

My Home, My Way: Podcast Transcript.

Episode 8 – ‘Home’ as a Safeguard for My Daughters

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

Bobby Noone: I really had a very strong vision for Tammy and Kelli having a home of their own.

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

Bobby Noone: That's such a safeguard for Tammy and Kelli to have a house that is a home that suits them.

Jake Briggs: I'm Jake Briggs and welcome to the final episode of My Home, My way - a podcast about people with disability making their home, their own. Over the last seven episodes, you've heard practical advice and stories of people with developmental disability, their allies and families, making a home on their terms.

From how to get started, to overcoming fears and busting the myths out there.

To make a home feel like yours - and not like a workplace.

...Having paid and unpaid support so you can live in your own home, even if you have complex needs.

And stories of renting or buying a home.

This episode is about safeguards - the things that protect you from harm, abuse, neglect or exploitation.

And since this podcast is about home, we'll join the dots between how living in your own place can help keep you safe, as well as be a place that helps relationships and networks happen - some other big safeguards.

In this episode, you'll meet Bobby.

Bobby Noone: Hi, my name is Bobby, Bobby Noone. I am about to approach my 70th birthday this year.

Jake Briggs: You'll hear about safeguards that Bobby has in place for her daughters now. And how Bobby is making sure those safeguards stick around into the future.

Tammy and Kelli are Bobby's twin daughters.

Bobby Noone: Tammy really loves live music, and she's got albums and vinyl and turntable and speakers. Kelli is more of a (I hate to say it), a Sunrise morning television kind of person. She owns the big smart TV in the lounge room and sports. So they're quite different in what they like.

Jake Briggs: Tammy and Kelli moved out of home at 25, and for the past 20 years, they've called an inner city suburb of Brisbane home.

Bobby Noone: And my daughters live in Bardon. It's a tree lined street, nice wide roads. It's a house with a great garden. When you walk into their home, there's a big photo wall, which has their family and friends and photos of themselves.

And the house was quite well-designed. Quite a big house, four bedrooms. It is big enough for each of them to have spaces where they could do things that they like to do. Thank goodness for public housing, who knew about accessible housing, who built that house. I could never have afforded to buy that house or even to design it.

Jake Briggs: They've had a number of small businesses. Living in Bardon was handy for that too.

Bobby Noone: It's also quite close to the city and that, that was fortunate that they got there because, um, a few years ago they had a little business called Wholemeal flowers and that was doing markets in the valley.

Jake Briggs: Tammy and Kelli use wheelchairs. They've got limited speech and have regular seizures that can go on for days, and impact their health. So, having a home that's safe and nurturing is really important to them.

Bobby Noone: Tammy and Kelli do have very complex support needs and require lots and lots of equipment, more equipment than I ever thought that they would be needing to store. But it's trying to keep their home, like their home.

Everyone values their home, their safety and their space, but Tammy and Kelli, it just really needed to work at it because they're at risk of it not becoming a home because of the amount of support that they need.

It's at risk of becoming a hospital ward. Or a home without character or atmosphere, personality, individuality for Tam and Kelli to be able to be who they are in their home and not be too, you know, just seemed what suits Tammy will suit Kelli.

Like they do have two recliners in the lounge room, which don't look like a hospital recliner. Which look like a recliner that anyone has in their lounge room. Their dining room table. It's high enough that they can get a wheelchair underneath. So they can sit at the table, but it's just a timber table with, you know, it's actually kind of like a carved table.

Bobby Noone: And their bedrooms, their electric beds have rails on them, but the rails go underneath. When the bed is made it's a nice doona on there. It doesn't look like a hospital bed, even though it is functionally like a hospital bed.

Their equipment is stored in a storage room, out, out the back door, which is very insightful of the department of housing to think about providing a place to put equipment that is not in your lounge room or where people come to visit.

Jake Briggs: While they've got significant support needs, their home doesn't look like a hospital or a workplace.

Bobby Noone: Tammy and Kelli have eight support workers. Those workers come to work in Tammy and Kelli's home. All the information that support workers need, in order to support them well, is not taped up on walls. It's away in a file they can access that.

And try not to get those things that it becomes like an office. It's not the office, it's a spare bedroom.

