

TRANSCRIPT

EPISODE 53

“Embracing Autism and Diversity in the Community”

00:00:03:02

Carers QLD announcement

Choice and Control is a podcast celebrating meaningful inclusion of people with disability in our communities brought to you by Carers Queensland, your NDIS, local area coordination partner in the community. Each episode provides a conversation space for people with disability, their families and carers to share their stories with you. We also hear from members of the wider community, local businesses and community leaders who share information, ideas and possibilities to give you more opportunity and more choice and control in your life.

Autism Awareness Month is an important time to recognize and celebrate the unique abilities and strengths of people with autism. At Carers Queensland, we are committed to promoting inclusion, challenging stereotypes and breaking down barriers to create a more inclusive society. We also aim to remove the stigma surrounding autism, challenge preconceived notions and promote a more inclusive society.

00:01:00:20 **Tracy (voiceover)**

Our first interview in this Autism Awareness Month episode is with Amy from Dalveen who is a member Amplifying Young Voices reference group, part of our School to Adult Life Transition program. Since being diagnosed with autism spectrum disorder in 2019 and gaining access to the National Disability Insurance Scheme (NDIS), the 22-year-old is on a journey of self-discovery. We started by asking Amy about what she would like the world to understand about Autism.

00:01:28:15 **Amy (interviewee)**

Just in general, autism is very misunderstood and a lot of people see people like me with autism as being immature or childlike, which often results in us not having a voice of our own. So I think a lot of people need to maybe just rethink about what autism is. Maybe it's not what they thought it was when they were younger. And yet we all have our own personalities and interests and skills. And having autism isn't it doesn't always impact on that. Sometimes it makes it better. But yeah, I think just working out what autism actually means is a big thing.

00:02:20:22 **Emily (interviewer)**

What would you say your unique strengths are?

00:02:24:24 **Amy**

I can see things very differently to others and work out problems in my own unique way, which can be very helpful when like at work and things like that. I'm also very good at retaining information and I probably annoying my friends a bit. I'll just randomly whip at a good fact about something. But yeah, but I do that quite a lot.

00:03:02:04 **Emily (interviewer)**

That sounds like a good fit. Sounds like a great thing to have, right?

00:03:14:24 **Amy**

Yeah, definitely. Definitely is useful. I'm also quite stubborn, which I think is good. Some people might not, but I'm determined to make certain things happen, like live independently and things like that. And it has its benefits, but I know it does probably annoy some people.

00:03:29:13 **Emily (interviewer)**

So do you think businesses and society are becoming more understanding of the needs of people with autism and improving what they do?

00:03:29:13 **Amy**

I think some places are definitely shopping centers having like quiet time is a very helpful. It doesn't it doesn't happen out here because I'm quite rural, but I imagine it being very helpful kind of other businesses. But university has become very online and it's so helpful for me so I can fit it into my routine and schedule. And so when I have days where I can't study, I'm not going to miss a lecture because all recorded and I can do it when I am feeling well enough, which is very big deal for me. You know, think back in the days there wasn't that opportunity, so a lot of people missed out. And because I'm quite rural, university wasn't always an option, but now it is. And I love it.

00:04:38:15 **Emily (interviewer)**

What more needs to be done to remove challenges for people with autism?

00:04:41:21 **Amy**

The largest thing that needs to be done is just to remove the stigma about autism. There is kind of that idea that people, children, especially with autism, are just misbehaving, kids who just won't listen. There's also I think I think people need to re-learn what autism is and maybe realize that it is a bit different to what they think the amount of times I've heard people say, everyone has a little bit of autism in them, don't worry, you'll find when realistically that's very different. It's not that I would like things to be a certain way in my mind, I have to have a certain way because I just can't function without it. And it's very annoying sometimes, but sometimes it's useful. And I think just realizing that we have as people with autism have skills and we're often very good at particular skills. If people learn to accept those and work with us through those, we often can do quite a lot, which I think is very important.

And I think our society will go so much further if we accept neurodivergent people as people and as equally valued as everyone else, and not just neurodivergent people, but with anyone with a disability. I think we all have our skills and we're all people at the end of the day. So I think that just needs to be remembered sometimes, definitely.

00:06:20:12 **Emily (interviewer)**

So you're a member of a School-to-adult-life transition group (STALT). What sort of work have you been involved with in this group?

00:06:34:07 **Amy**

Mostly with the group, about monthly have a meeting that goes for a couple of hours we think of ways to help the transition of being in high school to adulthood for those disabilities. At the moment, we have all kind of agreed that having like a mentorship would be very helpful, as well as not excluding children with disabilities from mainstream school.

