

## **My Home, My Way: Podcast Transcript.**

### **Episode 2 - Busting Myths: Complex Needs are no Barrier to a Typical Home Life**

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

**Sheree Henley:** My son, Isaac who's 24. He has his own house and he needs support to be a homemaker.

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

**Sheree Henley:** I looked for other families who were doing it, and I asked them about how they went about it...

**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 five 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 family, 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.

**Jake Briggs:** In this episode of My Home My Way, we're going to bust some myths about people with disability living in their own place. Things like ... "It's not possible." "It's not safe."

**Sheree Henley:** There was definitely people out there that thought I was nuts when I said I wanted him to live in his own place.

**Jake Briggs:** Sheree Henley and her son Isaac have busted many of these myths.

**Jake Briggs:** Here's Sheree....

**Sheree Henley:** So, my son, Isaac who's 24. He is a delivery man. And he's a Canberra Raiders fan. He's a swimmer and he's a neighbour.

So, Isaac needs support for many things in his life. He has support for managing his own personal care. He also doesn't speak to communicate. He uses a pod communication book, plus he uses gesture and hand-holding. And the supports are there to help facilitate the communication and help others to understand what he's saying. He also needs support to manage his emotions. So, he can experience some challenging behaviours because of anxiety. So, he needs support to remain calm and concentrate and focus on what he's doing. And, support to stay safe in the community and at home.

And he also needs support to nurture relationships with the people in his life and maintain those relationships as well as finding new ones. So, they're some of the key areas that he needs support in.

**Jake Briggs:** With these complex support needs, the first myth that Sheree came across was that Isaac was destined to live a life that looked different to everyone else's - because of his disability. The myth that an 'ordinary life' wasn't possible....

**Sheree Henley:** When Isaac was about 10, I really started to realise, gosh, I need to start thinking about his future and my future as well. And so, I sort of looked around to see what other families were doing and I could see some families were going down the disability separate, segregated way. And I thought, maybe there's another way?

And I looked at what other families were doing in the typical and ordinary space. And I could see other families that went before me achieving things that were wow, like, just so ordinary, like working and having a girlfriend and living in your own home. And going to an ordinary, typical, neighbourhood school.

All of those things, I never knew they were possible.

So I think having an open mind and believing in what's possible and seeing it and hanging out with those peeps that encourage that, has been really a key thing in, in achieving, a typical and ordinary life for Isaac around what he really enjoys.

I've got an older son, Ben. I try to just watch what Ben does and try to figure out a way to make that happen for Isaac.

So, I'm always thinking very carefully about the vision for his life and, and checking in to make sure that, are we achieving that? Is that typical and ordinary?

**Sheree Henley:** And any decisions that we make about his life, I check against that vision just to make sure. And I try to share that vision with others.

**Jake Briggs:** When Sheree talks about a vision for Isaac's life, she's talking about what she imagines for Isaac's future. It can be called a Vision Statement. It's usually written down, and made collaboratively, with the person and other important people in their life.

You can see Isaac's Vision statement on the Show Notes

So why is a vision helpful when it comes to busting myths about people with disability? Sheree puts it like this....

**Sheree Henley:** If you don't have a vision someone's going to make one up for you and you might not like it. There are things that I know that Isaac really wants. So I try to sort of start with what's typical and ordinary, but then focusing on Isaac's passions and loves and sprinkle it with that.

**Jake Briggs:** Sheree used the idea of a vision to guide their planning and to think about the kind of home Isaac might like and what's important. And now, Isaac is living in a home of his own that has those things that are important and unique to him. Things like having a backyard and having space to move.

**Sheree Henley:** The vision for his house. I can see that it needed to be, where he could just be king of his own castle and choose the pictures on the wall, and the colour of his bedspread.

But also that I could see what was important to him is he really likes spaces to roam in. So he really loves the garden and he likes having the park over the road.

And in the house he likes to have, he particularly likes the long corridors and he likes the wooden floors and he likes tiles on the walls in the kitchen and the bathroom. So I've, I've got to see the kind of house that Isaac really enjoys.

