# Accessing Healthcare: a Blind and Low Vision Perspective – Full Transcript

## Introduction

**Rebecca McBeth:** Kia ora koutou, welcome to eHealth Talk NZ. I'm Rebecca McBeth. I'm the media editor at HiNZ, and this episode is the first of a four-part collaborative podcast series with Blind Low Vision New Zealand. And today I'm joined by Neil Jarvis. Neil is a freelance digital accessibility consultant with over 30 years’ experience working for not-for-profit, governmental and private sector organisations.

It’s very lovely to have you on the show, Neil. Welcome. Can you start by telling our listeners a little about yourself and your background in digital accessibility?

**Neil Jarvis:** Rebecca, thank you so much for inviting me on to the podcast today, really appreciate it. Yeah, my name is Neil. I have worked in digital accessibility pretty much for as long as there's been a thing that was called digital accessibility. I started out originally as a user of the technology; I'm totally blind. I was wanting to find ways that I could access as much information as possible because I grew up not really having access to information in the same way that most people do. Blind people struggle to get access to books and magazines and letters and anything else really. And so I knew from a very early age – stage rather, I was in my late 20s by the time this happened – I knew that access to information digitally was going to be a game changer and it's definitely turned out to be that.

Having got into it as an individual who could see the benefits for myself, I also then got interested in it professionally and yeah, for the last few decades I've done various things in various organisations whereby I've either advocated for accessibility, and have promoted that on the international stage, or I have worked quite closely with organisations to actually get them to improve their specific accessibility implementations.

## Accessibility in Healthcare

**Rebecca McBeth:** So how accessible would you say our healthcare system currently is for blind and low vision New Zealanders when it comes to things like forms and filling in information and generally interacting?

**Neil Jarvis:** Yeah, it's a mixed bag and probably mostly not a great experience. You’ve got to start out by saying, there are some fantastic people in the system who will go the extra mile whenever they can to make the experience that patients have one that is as good as anybody else's. But those people, the pressure is put on them. I think that's the problem. So what happens is, they are working in a system that in itself is not very accessible. Whether that comes down to the letters that are sent out to patients to invite them to an appointment, or to follow up on an appointment and give them information, that often nowadays you get information that's been sent to your GP and you're copied in. But it's in a way very, very often that is not accessible if you can't read printed information. And I should say, even those printed letters often are produced in poor quality print, so even if you can read print – if your vision is low but you still have the ability to read print – it’s still harder than it needs to be. There is a resistance to sharing information electronically. We might come back to that later, but that resistance is a real issue and a real problem because that's how so many more people could access things nowadays.

Then there's the simple fact of, as you say, filling out a form. We all have to fill out forms all the time, whenever we interact with the health system. Whether that's just on arrival when you first get to report to, say, a hospital clinic or something like that, or often you're asked to sign a waiver or something at the point that you're about to undergo surgery. Which, first of all, I think that's probably questionable in terms of the timing for anybody. But for someone who can't even read what they're signing, that's ethically questionable. So there's lots of examples like that. Then, and I know we will come on to this later, but the issue of how people interact with online content is very mixed. Sometimes it can be really good, sometimes it's very poor.

**Rebecca McBeth:** So have you had a personal experience that highlighted that lack of accessibility in the system that you're happy to share?

**Neil Jarvis:** Yeah, I've had lots of them. I think most of us probably have who are in our situation. Whether that's just the examples I gave earlier, like a letter telling me that I have an appointment at the clinic on the 4th of August. That letter, frequently it's in a form that I can't use unless I bring my rather expensive technology to bear on the situation. Now I can do that, I'm in a fortunate situation, but lots of people don't have the skill or the access in terms of affordability to that technology. So what they end up having to do is ask somebody else, and sometimes that might be really private information and information that you wouldn't normally choose to share with anybody else until you were ready to do so.

But if you don't even know what it is that you're being sent because it's printed and you can't read it, there's any number of opportunities that information about your medical condition could leak out to anybody. And sure, you only show it to people that you trust, but that's still quite hard, right? So I've had that experience. I've been discharged from hospital with a whole wad of printed information that I have no way of reading. I've obviously been given, as we all get, prescription drugs which if you don't follow them correctly could be quite dangerous, and yet the instructions are given to me in a way that I can't read. Or even if I can read, I can only read haphazardly, because they're not well produced. So yeah, I've had lots of experiences like that.

**Rebecca McBeth:** Yeah, I think you've touched on this question already about why is it important for healthcare providers to offer information in a patient's preferred accessible format? Yeah, you've talked, there's actually patient risk, there's potential privacy breaches. Is there anything else that, you know, I guess it's just, it's part of human dignity and your human right to have it as well.