As for my part, I have a kind of a unique experience with school because I was in the mainstream school. I wasn't diagnosed until I was, I think I was 20 around that time. So my perspective is that kind of outside view of what the disability system is at school and how maybe teachers and students saw those students, which wasn't always positive, but sometimes was so it's kind of beneficial.

I got to see what everything was like from the outside. And it's interesting to see what might have happened if I was diagnosed earlier. And what I'm grateful for that happened because I was outside the disability section. But what I wish did happen because I missed out on it.

00:07:49:20 **Emily (interviewer)**

So looking back on your own experiences of high school, what more needs to be done for high school students living with autism?

00:07:56:17 **Amy**

Less discrimination if I was diagnosed while I was in school, I wouldn't have told anyone because I would have been so embarrassed and I would have been terrified of people treating me differently. If I could go back and change the school system. I would love if there was less exclusion and that for people with any disability, with autism especially, I think I read recently that about 40% of people have and I'm neurodivergent, which means it's it's not like that different from mainstream.

It is almost mainstream now. So why aren't we making it mainstream in these schools? It would be great to have like a sensory room or a quiet room where people can just re-organize their thoughts, reorganize the sensory situation and just more understanding from students and teachers of how important these needs are. And I think that a lot of students would have a much easier time because there are some amazing kids that I know who have autism that I'm just scared that they're going to be stifled out. Their passion will be stifled out because of school. And if they are, I think they'll do world changing things. That's my hope. At least.

00:09:27:05 **Emily (interviewer)**

What advice do you have for current high school graduates looking to move into employment?

00:09:33:06 **Amy**

Take your time. Definitely. And if it doesn't work at first, that's okay. Make sure you take care of your mental health as soon as you start neglecting that, everything becomes so much more difficult. Don't let an employer feel like you have to prove yourself because of your disability. I have felt that in the past that because I'm disabled, I have to be way better than everyone else just to prove that I'm equal.

When reality I am equal no matter what. And that's important to realize how valued you are.

00:10:13:10 **Emily (interviewer)**

Do you work for autism specific organizations at all, like Autism Queensland?

00:10:23:06 **Amy**

I don't currently. I would love to, but currently I don't. I work with some local groups for people with autism, like a Dungeons and Dragons group, but that's about it.

00:10:35:05 **Emily (interviewer)**

So what do you do with that group?

00:10:38:06 **Amy**

So we play Dungeons and Dragons every week and it's from ages 16 to 24. I was trying to remember my age and yeah, we meet every week. We are all neurodivergent and we are all LGBTQIA+ and it's a very safe space and for a lot of people there it's the only time they go out and the only time they've made friends. And we've been going for about six months now, and I'm very proud of our little group. It's the best thing every week. I look forward to it so much.

00:11:14:09 **Emily (interviewer)**

Have you ever had to speak out about the stigma and advocate for other people with autism and, you know, and what was your message when you had to do that?

00:11:25:06 **Amy**

I did don't often, but I did once, particularly when there was a change to requirements for driver's licenses. Having my driver's license is extremely important to me. It gave me my independence. It gives me freedom. And it's the proudest. My proudest moment is getting my license because I work so hard for it. And when I found out that there was a possibility that I wouldn't have my license or I'd have to keep doing tests to keep my license, I was I was heartbroken quite a long time.

So straight away I was emailing representatives, government officials, all the autism advocate groups I could find. And yeah, I it was really heartbreaking to realize that we weren't valued and it was just discrimination. And I've talked to a lot of people about what professionals and they don't agree with it at all. And I think to kind of show what we like, say what I was saying to everyone is that we are people and we deserve the same rights as anyone else, just because maybe our brains that work the same, that's fine.

We see things differently and often that's a benefit. We shouldn't all see things the same way, otherwise problems won't be solved. New inventions won't be discovered if we are all have the exact same brain and we need to be able to speak for ourselves and not have people speaking for us. Which often happens. Usually it's meant to be to help us by a carer that's speaking for us.

But in reality we need to learn to use our own voice because our voice is important and it's often treated like it isn't. But we are important. We're as important as the next person next to us. And I think we all have special skills that we can use to make our lives and other people's lives better.

So yeah, just let us have our own opinions, I guess, and let us have the same rights as everyone else.

00:13:53:04 **Emily (interviewer)**

Now that, you know, you've got autism, it was in your early twenties when you found out. When you look back, would you change anything or have you got to a good point now that, yeah, you're proud of who you are and you've got a different lens on life?

