

[Music] [Narelle] Hello and welcome to the latest episode of the Digital Access Show. Last week, we talked about the education system, and we talked with Sally Meshel and she was a support, uh, special needs teacher in New South Wales. And she talked about the fact that the education system is really set up well to handle lots of needs. However, families sometimes struggle with having a child with disability, and different things happen. And I think one of the things from today is I want people to never judge a family where there is at least one child with disability because really, you don't know what you don't know. And today's guest... who is going to pick up on that. His name is Andrew Leigh. And Andrew Leigh and his wife actually have four children. Andrew Leigh and his wife also have a company called the Helping Hands Community, based here in Brisbane. So I'd like to introduce you to Andrew. Thanks Andrew for coming on. [Andrew] Not a problem, thank you for having me. [Narelle] Andrew, tell us a bit about yourself and what you do. [Andrew] Okay, so obviously my name is Andrew. I run Helping Hands Community Services. Like you said, we are based in the Redlands on the south side of Brisbane. And we're a very small organization. We intend to stay that way. We're not for profit. We provide supports for people, mainly SIL supports for infinite living. But we also do community access, in-home support or personal care. That sort of thing. We do some support coordination. Some short-term accommodation things like that. So all the hands-on kind of care. That's what we do. That's why we're here. But the reason why we're here, obviously, is the reason you have me here today, is because of Brandon, my fifth child. [Narelle] [laughs] [Andrew] We started Helping Hands because we couldn't find good supports for Brandon. In fact, his last provider went through about 12 or 13 support workers trying to support him. And the last one actually assaulted Brandon in the street. [Narelle] Oh my gosh. [Andrew] And, uh... that was difficult to deal with, you know, but we thought that justice would prevail. We had camera footage of the incident happening. We had an eyewitness account and the guy admitted to it during questioning with police. Um, so we thought, okay, that's that. And then next thing you know, the police officer stood in my lounge room and said, we can't prosecute because Brandon can't speak. And he can't stand up in court and testify. Even with the admission of the person who did it. So that person still works in disability today. [Narelle] You're kidding, aren't you? [Andrew] No, no, still works in disability. [Narelle] Oh my gosh. [Andrew] Um, yeah, so... because of Brandon's lack of communication, he didn't get justice like other people would have. So that's the day we started Helping Hands because we decided we need better support. [Narelle] Mm. [Andrew] It was never an intention to start Helping Hands. It just happened. Me basically. And at the time we only ever wanted to provide support just for Brandon. That was it. As time goes on, we thought to ourselves, look, there are people out there like Brandon that... probably need some good support. So why not just offer the support side to people? And so we've grown organically. Like I said, we're very small. Definitely, um... We don't do a lot of advertising. We've started doing a bit more recently. Someone recently told me we're doing a disjustice to the people around us by not putting ourselves out there. You know, that kind of hit close to home, you know, because the whole reason we started was to help vulnerable people. And the fact that we could be helping more, you know, I saw the point in that. So we have started doing more advertising lately. But, you know, our point is we don't want to grow and become a larger organization and lose the reason why we exist. [Narelle] Yeah. [Andrew] So, as I said, we started because of one person who needed quality support and... that's what we try and maintain. I can't- I'll be honest with you, we can't say that we always hit that mark because I

don't think any organization there that does 100%. You know, I'm sitting in an office. I do do hands-on work. But, you know, while I'm sitting here, we have support workers out there working with people. And things happen. Definitely 100%. Incidents happen. And for me, it's about how you deal with that when it happens. And that's what we try and maintain is, you know, good training and all that sort of stuff. But making sure that we deal with these things in the right way, unlike what happened with Brandon. [Narelle] Yeah... so Brandon's non-verbal? [Andrew] Yeah. Non-verbal. [Narelle] So, as a parent, that must be very hard. [Andrew] Definitely, definitely. And, um... It's hard because I know Brandon so well. I know what Brandon wants. [Narelle] Mm. [Andrew] He does have