**Jake Briggs:** Often people with complex needs are encouraged to live in a group home with other people with disability. They don't get the chance to make really big and important decisions themselves, like who they live with and who their support staff are. They might only get a say in what they put in their bedroom.

Sheree would like to bust the myth that people with disability are better off living with other people with disability or that group homes are a safer and better option for people with disability.

In fact, Australia's Disability Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability says that group homes are still places of abuse and violence for people with disability, [according to their 2020 report](#).

The Commission report says that "although the experience of people with disability in group homes is not uniform, far too many people are denied autonomy" in the choice of accommodation given to them and denied many freedoms many of us take for granted in how a person wants to live in their home.

**Jake Briggs:** Here's Sheree...

**Sheree Henley:** I really could see that he particularly has an affinity for certain types of people. And, from a young age, he never really liked respite care and would always come home very upset and sad, and unwell, really.

He just didn't seem to like going to places where there were other people with disability. I think maybe that was because other people would get upset at the noises that he made.

He particularly loves to listen to really loud music and I thought "Nope, that ain't going to happen in the group home". Because someone else might not like that.

It was pretty clear that, you know, he did not want to live with other people with disability from a very early age, because he couldn't be him. Whereas in his own place he can be.

He does enjoy people and I've learnt over the years, the sorts of people he seems to really prefer. And they're not extroverts. They're people that are confident and have a presence, and they're people that stop and wait and give him time and pay attention to the little things that he does. He has a little yes and no, and it's really hard, it's a shake of the head and a nod, but it's very difficult to spot because he has trouble moving his head.

And these people really notice that sort of stuff. He loves those people that pay attention to him and give him time. So, we've tried to surround him by those kinds of people and choose supports that are that way.

**Jake Briggs:** Sheree and her husband's first step to Isaac living in his own place was to buy a house.

**Sheree Henley:** We are very lucky in that we could leverage the equity in our own home and purchase another property. I know that's not something that everyone can do, but you know, you can still rent a place or there, you know, there are alternatives. What we chose was to buy a place, first of all.

And then Ben moved into that house, Isaac's brother. He got in a load of friends or housemates for himself, and we trailed Isaac going and staying there for a week at a time. My thought was that the housemates as a group of people could share supporting Isaac overnight. You know, help him to have a shower and get dressed and go to bed. But it was pretty clear that that wasn't really the role of the housemate. It just didn't work. He really needed paid supports to do the personal care and supporting him with eating and things like that.

I learned that he still needs some paid supports for some parts of his support and that there is another role for the housemates, which was around the friendships and networking and bringing connection to him.

The other housemates did a good job in introducing him to their own networks. So, they'd have people that come over for parties and, or they'd go out to activities and Isaac could go in with them and with a support worker.

That was a really great lesson for me that housemates, they still had this beautiful role of including Isaac and helping expanding his networks of people.

So that was the first thing that we did.

So, the next thing we tried was us leaving Isaac at home and getting in supports to support him at our house while we went away.

And we found a lovely older couple and they liked to take off in their caravan every couple of months for a few weeks at a time. And they needed someone to house sit and look after their little dog, Joey.

We could go and look after Joey in their house, while they shot off on their caravan. And we got in supports to come and support Isaac in his own home. He was very comfortable with that. Isaac liked his own house and had been there for many years and it wasn't, you know, an anxiety-filled experience of going to a new house. The house was set up for him.

And it gave us an opportunity to figure out, what does it look like? What processes and practices and support do we need for him to stay overnight? So, we were able to nut out things that we hadn't thought of, things like, you know, what happens if Isaac gets up in the night, and I learned that the supports were quite anxious about sleeping, doing the sleepover, they felt that, I have to be awake all night. And so, I had to do a bit of teasing that out with the supports because, no, you don't have to be awake all night, sleep with the door open and you'll hear him.

And we also helped Isaac to understand where to go if he needed help in the night. So, teaching Isaac, "This is where the support sleeps, and you can go and ask them for help."

And we also had to help Isaac understand where we were going and when we would be back so that he didn't get anxious. So we developed some visual schedules around that to help him have an understanding of where mum and dad are. And we also introduced him to FaceTime.

So there are all sorts of really little but important things to Isaac that we learned from us going and housesitting for a couple of weeks and getting in the supports.