**Neil Jarvis:** You want to control your own information, don't you? You want to be in a position where you decide who gets to know what about you. And it's not that you don't want people to know or you don't want – well, sometimes it might be about that actually, but by and large it isn't about that. It's about you controlling the narrative when you are ready to have those conversations.

Sometimes the very first inkling that you might have, that there is an issue even to be discussed, might be in one of those letters. That could prove quite problematic. Now, you know, a good healthcare professional will think around that beforehand and many, many do, and they will call you or they'll ask you to come in or whatever it happens to be. But it's still one more barrier that often you have to face. You are relying on you having that person who does think outside the box a little bit, or that they actually, because they're busy people, right? They might actually just not have remembered that day that you were that person who couldn't read their typed letters. So that's a real problem.

And it kind of gets amplified when you do turn up in person to a healthcare centre. And again, some people are brilliant. They know exactly how to react to you. They know exactly how to help you, or if they don't know they ask you and you can tell them. And of course that's the message we always give, if you're not sure, just ask, but ask in an appropriate way. But far too often people just freak out when they see a disabled person, certainly when they see a blind person, and they don't know how to handle it. And they just end up being often unhelpful, not intentionally.

But they don't know what to do, they haven't had training, and so they end up trying to – simple things, direct you to a seat while you wait, but they point at that seat. No good to me! You can point for as long as you like, I'm never going to be able to work that one out. They don't know how to guide you often, if that's what you need. So all sorts of things like that. Like I say, there are plenty of examples of people who do it really well. But when you go to a clinic or a doctor's surgery, by definition, it's quite a stressful time for you. So you don't want more stress piled upon that that you don't need to have.

**Rebecca McBeth:** So from your perspective, are there any particular examples of doctors or healthcare organisations or providers that are getting accessibility right that you can share what we can learn from them?

**Neil Jarvis:** Yeah, I had an example quite recently where a clinician who I'd been to see, when we were having our consultation, she picked up very quickly that her normal way of working with a patient and asking them to do things between sessions wasn't going to work for me because they were visually based.

So she literally changed tack in the course of our conversation, not with any prompting from me. This was all from her. She did it. She did it really well. She did that thing that everyone talks about. She thought outside the box and she gave me really simple alternative methods to do what she was asking me to do. None of which were difficult, none of which were hard, but someone had to think about them and she did.

She then followed that up later by realising that there's no point sending me written letters about what she wants me to do next, and the next appointment and all those sorts of things, and the blood test that I needed to go for and all of those. So she just sent me the same information by email. Didn't think about it. I didn't even have to ask for it. It just happened. Now that is how the system should work.

And it was a really good lesson to me because I realised after all these years of being told we can't possibly send you email, it's not possible, it's a security risk, we don't know how to do it, the technology isn't there, even though people have been using email for 30 years. In this one instance, I was met with someone who said, this person needs email. He doesn't need or want bits of paper that he can't use. So, yeah, people like that really do make a difference, but they just go to show that it can be done.

**Rebecca McBeth:** And it's so simple as well. Send an email because then obviously you have a screen reader that then reads that for you.

**Neil Jarvis:** That's right, that's right. And she knew that in the conversation that we'd had. We had a good conversation about how we were going to work together and what worked for me and what didn't work for me and all those kinds of things. But most of the solutions that she came up with were not technical solutions. They weren't technology based. They were just common sense.

Sometimes if people just stop and think they can do wonders without actually having to invest a single cent in it. Yeah, I would commend that. And it just showed to me that things can be done well if someone thinks about it.

I guess at a more systemic level, because you do need to solve these things systemically, you don't want to rely just on individuals to have that common sense.

Systemically, I think of examples like the pandemic. And the pandemic was fraught with really poor examples of accessibility for a lot of us. Because things were done quickly – we understand why that was – but because things were being done with a lot of guesswork going on, I suppose, at times, disabled people really did miss out a lot on vital information during the pandemic. But one thing that the system got right, certainly in terms of access to a particular system from a blind person's perspective, was the Book My Vaccine portal, which when they set that up they actually planned for accessibility. They didn't think about it afterwards. They didn't suddenly remember at the end of the day, oops, what are we going to do about these blind people? They actually factored in accessibility to the planning of that project and they had their system tested before it went live, and it was a really good experience for those of us who used it. And that again just told me that if you do the right things, if you plan correctly, if you budget for things properly and if you embed good ways of working into your everyday work, you can get it right.