ways of communicating. Still limited compared to somebody who's verbal. But I can quite quickly pick up on what Brandon wants. Training staff in his methods of communication is a real barrier for him and for his support. We, you know, we have things in place to make that process easier. And there's always a staff turnover in any industry, but especially in disability. And so, having a process where new staff members can come in and learn Brandon's communication is pretty important in top priorities. Because, you know, a lot of behaviours, you know, he has PBSP. He has restricted practices, things like that. A lot of behaviours come because of the frustration of not being able to communicate what he wants, what he needs, things like that. [Narelle] Yeah, I've got to agree with you there, I... Even for me, when I can't read something, it is the most frustrating thing. Because you know that there's a way to do it. But other people are not sometimes patient enough or just don't think outside the square. To say, well, I can do it this way, but other people do it differently. [Andrew] Yeah, and that's it. That's all it comes down to, isn't it? It's just... a bit of common sense, a bit of patience, and trying to see things from another person's perspective, really. [Narelle] Yeah. So what tools do you use? What tools does Brandon use to communicate? [Andrew] So, Brandon has a little bit of a PECS, the picture exchange communication system. [Narelle] Can you explain what that is for people? A lot of people won't be aware of it. [Andrew] Yeah, definitely. So, PECS is quite intricate. And it's more intricate than the basic explanation I'll give you. But basically... if you just printed out a singular, laminated, and... they use those pictures to communicate. Typically they'll take one out and pass it to you indicating that that object or that activity is what they want to do. So, you can build on that and people have, um, say, a strip of hard plastic with Velcro on it. And then they can put multiple words together and build a sentence. And then give you the strip of plastic, which would then read a sentence to you. [Andrew] So, you can- it does grow with a person's ability as they learn to communicate better, so. Yeah, it's more than just that, but that's the basics of it. [Narelle] So, it enables Brandon to communicate. [Andrew] Yeah, definitely. [Narelle] And effectively? [Andrew] For Brandon, not so much, that's the one we're sort of working on at the minute because he has so many different methods of communication. [Narelle] Yeah. [Andrew] We're trying to focus on one. So, Brandon has ASD level three. [Narelle] Yeah. [Andrew] But he also has an intellectual impairment as well. [Narelle] Sorry, what was that, a visual? [Andrew] Intellectual impairment. [Narelle] Intellectual, yeah. [Andrew] So, the combination of the two makes it difficult for him to pick up things. You know, quickly. So, for him to learn something can- the process can take years in some respects. So, you know, that's one we're focusing on at the minute. But he also has some sign language. [Narelle] Yep. [Andrew] And he can actually facilitate as well. So, facilitation is a method of communication that's... still to this day sort of looked down upon in the communication world. Effectively, a person has a, a QWERTY keyboard. And

it can, it can be on an iPad or it can be just a physical board. And the communication partner assist them by holding their hand. And as they type, the partner pulls back and they will type the letters. As they grow, the communication partner does less support. So, they might touch their elbow or touch their shoulder. Just so the person typing... ah, basically can feel that there's someone that's supporting them. And eventually the idea is that they will then be able to do it themselves without the support. The really cool thing about facilitation is that, if a person is capable of doing it, they can basically write out anything in the world and tell you, whereas you know, PECS, sign [language] is limited to what they know. The signs they know are the pictures they have available to them. Facilitation is really, really cool, because Brandon, for instance, he doesn't do it often because it's really difficult to find people trained in it. But, I remember one day I was asking Brandon what he wanted me to make him for dinner. Um, and Brandon loves food. The big driving factor for Brandon is food. And he just kept saying no to me. No, no, no. And bit strange. Y'know, he always wants food. So, I say, what's wrong? Why don't you want any food? And he literally wrote out, I don't want you to make dinner for me. I want Laura - who's my wife - because she cooks better than you do. [Narelle] [laughs] [Narelle] So you got put in your place [laughs] [Andrew] I did, I did, yeah. But, you know, he didn't have the signs for that. He didn't