness.

And, and I think it's really great to see organisations like Writers Victoria really foster new and emerging voices through their Writeability and Publishability programs and that is being also done in New South Wales with Varuna, the writers house also starting up more disability led writing programs to really encourage those new voices, and to try and make the publishing industry more accessible.

Kirby Fenwick

What do you hope readers will take away from The Shape of Sound?

Fi Murphy

I hope readers will recognise that communication is a two-way street. When you're talking to someone being open and clear is extremely important. But so is listening and taking on that information. And deaf people for so long, have put in so much work in order to kind of communicate with other people.

And I kind of really want people without hearing loss to kind of really recognise and appreciate the amount of work and effort that people with hearing loss do on a daily basis. Because quite often, I've seen the joke, and I've heard the comments from friends and family talking about people with hearing loss in their families and communities that they put no effort in, they never pay attention. They just don't try hard enough. And it's the complete opposite.

If you've got hearing loss, chances are you are trying twice as hard as everyone else to keep up and stay engaged and be involved. And I would be so happy if people without hearing loss started to reflect on their own ways of communicating. I think there's a lot to be learnt about what it means to listen to truly listen in a conversation.

Kirby Fenwick

It makes me think of something you wrote about in the book, ‘listening fatigue’, which was something that really stayed with me as being an idea that speaks directly to that intense hard work and the exhaustion that follows. You write in the book that’s something your learnt about from the Deaf community. Can you talk a little bit about what listening fatigue means?

Fi Murphy

I was really struck when I first read about the concept listening fatigue, because I just assumed everyone felt exhausted and absolutely smashed by the end of the day and worn out and unable to understand things. I didn't realise that my brain was tired every day. And it kind of gets to a tipping point where even if I'm trying really hard, words just don't make sense anymore. And I can hear all the sounds, but I kind of get to a point where my brain just kind of stops making sense of anything.

And once I learned about that concept, I was like, oh my goodness, no wonder I become so irritable after certain situations and just agitated and really stressed and confused, because I just have reached my fatigue point. And it's something that's been really helpful for me going forward because I can kind of pick and choose situations that I enter into knowing that in certain conversations, it's gonna be a lot more taxing and in certain environments, such as like a busy cafe, I might only have say 25 minutes of like, good concentration, and then my brain will start to kind of become fried.

And then I can kind of put in a bit more buffers and breaks and be kinder to myself and it's really changed my routines and life and I'm so glad to have discovered that and that was really only through the deaf community. No audiologist had ever mentioned listening fatigue to me at all or gave me any tips or any clues about how to protect my brain on a day-to-day basis.

Kirby Fenwick

I just want to return to what we first discussed at the start of this conversation, about how for so long your hearing loss was something that you kept a secret. What does it feel like for you now, it's definitely not a secret anymore there's a whole very excellent book out there, how do you reflect on that?

Fi Murphy

It's incredible how much energy and joy I've gotten from being openly proud about being deaf. I hadn't recognised how much energy it required to keep a secret and that it is physical burden that was weighing me down and really keeping me closed off from other people and quite reserved and shy about revealing myself for fear that somebody would guess that I had, guess that I had a disability. It's been exciting and invigorating.

And I'm so hopeful for how much more I'm going to learn about deafness and disability. And I feel very much just at the beginning of this wonderful journey of writing more about deafness and disability and discovering more artists who are also working in the same area. And it's, it's thrilling, I couldn't have imagined it at all when I, I couldn't even foresee revealing my deafness. So, to be openly talking about it, I think my younger self would be shocked.

Kirby Fenwick

Thank you for listening to Inform, a production of Independence Australia. Inform is hosted and produced by me, Kirby Fenwick. Our managing editor is Alison Crowe.

This episode of Inform was recorded and produced on the lands of the Wurundjeri people of the Kulan nation. We pay our respects to elders past and present.

Our thanks to Fiona Murphy for joining us to discuss her book. The Shape of Sound is published by Text Publishing. You van find it at all good bookstores and it's also available digitally. For more information about where you can find yourself a copy, check out the show notes at www.informonline.org.au

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