

My Home, My Way: Podcast Transcript. Episode 5 – Creating a Web of Support

Jake Briggs: For us people with disability, living in our own home isn't something we expect to just happen...

Linda Hughes: I'd go away for a weekend, and Jacob would have this wonderful time without me.

Jake Briggs: Often, we have to make it happen - by ourselves, or with our family and our allies.

Linda Hughes: He could drive his own life without me being there.

Jake Briggs: I'm Jake Briggs and welcome to My Home, My way - A podcast about people with disability making their home, their own.

Living in a group home is often given as the only option for people with a disability - but that's not true.

It's not what's always best for us.

And group home living is not the typical way we make a home.

We don't say, "Hey, I'd like to live with 5 strangers with the same diagnosis as me, that someone else chose, and have our home run by a service."

So what's the alternative?

My Home, My Way has practical advice and stories of people with developmental disability, their allies and families, making a home on their terms. With support models that enable, even people with complex needs, to live in their own home.

By the way, this podcast is sensory-friendly, with a sensitive use of music, so you can listen comfortably.

This episode is about getting the right supports to thrive in your own place.

You'll meet Linda and her son Jacob and find out...

What are supports in real life? What can they look like? What is their purpose?

And how can they help someone like Jacob to live in his own home?

Jake Briggs: Jacob is in his late twenties. He lives with a flatmate, Lucy.

Let's meet Jacob, through his mum Linda.

Linda Hughes: He loves his sport. He absolutely loves watching sport on TV and cricket would be his favourite sport.

He's a man who does public speaking as well. He's president of the University Toastmasters in Newcastle. Toastmasters is pretty interesting because as a man who doesn't communicate with words, as a man who has complex communication needs, Toastmasters probably wasn't the thing that I would have thought would be up his alley.

He needs a lot of scaffolding to participate, a bit of support to, to fulfill his roles, but he loves it. And he's been a member for a number of years and has a number of very good friends that he socialises with beyond Toastmasters from that.

Jake Briggs: Jacob uses technology to communicate.

Linda Hughes: He uses an iPad with what's called a Pod. So he's able to point to the picture symbols. And there'll be some text with them as well for the people who aren't familiar with the symbols. And he's able to construct full sentences.

He's probably more of a direct communicator. There's some important things that he's able to do with communication that give him a lot more freedom and also important safeguards.

Jake Briggs: He's a really social person.

Linda Hughes: He loves being around people. It's something that he really, really loves - having people around that he cares about. He calls his grandmother every day, because he used to see her every day.

Jacob has been Face Timing people while he's playing a game of UNO online. He's doing Zoom trivia sessions with friends. Everyone sits there having a drink. And Jacob's asking trivia questions.

And there's other things as well. Jacob being really aware of when his friend's birthdays are coming up. He makes a card, he'll often take a photo and print that up, and that becomes a card. Or just something as simple as a Facebook greeting, "Hey, it's your birthday. I hope you're having a great day."

Jake Briggs: Jacob's been living in his own home for about 5 years. His decision to move out happened over time.

Linda Hughes: I'd go away for a weekend or I'd go away for a short period of time when Jacob would have this wonderful time without me, he would be doing things in the evening. And he was going to art gallery openings and going out for drinks with friends. And had a lot more things going on in his life when I wasn't there.

I'd be away on holidays and thinking, "Oh my poor son, he's missing me." And I'd look on Facebook and he was not at all missing me at all.

Through that he was able to tell me that he was confident he was comfortable. He was content. He could drive his own life without me being there and that's all anyone can want for their son or daughter, I think.

When he started living in his own home, I left home because the family home has wheelchair access. It made more sense for me to leave home than for Jacob to move. So I moved to a rental home quite close by.

Jake Briggs: One thing that makes it possible for Jacob to live in his own home is the supports he has around him.

When you hear the word 'support', many of us would think, 'support workers'. But that's not what we mean here. For Linda, supporting Jacob to have a good life is all about relationships. His supports are the relationships he has with people around him.

Linda Hughes: Relationships are what sustains all of us.

If you ask people what's good in life, it's relationships. In any survey around what makes life good for anyone in the population, what makes people healthy - it's relationships and social connectedness.

If you think about all of those things in the lives of anyone's life is so important, but they're the things that often get missed out in the lives of people with disability.

We might think about the support a person needs. You might be thinking about the personal care or other support that a person needs. This idea of relationships is the last thing you think about. Whereas I believe it's the first thing you think about.

It's as important as taking medication.

Having people who care about you, who you see, who you share interests with. For example, Jacob's Toastmasters friends, people who you really connect with.