have the PECS pictures for that. So having the ability to facilitate is great for him because it gave him the ability to say something he otherwise would not be able to say at all. [Narelle] So Laura cooked dinner and he was a happy boy. [Andrew] Yes, that's right. That's happened. But, um, facilitation's a method of communication that's... a bit up in the air. There is, there's definitely room for abuse. There's cases in America where people have said that someone's facilitated something that they haven't. So it's, you know, a method that's not used very often. So Brandon has several methods of communication. Um, he does sign language as well. Um, however, he... so we had a speech therapist once tell us that they've never met someone with Brendan's you know, types of disability. you know, so much language. Um, which was great. But at least half of Brandon's are made up. Um, specific to him. Um, and then there's a portion that's Auslan and a portion that's Makaton. Um, you know, he's gotten through his life with different people teaching in different signs and, you know, it is what it is. But, he actually knows quite a lot, which is great. But he does get lazy sometimes. So he kind of slips. So that, that's a bit of a barrier too. But then he also has a method of communication, which a lot of people don't realize. Um, you know, taking you by the hand and leading you to something or pointing at something or picking something up. Um, you know, he doesn't have, uh, his sensory profile indicates that he, he doesn't necessarily know how hard he's, um, grasping you, you know, when he's holding you or, you know, hugging you, bear hugging, you know, he doesn't pick up that, it may be a bit too tight for someone. So some staff over the years have you know, had it in their head that he's hurting them on purpose and all that sort of stuff. At the end of the day, it's... like you say, perception is a big thing. And, you know, he's going to communicate to them that he wants something. He needs something and... they're so focused on that he's trying to hurt them, which isn't the case at all. Um, than I'll see that he's leading them to something. And then because he's not gotten that, it's led to behaviors and that reinforces to staff that he's trying to hurt them and things like that. So, um, communication is a huge, huge thing. [Narelle] Yeah. How does he communicate with the rest of your kids? 'Cause Brandon is not your only kid. [Andrew] Um, so, uh, basically, um, through, through us, through me, you know, Brandon... well, Brandon, moved into his SIL support when my

oldest, must have been about three and a half. Um, just as my middle, um, daughter was coming along. Um, that, you know, his house is their second home. Um, but, um, because my middle one is just turned three, um, recently. Um, she's still quite young to grasp that sort of stuff. So, yeah, he uses me to communicate with them. Um, and my oldest daughter just knows, Brandy, um, she doesn't stop to, she has, um, ASD level one herself and ADHD. Um, so communication has been a barrier to her as well, especially things like body language and, you know, things like that. Um, so sometimes she doesn't stop to listen to other people who are verbal, let alone someone like Brandon who's not. [Narelle] Yeah. [Andrew] They have their own ways. Um, you know, for instance, um, Brandon does exercise. He already does the medicine ball. And my daughter Amelia will come in and start playing with him. And, you know, he says finish. He doesn't want to play anymore. Um, but like she will just keep throwing the ball. And yeah. Keep throwing it back with gritted teeth. You know, he'll, um, groan a little bit, but he'll keep doing it. So, you know, like you say, it is typically that sibling relationship of... [Narelle] Oh, I was just gonna say, isn't it typical older brother? [Andrew] Yeah, definitely. [Narelle] Yeah. [Andrew] Little kid, but I still love you. You know, very patient with them. [Narelle] I actually don't know who I feel sorry more for - Brandon for having younger sisters, and a few of them or the younger sisters having an older brother like Brandon because one of the things you often find with older brothers, they become quite protective. [Andrew] Oh, definitely. A hundred per cent, he's very protective of them. It's really cool watching their relationships form and stuff like that. Like it's a bit of a different relationship with him because she lived with him for three and a half years whereas the other ones, um, you know, they go to his house a lot but, you know, he wasn't around all the time. [Narelle] Yeah. And for people listening, Brandon, is what? 20 or 21 now, isn't he? [Narelle] Older. [Andrew] 25 now. Yeah. [Narelle] Yeah. 25, yeah. And with all of this and with learning with Brandon, what have you learned about communication? What have you and Laura