So all those rooms are Tammy and Kelli's rooms and not worker's rooms. Someone might sleep there overnight, but it's a spare bedroom like you would have for someone sleeping overnight.

And they have a dining room table that people do not work on and leave notes for other workers.

All those kinds of things are really, really important. To not let Tam and Kelli's home become a workplace or to not reflect them.

I want to give a really strong message - this is their home.

Jake Briggs: Episode 4 was all about this stuff - making a home. How having control over your space can make a difference to your wellbeing and sense of who you are.

Bobby Noone: Home is the space where you're very comfortable about who you are. And so you also want to take that with you when you go out into the community that you feel good about yourself. Like that's where your identity is formed about what you wear, which interests are, who your friends are, what, what are things that you like to do?

If you don't have that at home, it's really difficult to be confident about being a community member, having an identity.

So that's such a safeguard for Tammy and Kelli to have a house that is a home that suits them. And yeah, they've grown into that home and, you know, lived in the street for 20 years. That is kind of almost a very, very critical part of Tammy and Kelli's support. If the home isn't good, then other things can't happen either.

Jake Briggs: A sense of home also makes it easier for social connection to happen - especially if your mobility is limited. And good relationships can be an important safeguard for everyone.

Bobby Noone: What keeps Tammy and Kelli safe? I think having people around them that know them.

When Tam and Kelli first moved into this house in Bardon, I was a little bit anxious at first because we knew that the neighbors next door had asked that we put up a screen of trees.

Because there was that perception of people with disabilities moving next door.

But since then, it's very different. Like, for example, if an ambulance has been there during the week, they'll pop over. Mary will pop over and say, "Is everything all right? I noticed the ambulance was here. Are you okay? Do you need a hand with anything?"

A paling will fall off the fence. The neighbor next door will go, "Hey, I've just got my drill out. Do you want me to put that paling back on the fence?"

That's what all neighbors do, I think, yeah.

I think it's good where they are too, because there's a bit of a culture of neighbors, talking to each other people, seeing each other 'cause they walk and exercise.

Tammy and Kelli have a great little balcony that looks out into the street and they really enjoy looking out there and watching people go by. The neighbor next door, they exchange eggs for the limes on Tammy and Kelli's tree. Tammy and Kelli get invited to street parties. So, people are looking out for them.

People feel comfortable walking up their driveway to say hello. They have a book library out the front. People stop in and have a book and have a chat and bring their kids. Yeah it's very important that they are well known and they know people to say hello.

So that they're visible and they're not just visible. People know who they are.

Jake Briggs: Tammy and Kelli living in their own place means they can have friends over too.

Home is a place where relationships can grow.

Bobby Noone: Health limits them from going out or doing things. And home is even more important because they need to be able to invite people into their home.

Kelli has been particularly having lots and lots of seizures and hasn't been able to get out much.

And a friend of hers came to visit. That just changed Kelli's day dramatically. And that's a safeguard for Kelli.

They need to be able to use their home as a way of seeing friends or... For example, like Kelli. She's really been limited this year.

Bobby Noone: So what she's done is have some creative days. Like 'paint and sip', where people come and do painting and have a glass of wine and nice food. Or create pottery. Like there's many people who just want to come and share that with people and people come along and enjoy and create things.

Home is a perfect place to do that. That's really important for Tammy and Kelli, that they both can make their home work for them when they're in the home.

When they first moved out, Tammy and Kelli were in a small flat. Now they've got a bigger place, there's space for them each to have their own friendships.

In the flat people would come and visit and you'd be visiting Tammy and Kelli. There's no opportunity for them to have a friend that's just visiting them. In this home, they're much more able to be in spaces and have individual friendships instead of being seen as a block of people.

Jake Briggs: Neighbours and friendships are safeguards. So is making sure their home stays like an ordinary home. Another safeguard that Bobby's set up is a network of friends and allies.

Bobby Noone: I'm a single parent and I don't have a lot of family in Brisbane. And my son's overseas in Ireland, which is a very long way away. And so it's really important that other people are in Tammy and Kelli's life.