**Rebecca McBeth:** Yeah, you may have already answered this, but the next question was about, I guess the systems or the technologies that do need to be in place to automatically provide patients with accessible formats, It might be Braille, large print, accessible PDFs, email. What do you think would need to be in place so that we're not relying on individuals to just get it right on the day?

**Neil Jarvis:** I think that's a really good question. I think it gets to the heart of this whole issue really. And first and foremost, I would say it's a willingness to recognise that this is necessary at an organisational and a systemic level. So we can get on to talking about the technology that would be needed to be put in place and all that kind of thing, and any organisation will need to address those issues, but no technology in the world will make an ounce of difference if the attitude is wrong. So if the response to, “Could I have my information in a form that I can read?” is, “Sorry the computer says no,” then there's nothing that any technology can do that will help me. It's an attitudinal and a systemic issue that we have to address first and foremost.

So that is about making sure that it's a logistical issue rather than a technical issue. So it involves, like we said earlier, planning, budgeting, training staff, making sure that people understand what being blind or being disabled means for people, what it might mean to people, how you might want to respond to that when you're faced with it.

But most importantly, just planning and budgeting and recognising that accessibility is just as important as everything else. As all the other bells and whistles that you're putting on to your systems, although I would argue that accessibility is not a bell and a whistle, it's actually as important as security and privacy because it's potentially life-changing if you get it wrong. So do all the logistics, do all the planning, do all the effort that you need to make sure that the acceptance of accessibility and the recognition that it needs to be done is part of your daily workflow, and then you can start looking at, right, what are the actual bits of exciting shiny technology that we need to make that happen. That's a detail. The real strategy is the planning.

**Rebecca McBeth:** Yeah, yeah, it's got to be sort of core to it, doesn't it? So it sounds like the answer is going to be no, but is there currently any kind of national policy or mandate within health that does require accessible communication formats to be standard across all providers? And what might that look like?

**Neil Jarvis:** Not in New Zealand there isn't. And that's why we have the situation that we have, which is a bit of a postcode lottery, really. Or even not even a postcode lottery, it's often a lottery based on which surgery you go to or which clinician you talk to. So no, there isn't any kind of national policy. There should be.

I'm not saying that just having that will solve all the problems. The United Kingdom has very strict policy on accessible information within the health service. It isn't always followed through. But at least when it isn't, people have got a tool that they can use to go back to the provider and say, you know that you need to be doing this right. You know that this is a responsibility. And they're more likely to get their way as a result of that. What we need is a national policy. But better than that, we need an acceptance that there is a right of access. And I think that comes down to a need ultimately for the law to say that, whether that's in a law that promotes accessibility at a national level. Personally, that wouldn't be my way forward. But I don't want to be prescriptive. I just want there to be standards that say we are a provider of a really important service to our citizens.

We need to make sure that all citizens are getting the benefit of that service as far as is possible. Of course, there are going to be times when we fall short, but if we actually say that as a bare minimum we expect that we will communicate with our disabled stakeholders in such a way that they can actually understand what we're communicating to them, that's a really good start I think.

**Rebecca McBeth:** So how do the fragmented IT systems that we have in New Zealand, and there’s a range of patient portals available as well, how does that impact accessibility for blind low vision people?

**Neil Jarvis:** I think that kind of brings us back to the post-COVID lottery thinking that I touched on earlier. It depends where you are and it depends which practice you go to often as to how accessible the portal that your practice uses is. So I'm actually quite lucky, the practice that I go to uses a particular health portal which is actually pretty good now. It wasn't at one time, it was pretty poor. But nowadays it's great, I can actually book an appointment through it, I can check my prescriptions that I've had – going way back, I was quite surprised – I can see my blood test records, all those sorts of things that the whole point of those portals is, that we have more transparency nowadays and access to those sorts of things.

And in this instance, it works really well. I've talked to other blind people who use other portals and they just have a terrible time with them. They can barely get into them. If they do get into them, they can't do much once they're there. They can't book an appointment. They can't read the messages that are left for them in those systems. So, to all intents and purposes, they're absolutely useless for them. So, it's a very much patchwork experience that we have and very much one that does rely on you being in the right place at the right time, which is not how something as important as accessibility should be.

**Rebecca McBeth:** So what in your mind would an ideal sort of inclusive digital healthcare experience look like for a blind low vision patient, starting from that booking of appointments right through to perhaps follow-up care, you know, as in at the hospital?

**Neil Jarvis:** So we've talked a lot today about the informational side of it and it is one of the most important, probably the most important aspect of it. Because we often say that blindness and low vision are actually informational disabilities. That's how they manifest themselves particularly, is that we don't have easy access to the same information that everybody else has, so anything that gets around those barriers is going to enhance and improve the experience that we have as patients. Whether that's communicating with us in a format that works for us, obviously for many people paper works for them and that's fine. I'm not saying people shouldn't be communicated with by paper letter, that's totally fine if that's their approach.