All of that stuff is just a very important thing for everybody. And it's very important to my son

Jake Briggs: Yep, relationships are essential for all of us. If you've listened to earlier episodes, you'll know this next one.

One of Jacob's supports is called A Circle of Support.

Linda Hughes: The Circle of Support has been an idea since Jacob was really, really young. And, you know, I'd hear about people who had circles of support and I was really excited, but I hadn't got to the process of enacting it.

Jake Briggs: The basic definition for a Circle of Support is a group of people around a person with disability that meet regularly.

Here's a more formal definition. A Circle of Support is usually led by a family member to ensure the safety and wellbeing of their family member with disability, now and into the future.

Linda Hughes: One of my friends said, "Linda, Jacob's leaving school soon. You better get that Circle of Support together and I'm putting my hands up." So that was actually it.

Relying on me it wasn't going to happen because I just felt a bit anxious about it. But once that role was handed to my friend, it all fell together.

Another friend of mine does facilitation of workshops. She put her hand up to facilitate the process and then we just started to roll from there.

Jake Briggs: Linda explains how Jacob's Circle evolved from just brainstorming... to brainstorming and action.

Linda Hughes: The Circle of Support is really great at ideas and that sort of, sometimes it's taking it to the next step and being able to implement those ideas. So that's where it really gets down to the art of asking. And if someone suggests a really great idea, you can sort of say, "Oh, can you do the next thing as well?"

So that it doesn't, the Circle of Support doesn't just end up being a whole lot of things that I'm left to do, or Jacob and I are left to do.

It's more than brainstorming. It's brainstorming and action.

Who is in his circle? He's got a really great circle. He has important family members he's really close to. Grandparents, aunts, uncles, cousins.

We have one friend who, in Jacob's circle, who's an advocate. And her role is, if I'm not around and Jacob has to go to hospital, that she goes with him. And she's the advocate for Jacob in that setting. And she just knows the system well and knows exactly how to make it [hospital] go well for him.

There are some roles where somebody who's really techie, who can help us work through some of the technology.

Linda Hughes: There's a friend who also has a disability similar to Jacob's and she's got a lot of insights that can be really, really useful around equipment, and who's the best OT and those type of things.

And there's times when we're really active, the Circle of Support is very active. And there's other times where it's just about getting together with Jacob and drinking wine and eating food.... sustaining those relationships and having fun together.

Jake Briggs: Yes, having fun!! That's important, right! As Linda explains, Jacob's circle can be pretty casual, and very social. Jacob, during summer has usually hosted something called 'Drinks on the deck'.

Linda Hughes: That was a Friday night invite of Circle members and their families for drinks over at Jacob's house. And people would just bring a plate and whack stuff on the barbecue... and it got to the point where people would text on a Thursday saying, "Are we having Drinks on the Deck?"

And Jacob started Drinks on the Deck while I was away. And then it was just something that continued.

That's the sort of informal. But then there'll be more formal times when we actually do take minutes and people have roles and there's certain things that we want to have happen and want to have done.

Jake Briggs: While a Circle of Support is ultimately about relationships, it can also be an important safeguard.

Linda Hughes: Having people around Jacob who care about him, it's an important safeguard.

When people are isolated and don't have people around, they're less safeguarded, then that heightens their vulnerability.

Jake Briggs: A Circle of Support can be really useful when it comes to planning to move out and to setting yourself up in your own home or a share house.

Linda Hughes: So a Circle of Support, it's generally people who are friends and family of Jacob's who come together to sort of brainstorm and think and help plan and help Jacob craft what's his future. And sometimes they'll be involved in helping enacting those things and using their links in the community and helping with the networking and all those things. So that's a really important role.

It's been really important for us, particularly around those transition times when we're thinking about Jacob leaving school. When Jacob was moving into his own home.

Jake Briggs: So Jacob's Circle of Support is one key support. Another is his team, or 'crew', as Linda sometimes calls it.

Linda Hughes: Jacob has a team or a crew of support workers around him. Jacob needs a fair bit of support day-to-day to do the things that he wants to do and the things that I suppose he needs to do. And they are paid a wage to be there.

The really important role that his crew have is to help Jacob link with his network of friends and family, and to really cultivate and support those informal and freely given relationships that Jacob has, which are really important to Jacob. Really like everybody else.

While we're just talking about relationships and how important they are, it's just important to acknowledge that, you know, if I want to go out for, with a meetup, with a friend, I can just easily call. I've got the physical ability and I'm able to do this very, very easily.

That kind of stuff is stuff that Jacob needs support for. So he just needs someone to assist him in doing that, in the same way that he might need assistance with other aspects of his life.