One thing that I've done and this kind of happened because Tammy and Kelli moved from a service, which was a collective, into self direction and it was about, so how do we keep them employing their own workers? Making, and assisting [them] to make their own decisions? Have those people around them. Keep the vision. Keep the things that we know, which were important to them in their life.

And one of those things that I have done is ask people to be part of a network. And people were really excited about being involved.

There's about six people in the network. They all have a particular role. The initial thought was that we would come together twice a year.

But I think it happened a bit more regularly. And also I had a bit of a health scare and ended up in hospital. So that was a good cue to the network, like to say, Oh, what do we need to know? Where's the information? So it was a very good practice run.

And also I went to Ireland to see my granddaughter when she was born. So that was another good practice for the network.

Some of those roles are like one person is a person around health. And another person is a facilitator, which is really important. This is around equipment, and finance someone who can run the pays when I'm not around.

Bobby Noone: Human resources, recruitment. Even thinking through the legislation and things like that. Someone who's knowledgeable about NDIS.

There are other options for that, but it's just a really good safeguard.

Well, the temptation is to bring all this together, it would be easy to have all those meetings and Tammy and Kelli's home. But I know Tammy Noone. If she sees someone turning up to her home with paper and pens, she goes, "Oh, no, I'm out of here. I don't want that at my home."

While Tammy does not want people turning up with pieces of paper and pens, the network meets informally at Tammy and Kelli's place for Sunday brunch. They'll still be able to be involved in that. And also Tammy and Kelli's workers get to meet the network and know who they are.

So it's really important that people in their network know where Tammy and Kelli live. That's why we have the brunches on the Sunday. It gives you a whole different perspective of who they are. When they're out, they're different.

As much as I know that the network are really important for all that administrative things and vision and things like that... it's just really important that the network understands the value of home for Tammy and Kelli.

And what that offers them and why it's important to keep that as it is.

These people happened to be in Tammy and Kelli's life, but hadn't been asked to come in that formal way. So this is a way about safeguarding that.

Jake Briggs: Before the NDIS, Australia's national disability insurance scheme, Bobby, and Tammy and Kelli's dad Jimmy, did a massive amount of support. Now, Bobby can go back to being a mum.

Bobby Noone: As somebody who's played taxes all their life, I just really appreciate now that the NDIS has come in and it's offered so much to Tammy and Kelli around the formal support.

When Tam and Kelli first moved into their unit, they didn't have enough funding. So Mum and Dad needed to be part of that over weekends, particularly with penalty rates and things like that.

That was one of my worries that I think I brought to the network about having additional funding, which meant I didn't have to be part of their physical support or part of the calendar.

Bobby Noone: But actually, what is my role now? I don't go there on a regular basis. I pop in, they invite me for things. I could have lunch with Kell. I could sit out the front with Tam. Also, Tammy and Kelli come to my home, which is really, really nice.

I've never actually had that opportunity. It would be mainly, they would come for support.

But they're coming to say, hello. Which is a real switch. So I'm gradually learning how to get into that role and to take off my hat when I go to Tammy and Kelli's home.

This is a home, I do not need to manage the support team. There's other people who do that. And so I'm there as Tammy and Kelli's mum.

As well as me being able to be mum, the dad can be their dad and go to football, go to a blues event down the Gold Coast. That's something really lovely instead of being a support worker, as a parent.

Jake Briggs: Since Bobby is now less involved in the day-to-day support, she needs to make sure that Tammy and Kelli continue to get high quality care...

...but not at the cost of a good life.

Bobby has a group she calls the Leadership Team - employees who focus on key parts of Tammy and Kelli's life.

Bobby Noone: There was some things that I think I'm really good at and that's holding the vision and the overall umbrella over this, but I'm terrible at HR. So it's really important that Tam and Kelli's support team have specific roles.

There's a Leadership group who are people like a senior worker, team leader and an informal supports coordinator, that blends the formal and informal.

I know it sounds funny saying in informal support coordinator, but for Tam and Kelli, it needs to be intentional because it just doesn't happen. Someone needs to be able to think through that out of the team. Who's not actually a support worker. Who can dream a little bit, who can be creative about that.

It would be very easy for the formal supports to overtake Tammy and Kelli's life because they're so critical.

They also have a support coordinator, which is different to the people in the teams.