But we need to get past this thinking that one size fits all and that everyone, one way or another, if we hit them hard enough to make them do it, we'll force them into using the system the way that we want them to use it, rather than the way that works best for them as consumers of the service. So, first thing I would do is when someone enrols into a practice or with any health provider, I would actually make it a requirement that they are asked, “What is the best way for us to communicate with you? When it comes to sending you information about your appointments, about your follow ups, anything that we happen to write to you about. What is the best way for us to do that?” And then when they tell you that, actually do it. Don't just put it on a form and then put it in a drawer and think, that's interesting, we might be able to use that in a survey later. Actually do something with that information.

And if you don't know how to do it reach out to people that do, because there are lots of people out there who can advise you on how to have an accessible healthcare regime really. Then when it comes to the, kind of the more face-to-face, more personal experience, when you turn up for your appointment or for your procedure or whatever it happens to be, make sure that the people who greet you and then the people who are going to be performing the surgery on you or whatever it happens to be, at least – not saying that they need to be experts in blindness, because you know it's hard, but they do need to at least understand that blind people are human beings too. They have feelings too, they get stressed too, especially in those situations. So what is the easiest way that you can make them comfortable, put them at their ease, that respects them as individuals and as human beings, that treats them like adults, if indeed they are adults, and does not patronise them. And again, it isn't hard.

Those that do it, do it well, but not enough of the system does. Invest in disability awareness training and that sort of thing for your leadership, but also for our front-facing staff so that they know that when they come across someone who has any kind of disability, doesn't matter what it is, they actually have some grounding as to how to deal with them. And first thing they can do, and I'll give you this for free, just ask. Just say, how can I best help you now that you're here? And listen to what they say.

**Rebecca McBeth:** We did touch on it about the importance of privacy for blind patients. Obviously, if you don't have sort of a digital way of entering information, or if the information is not available to the clinician already about you, which it often isn't because systems aren't connected, presumably that leads to having to publicly speak potentially in a waiting room or somewhere and sharing private patient information, which is actually a serious breach of privacy.

**Neil Jarvis:** That's actually a really good point that I haven't mentioned, but you are spot on about that. I have been in situations where I have literally had to dictate, because I couldn't fill the forms in, I had to dictate the information to the helpful staff member who is trying to do their best so that the forms are filled in correctly.

Yeah, you're doing it in the middle of the waiting room when everyone can hear about your most intimate details sometimes. That's not right.

**Rebecca McBeth:** I agree. So what do you believe is the most important priority to make our health system more accessible for blind low vision people?

**Neil Jarvis:** I think the priority is to recognise that there is even a problem. Because I think the problem, the biggest problem that we have is the system generally assumes that it's not their problem. We'll find a solution, we'll get someone to read the letter to us, we'll get someone to come with us to the appointment and fill out the form. Which again is not always appropriate or even possible even if it is appropriate.

So first of all recognise that there is a duty of care here that they have taken on by virtue of being a healthcare provider and they have to ensure that to discharge that duty of care they are asking the right questions and they are providing the patient with the best means possible at their disposal to be able to answer them and to do what they're being asked to do as a patient.

And inevitably when you start asking those sorts of questions you come up with very simple answers which are, well I need to communicate with you in a form that you can actually understand and a form that you can read. I need to treat you as I would want to be treated myself when you present to the hospital or to the practice and treat you as an adult who wants their dignity maintained and all that sort of thing. I don't think any of this is going to be a shock to anybody once they start thinking about it, but the problem is that the system has encouraged providers to hope that they can kick the can down the road and not deal with it until – because each individual is separate, so they don't have to deal with it for this person, and they won't see the problem again until the next one comes along.

Blindness and low vision are not high instance disabilities, so you may not see them every day. But you will see somebody every day who needs assistance in ways different to, quote, “the norm,” unquote. Whether that's someone who is blind, or whether they're deaf, or a wheelchair user, or they're older, or their first language isn’t English, whatever the situation is, the system can't just say, well it's your problem, you sort it out. Because that just means that things don't get sorted out and people go untreated.

## Conclusion

**Rebecca McBeth:** Well thank you so much for joining me today Neil, what a fascinating discussion. And we will be exploring further themes related to the experience of blind low vision people in the health system in future episodes so be sure to like and subscribe to this podcast to learn more. Mā te wā.

**Neil Jarvis:** Thank you.

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