learnt? [Andrew] Um, look I think, um, communications is the most frustrating thing there is. Um, and I think it's also the key to everything in life. It's the key to good support. Um, and it's not just the spoken word or the written word. You know, there's so many things that a lot of the time people fail to see. Um, and I think if you're not patient with a person, you can really miss what's going on. Um, whether it's sub context to something they're not saying, or, you know, whether it's the things they are saying, um, or, you know, signing or, you know, text or whatever it is. I think, um, understanding another person is definitely, um, key to any relationship or, you know, good support or anything in life really, so. Brandon's taught us a lot. Um, definitely. [Narelle] How do you train the support workers to communicate with Brandon and with other people? Because as we've talked about, everyone has their own communication styles. What's the trick to getting the people that work for you to understand that? [Andrew] So with any of our participants, we, do at least one buddy shift with new staff anyway. With someone like Brandon who has more intensive supports, um, we usually do between two and three buddy shifts. So, you know, a lot of things are, um, it's.. sometimes you can read as much as about a person as you can, but, you know, until you're there, with them, seeing these things happen, um, it's really quite difficult to explain everything about a person to somebody. Um, so buddy shifts are really, really important because, um, you know, we have, um, sign books, um, where it literally has pages of Brandon's signs, which is me, um, reenacting them. So there's a description of what they are, there's a photo. Um, so before they even meet him, they get to read that. So they have a little bit of basic

understanding beforehand. Um, so there's training with that. Um, but then as I say, you know, Brandon develops new signs all the time, just out of necessity and stuff. Um, so on, you know, on the buddy shifts is when we really try and get people to understand him well. And, um... We are constantly in contact with support workers, so. Though we get people all the time sending us videos saying, what's Brandon trying to tell me, what's this? You know, what is that? Um, and sometimes I don't even know. Um, so, yes, due to context and, you know, after several times, you kind of figure it out. Um, so, yeah, that's our biggest thing is basically just buddying with people. But as I say, we have resources of his communications. Um, but, you know, we have, uh, videos and pictures and all that sort of stuff and descriptions. But, um, yeah, concentrating with practitioners, whether it's care or support, or whether it's speech therapists, or, you know, exercise physiologists. Um, he has a team of allied health around him to help him be as independent as possible, basically. [Narelle] Yeah. With the support workers and this allied health team you've got around, do they have the basics of Auslan, or is it something that they've got to learn as they go when they're working with Brandon? Yeah, basically it's something they learn. We always are happy to help, um, put people on courses to learn. Um, signs and things like that. [Andrew] Um, if that's what they want. Um, but basically, yeah. You'd be surprised how many people have worked 20 years in disability and never worked with a person who signs. Um, so, it's, it's really interesting because over the years, I've learned, um, that who you think might be the best fit for somebody based on paper. Just isn't the case. So, you know, we started off with Brandon especially, but, you know, we have a vision of the perfect support worker for him. Sometimes that is the case. Um, but his absolute best support worker is, you know, she's in her late 60s, um, you know, New Zealand lady. And... very calm. But, you know, she's not phased by anything. They have the best relationship. She, they sit on the couch at night and she massages his legs. And as soon as she comes through the door, he's just so calm for her. Now, you wouldn't have said when we we're looking for a team for Brandon, you know, we want, you know, an older lady or something like that. It's, you know, young males getting to do things. So, it's super different. It's not like a lot of the same person. It's a lot of different personalities, people, backgrounds, all that sort of stuff. Um, and that's probably the biggest thing is the diversity. Because everybody brings something different to the table. [Narelle] What's Brandon's favorite thing to do then? [Andrew] So his favourite thing used to be swimming. But, when he left school, his anxiety got so bad. Um, getting out of the house was almost impossible. He would, you know, scream, throw things, um, spit and bite. All that sort of stuff. We're not sure why. Just the transition