**Jake Briggs:** By now, Sheree and her husband have sold the other house they'd bought for their son Ben, his housemates and Isaac to live in.

If Isaac's going to live in his own place, the best place seems to be - the family home.

**Sheree Henley:** We decided, okay, this seems to be the best thing in that he stays in his own home. Because it's set up for him. We've taught him all of this stuff.

**Jake Briggs:** Instead of Isaac moving out of the family home, he stays, and Sheree and her husband buy an apartment for themselves.

**Sheree Henley:** We moved into that apartment fairly slowly over about a year.

So, we took it in turns at staying over there and we would come back for periods of time and less and less and less, then until we finally fully moved over there. And we had the team of supports all set up.

That's worked really well in that Isaac now kind of knows where we are because he comes and sees us in our place. He knows my house and mum and dad's house. He knows what's expected and he knows that when we go it's okay.

**Jake Briggs:** So, after a year of transition, Isaac lived by himself in the old family house, with carefully chosen supports.

Some people might stop there. But Sheree is always thinking about what's ordinary and typical for people of Isaac's age. Many people in their early twenties, who live out of home, have flatmates.

They hang out with their flatmates at home, go out with them, and meet other people through them. Sheree wondered, was that something Isaac might want too?

**Jake Briggs:** The next thing was, would he like to have someone to live in the house with him, and who would be that person?

**Sheree Henley:** We kind of nussed out what the arrangements might look like. And, that was difficult to figure out. I looked at lots of other models in Western Australia and, you know, on the internet and overseas and some people get paid a stipend.

I wanted to compensate them in some way, because it is a bit of an inconvenience when you've got a team of five people coming through your house, each day. But avoid being so grateful and letting them stay for free.

We wanted it to be as normal a housemate arrangement as possible, but also we wanted to have some expectation that they would bring in the social contacts like they did over at the other first place.

We started to look for somebody to come in that was the right kind of person for Isaac, and that was quite connected and good at bringing relationships for Isaac. And it took us such a long time to find someone.

I guess there were some expectations that they would be around. Like we need it to be a housemate and to be someone that brought connection to Isaac, you couldn't be someone that hid in their room and played PlayStation all the time or just went out a lot. You kind of need to be about to build a relationship with Isaac and we drafted up some ads and put them out and got lots of interest.

It felt like finding a needle in a haystack, but they are out there. There are! We found someone. And she was a young lady that happened to work as a support worker.

We did initially get her to do some support work, but we both in the end agreed, "Nah, that's not what we want you to do. We just want you to be a housemate." We've got a bit side-tracked there cause she was a support worker, lost track of the vision where we just wanted her to be a housemate.

So we got ourselves back on track and she was just a housemate. And Isaac really liked her and she really liked him and they got on really well. And she had a lovely family that she used to bring over all the time. And Isaac, got to meet them. She had six brothers and sisters or something, and she came from a family of two mums.

She had really great values. But she worked really hard. Long hours, and didn't have a lot of social connection herself. Even though she was a very social person, she spent a lot of time working and studying.

And the only sort of social stuff she could do was kind of one-off little parties, you know, occasionally. And we, we kind of soon discovered that one-off little parties are not going to work. It needs to be consistent meeting up with people over the same kind of activity in the same place...

After 15 months, this housemate decided that she wanted to leave for her own reasons. And that was fine because that's normal. I remember when I was living in a house. I'd stay there for a year and I'd decide, "It's time to go and do something different."

We learnt some more lessons; you know. We need to find people that are involved in their community. Finding people that are involved in a dog walking club or a book group, or they're gamers and they go and do gaming conventions every week or something.



I don't know! Something that was around something that Isaac could be also interested in, and get to hang out with those people. And this person could bring in their networks to Isaac.

I think it's something that's been worth pursuing. I mean, you don't have to have someone living with you and if you didn't want to, then that's fine.

But maybe one day when he's a bit older, he might want his own space. I remember when I was in my youth, all those years ago, I shared houses for many, many years. And I decided, "Nah, time to live on my own." And when he does, we'll know.

But he still seems to be interested in having someone in the house. So, we'll give it another shot.