Our friends, and our family and our relationships are really important and life-sustaining to us. And they're also a really important safeguard. So his crew do a lot of things with Jacob, but there's important parts of the role there just in supporting other relationships.

When we're looking for support workers, we're always looking for people who have pro-social skills, because that just makes it easier. Some of the job description for working with Jacob is being able to break the ice. Being able to seek out new social opportunities. Being able to start up conversations with people you don't know or don't know well.

So that we're choosing people who feel comfortable in supporting Jacob with his relationships. So it's important that we're recruiting the people who have that skillset.

It's important that they know that Jacob needs support to develop relationships and maintain relationships. And they're not fulfilling the role of the relationship instead.

There's a problem that sometimes in support work is that support workers become the relationship rather than actually helping a person to develop relationships, to develop freely given relationships.

So the support workers' role is supporting Jacob with doing those things. Things that he might find a little bit difficult to do on his own. He might need a bit of support or a bit of prompting.

So his support workers will support Jacob to keep in contact with people. So he might send a text message and say to a friend, "Hey, what you doing? Do you want to have a FaceTime later on today?" And they'll make a time to catch up on FaceTime.

Linda Hughes: One of Jacob's team members is a musician extremely well-connected really helped Jacob connect with other people, for his micro enterprise, which is around showcasing live music around Newcastle.

And then you've got people like his housemate, Lucy. She provides some, what we might sort of regard more as, informal support and mentoring and companionship to Jac. And she receives a reduced rent and shares his Jacob's house. And then, we have a range of people who are Jacob's friends and family.

Jake Briggs: So Jacob's Circle of Support sits alongside and overlaps with other kinds of supports, paid and unpaid. Linda brings in different people at different times. She thinks it's good to have a mix. Jacob's Circle of Support is evolving to something else called a Microboard.

Linda Hughes: We do want to formalise Jacob's Circle of Support so it is a micro board.

A micro board is a board or a committee for one person. So we might have communities, community organizations that have a board and or a committee that sort of look that oversees the work that they do. In this case it's just a board or a committee for Jacob rather than a whole organisation.

So hence the term micro - meaning small - board. So we are in the process of putting that together. And of course the part of the important roles of the people involved in Jacob's Microboard as well as his support crew is in establishing relationships, building relationships. You know, ensuring that there is more people coming into Jacob's life.

It's not hard to do, to actually set up the board. I think.

What does require more time is thinking about the relationships. It's thinking about the sharing of information, collecting, you know, the information that needs to be documented about Jacob. And again, I just want to sort of reiterate that, that we might be collecting information about Jacob.

And this is just because Jacob's not able to tell us this stuff. So it needs to be collected by the people who are supporting him.

There's certainly, there's times when I think people with disabilities are over scrutinized. And there's a lot of attention, particularly in traditional support, a lot of attention paid to what they're doing, and sometimes that's not fair and it's actually overbearing. We're trying to find a little balance between that, so that, so that it's a safeguarding process for Jacob.

Jake Briggs: And what does Linda wish she'd done differently?

Linda Hughes: My thinking around Jac having people around him, having relationships around him, I just wish we started sooner.

Linda Hughes: I think my theme throughout it is relationships... how you might be able to think innovatively of the way you use your NDIS funding to help grow relationships, to help them thrive and prosper.

A small investment will always reap far greater rewards, in terms of, you know, life satisfaction. In terms of wellbeing and in terms of safeguarding. So that's actually a really value for money, if you're using NDIS funding, a real value for money to get really good outcomes for people.

And it really should be part of everyone's plan really. Particularly people who you might find themselves at risk of isolation or, at risk of not having freely given relationships in their life, this should be a really important part.

And I'm just going to say that with, I suppose with some respect for people who might've experienced rejection and might feel that that's not something available to them, but that's not the end story, that this still can happen and it still can be possible.

Jake Briggs: That was Linda Hughes.... talking about how support for her son Jacob comes in many forms - paid and unpaid.

A Circle of Support is a group of people that meet regularly... to plan and achieve someone's goals for a good life.

A Microboard is a more formal, legal version of a Circle of Support.

Housemates are another kind of support. So are your team and 'crew'.

And, as Linda says, it's all about relationships.

Jake Briggs: In Episode 6 of My Home, My Way, find out about renting your own place.

Rachel High: My parents actually planned to get this apartment...

Jake Briggs: You can find the Show Notes for this episode, with the main points, and a transcript on the My Home, My Way website.

The My Home, My Way website also has lots of resources, stories and tips for you to get your own place on your terms. Or to support someone else to.

Type “My Home My Way” into a search engine, or go to www.myhomemyway.com.au

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Thanks for listening.