of having a, I guess, a routine for so long, and then not. It was probably... Um, so getting him swimming in the last few years has been really, really difficult. Occasionally we take him to a beach and he goes in. [Narelle] Yep. [Andrew] But his most favourite thing is driving. Like, he will sit in the back of the car and drive for hours. [Narelle] Yeah? [Andrew] There's not a whole lot of stuff that takes Brandon's attention. Driving, music and food are his three biggest things that he loves. [Narelle] Well, a computer gives communication, doesn't it, too? [Andrew] Oh, definitely. Yeah. Brendan will listen to any sort of music. [Narelle] Yeah. [Andrew] But he loves base. So, um, if he's listening to it in a nearest speaker, he'll put his ear or his hand on the speaker and listen for the vibrations. Um, if he's in the car he'll try and get you to turn it up to like a hundred. [Narelle] [laughs] That's awesome. Andrew, with everything you've learnt, and, you know, obviously, I don't know what age you are, but you sound relatively young

to me. What are the take aways? What's the advice you could give to anyone, any age, about people and communication? And, you know, it's, for me, obviously, I'm passionate about it. And I know through previous discussions you are. And it's not your age, it's, I suppose, what I'm trying to say is at any age, everyone has knowledge. What's the knowledge that you can give people? What's the take away? [Andrew] Yeah, touching on something you said earlier was, um, you don't know what's going on in somebody's life. Um, you know, even if you are friends with them or close with them, you don't know what's going on inside somebody's head. Um, and I think it's so easy to judge based on the spoken word. Um, what a person is thinking or feeling. Or saying. Um, and I think a lot of communication is not spoken word. Um, you know, tone of voice, body language, you know, all that sort of stuff. Um, and I think be patient with people and try and give them the benefit of the doubt. Because at the end of the day, you know, people lash out when they're angry or, you know, sad or even just tired. Um, you know, people withdraw, things like that. But I think understanding someone is the key to communication and, and compassion, all that sort of stuff is, um, the key to understanding what someone's trying to get across to you because it's not always just what they say. You know. [Narelle] That's the best takeaway you could have given, isn't it? [Andrew] Oh, yeah. [Narelle] Thank you. [Narelle] Thank you. Andrew, how can people get in touch with you to find out more about Helping Hands? So you do supported independent living, you do support work, you do a bit of support coordination. How can people find out and meet with you? [Andrew] Not a problem. So you can jump on our website, which is, um, [www.helpinghandsinc.org.au](http://www.helpinghandsinc.org.au). Um, it's currently being redone. So, um, if you look in a few weeks, it might look slightly different. So it's still the same website. Um, or you can call us on 1-300-11-13-11. Um, and we have a small office here. We only have four staff in the office. Um, so typically if you're phoning us, you'll get the same person generally over again. Um, so yeah, it's, you know, jump on our Facebook, our Instagram and message the page. Um, yeah, we have a lot of people following up just for advice. Um, you know, obviously we do support coordination, but we are super passionate about, um, how to access NDIS, which obviously is quite difficult for some. Um, especially, you know, if they don't have support in their life who, you know, don't have a disability themselves. Um, so we do like to help people for free to, you know, whether it's getting on the NDIS, whether it's early intervention, things like that. Just advice or, you know, looking for some supports and they don't have support coordination. Um, you know, especially if it's in this area, we have contact, so. We're always happy just to have a chat and see if we can help no matter what, how big or little the problem is. [Narelle] Thanks, Andrew. And seriously, I think anyone needs to go and have a chat with you because to me, I find it very inspiring the way you've worked out systems and processes that you and your wife and your kids can include Brandon still in your life. That he is the big brother, that he is the son, even when he throws the temper tantrum and all kids have their temper tantrum. It happens. And, you know, well done, and... This is another episode of the Digital Access Show. And again, I am very honored to have Andrew on. So if you like what we do, if you want to find out more, please, we're on [dasat.com.au](http://dasat.com.au) as our website. Like, subscribe, review. And if you want to meet Andrew, [helpinghandsinc.org.au](http://helpinghandsinc.org.au) See you next time. [Music]