Jake Briggs: Bobby realises how important it is to keep Tammy and Kelli's home, as their home, into the future too. The formal name for this safeguard is "succession planning."

Bobby Noone: It seems a very formal word, but I know, as I get older, I need to safeguard my role.

It's not just succession planning for me, it's succession planning for people that I go to to help me make decisions. Like maybe those people aren't always going to be around.

So always thinking about what's the next thing? What's the next thing? What's the next thing? That's really critical for Tammy and Kelli.

One of the risks could be if I'm the common link between the network and the formal support, is that's really risky. So we've done quite a bit of thinking about that, where the leadership team and the support workers have come together with the network to actually meet each other and do some planning.

Planning together. Because that's really important for the support workers to be part of that and to know who those people are instead of, "Oh, they're over there and we're here." So it's really important for Tammy and Kelli, that they are all linked and know each other and have worked together and have come up with ideas.

If something happened to me, someone might think Tammy and Kelli might want a different living arrangement. And I know that wouldn't work. This works. And you need to safeguard that home. For the future. Now and for the future.

So it's really important for Tammy and Kelli, that they are all linked and know each other and have worked together and have come up with ideas. It's really, really important.

And we've done that this year because we're things just become obvious. Like I think when I was unwell, the network didn't know, "So what's the structure? Who do we go to in the team? Who has that information? What if Bobby needs a signatory? We don't know where the banking stuff is."

A critical thing is you have to pay the workers. That just has to happen.

Safeguarding those things safeguard Tammy and Kelli and safeguard their arrangements. So people do turn up for work. People are well-supported at work.

Handing over some things, knowing what's important to hand over now and also thinking about safeguarding and your future.

And so it's really important that other people are in Tammy and Kelli's life to share that vision with me, so they're known. Yeah, because it's you know, it's a lot for one person, and that's a real danger for Tammy and Kelli ...it it could slip so easily that if something happened to me that someone might think that I mean, want to have a different living arrangement and I know that wouldn't work.

Bobby Noone: This works. We need to safeguard that home. So I've got the support arrangements for the future now and for the future.

Jake Briggs: Looking back, Bobby says there are things she's learned about stepping back, and making space.

Bobby Noone: Like in hindsight, it's a wonderful thing, but I think about how important it is to really be confident to ask people. The asking is so important. Like you think, Oh, don't ask because they're too busy. You should just ask. People can say no, I wish I was confident in that earlier.

If it isn't done intentionally, it's not going to get done itself. That's what I've kind of learned in my life. You actually have to do something and yeah, that's really helped.

I've learned to step back a little bit. In order for other people to be there, I need to step back a little bit.

So there's a little bit of room for people to come in. And also for Tammy and Kelli to see that. That I can have the role of mum. Other people can come in and form those different relationships. Otherwise, I feel like I'm just, am I too scared to let that go? I have to, I have to risk it because it's worth the risk.

One thing I have learned over the years is people actually have wanted to be in Tammy and Kelli's life, and making that space for them. If people are offering that, you should accept.

It's important to keep people close because they're there for the long term.

That's how Tammy and Kelli are safeguarded, and I don't think I can keep Tammy and Kelli safe. It needs to be a variety of people and I need to step back a little bit and give room for other people to develop relationships and for Tammy and Kelli to develop those relationships, not facilitated by me.

Jake Briggs: For the last 25 years, Tammy and Kelli's place has meant so much more than just a roof over their heads and a place to store their stuff. It's their home, filled with memories, history and meaning.

That was Bobby Noone, mother of Kelli and Tammy Noone.

If you're a family member, set up safeguards so not everything relies on you.

Make a home feel like a home, and not an office or a hospital.

Jake Briggs: It means everyone can relax, and feel safe.. and entertain friends and family, and build new relationships for the future.

Being well known, respected and visible in your community are also important safeguards.

It wasn't easy for Bobby to step back and invite other people in.

But because she did, the safeguards are in place.

Tammi and Kelli can keep doing the things they love, with their friends, and enjoy their home - now and into the future.

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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We'd love to know if there's anything we could do to make this podcast more accessible, and your feedback in general. Contact us through the My Home My Way website.

Thanks for listening.