**Jake Briggs:** Looking back, Sheree wishes she'd been clearer about finding a housemate, and what their role is ...

**Sheree Henley:** I wish I had been more clear on where to look and how to ask them and how to pitch the role to people, in a way that was understandable and palatable to them and not be overwhelming.

I wish I had been more clear on the role of the housemate and what their responsibilities were, if they had any responsibilities.

They are very different to supports. It became clear after lots of trial and error that their role was not to provide support as a support worker would, but to bring connection and involve them in their networks. I kind of wish I had known all of that first.

I had to spend years working that out but I think we got there in the end.

And we're looking forward to our next housemate and see how we go there.

**Jake Briggs:** Sheree's advice to other families is to keep trying and figuring it out, and to surround yourself with positive people.

**Sheree Henley:** So there was definitely people out there that thought I was nuts when I said I wanted him to live in his own place. And, "Surely the best thing would be to put him in some kind of facility where he would be safe and be well cared for with other people with disability."

And, just from the experience of him going to respite care, I just knew that that wasn't what he wanted. That might've been easy. Might've been easy for me to just find a place and put him in. But I knew that that's not what he wanted

Even though I was surrounded by lots of people who were going, "You're nuts," and "That's dangerous," and "That's not in Isaac's best interest", I ignored those people.

And I looked long and hard to find other people. And I found lots of people out there that are doing this. And, I surrounded myself with those positive people. And I, I looked for other families who were doing it and I asked them about how they went about it. And I doggedly pursued it because I knew that it was possible. And I knew that it was the right thing for Isaac. And I knew that even though it might've been a little bit more of an effort. That it would be much, much better outcomes and worth it. Every little effort that I made and the efforts that I made were very positive.

So, I'm very glad that I didn't listen to the naysayers. I stayed away from them and I pursued that vision for just living typical and ordinary life in his own place.

The key takeaway, I guess I'd like to get across is - you'll learn along the way and don't be worried if it doesn't work the first time. Don't give up because it's all possible.

You'll get there. don't give up.

**Jake Briggs:** So... what has living on his own meant to Isaac's life?

**Sheree Henley:** So, Isaac's been successfully living in his own house now for two years and 15 months of those, he had a housemate with him. The difference that it's made to him is you can see that he thinks of himself as a confident adult.

You can just see it in his demeanour when he comes to the door and he stands at the door and he'll open the door for you.

Also, the safety aspect, I felt that he would be more safe in a home where, he was surrounded by people who loved him. Neighbours and family and friends who could come into the house easily and not be bound by rules and restrictions that some group homes have.

And he's also had the opportunity to learn about being a homemaker. So, the supports don't do stuff for him. They're always trying to help him to be able to do things for himself.

So taking out the bins and doing the vacuuming and unstacking the dishwasher and doing laundry and wiping benches down and cooking his own meals.

And while he can't do any of those things by himself without any help, he's certainly able to do more and more and more of those things, getting more and more and more competent and confident.

The confidence I think is, is the real thing that I can see in him.

And his independence and his ability to say, "No, actually I don't want to do that. I prefer this." You know, he's more confident to do that rather than just being bossed around by mum and dad all the time. That's a beautiful outcome for him. He's 24. And so he should be that way. And I can see that he's following his brother's... the same way that his brother went. He's now very independent and he's bought his own place. So, why not for Isaac?

**Jake Briggs:** That was Sheree Henley, sharing the story of how her son Isaac lives in his own place.

When it comes to imaging what home might look like, Sheree always thinks, "What is typical and ordinary?"

Living with housemates, being connected, and having a place that truly reflects who you are.

Find like-minded people who are willing to look beyond congregated home arrangements.

One place you might find them is through the peer networks run by NACBO organisations - they are on the NACBO website.

And.... keep trying, and don't give up.

**Jake Briggs:** In the next episode, how to deal with fears about moving out.

**Unknown (Brodie?):** The predominant feelings were really around fear, fear of things going wrong.

**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](http://www.myhomemyway.com.au)

My Home My Way is made by NACBO, the National Alliance of Capacity Building Organisations in Australia.

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Thanks for listening.