00:14:07:06 **Amy**

I wouldn't change anything. It was really hard, but I learned a lot from growing up, not knowing I was neurodivergent you know, there would be a lot that would be a lot easier. But I worked for everything that I have now, and I. I've broken down. I pulled myself back together and I've learned about myself. I've learned more about myself than I thought I ever would or ever needed to. And now I'm very happy where I am. I am. I'm not working currently, but I'm studying. I have an amazing girlfriend and I'm very, very happy and hopefully sane, living independently. So I wouldn't change anything because it's led to me now and I'm so happy.

00:14:57:19 **Carers QLD announcement**

Our School to Adult Life Transition Project aims to identify positive pathways for young people with disability as they move from school to adult life. To help us better design our programs for young adults and their families, Carers Queensland is proud to work with our new reference group of young adults from different regional areas who have finished school and are exercising choice and control at home, study, work and in their communities. The Amplifying Young Voices Reference group share vital knowledge gained from lived experience to inform ideas for supporting young people who are still at high school to overcome barriers and feel empowered to plan for their adult life. To find out more, get in touch, or look for events and opportunities coming up near you. Visit our website at carersqld.com.au or call our inquiries line on 1300 999 636.

00:15:58:21 **Tracy (voiceover)**

The South Brisbane men's shed is a traditional men's shed, but with a special interest group providing a place for people with autism to come and talk with others who have similar experiences. Next up in this

episode, we talk to Phil Sharpe, the president of the South Brisbane Men's Shed, who shares what can happen in the community when people with disability feel comfortable and safe. I started by asking Phil about some of the opportunities the shed offers for fathers and male supporters of family members with autism.

00:16:31:23 Phil (interviewee)

The idea began with the director of Education Autism Hub back in 2017. We were incorporated in 2017, but prior to that, the director got in touch with other men's sheds with coordinators of Men's Sheds in Queensland at that stage and asked if they knew any people who might want to act as a steering committee for our shed and that happened in 2016. That steering committee got together and it was on the advice of the director that they had some spare sheds which could be used for them in the area, as well as having closer links with the autistic community. It could potentially include the fathers of autistic children as members.

So once we incorporated with the inauguration of the executive committee, the committee decided to have a role within the committee known as F.A.C.T. Fathers of Autistic Children Together. So that's how the men's shed was started, the beginnings of it. The fathers of autistic children are a very busy group. So that was expanded a little to be the fathers, grandfathers, supporters of autistic children. A logo was developed and the colors chosen for that logo were over a spectrum of colors, I've been told. And so those colors reflected also in the Shed Emblem, a choice of an acknowledgment of things beings on a spectrum. Our sheds is open to male and female members. Now that's only happened in we've always had female members, but they're now full members. And I'm thinking that as we evolve as a group, that might be a whole new journey. We can go on in terms of autism particularly, or people with difference.

The group in the early days went to the Gold Coast, to the Australian Men's Shed Association National Conference and presented about our shed and how it was having links with the autistic community and it was really well accepted and from that we gained some more impetus to go forward. Once the FACT co-ordinator role was filled and those that person was taking it forward, there were many functions that were held that we had, what we called BBQ & A's. So with invited guest with some, and the director of the Education Center at South Brisbane our campus that was is quite well versed in, in knowing about autism, so he was out he was our number and he's a member of the shed. He was our number one candidate in terms of those BBQ and A's.

00:19:51:09 Phil (continued)

So it was just an evening barbecue with questions and answers for at that stage, male fathers of people with autism. That expanded into having event nights such as State of Origin where fathers would come along and have a lovely night with their new friends and they had movie nights. The shed was kept open on Thursday nights for anyone to come in but aimed at those working members who most of the fathers of autistic children that we met were at this stage, whereas many of our members are retired. And so we can be there any time.

We have we have some members currently who acknowledge is being on autistic. However, we've also expanded to having members who are parents and grandparents and supporters of people with autism within our group currently. So it's a growing group, but we're potentially more now about the men's shed and just how we treat people, how we interact with people rather than specific disability groups. And that will become more clear as we talk further.

00:21:09:05 Tracy (interviewer)

So some of our peers, Queensland staff, have had discussions with you about our proactive approach for including people with disability in your shed. Can you talk us through the process your shared uses to ensure that any person, including a person with disability, can access and participate in your shed activities?

00:21:31:10 **Phil**

So we don't really have a process as such, but from day one we the, because this was sponsored by the State Government basically, we have a disabled toilet and shower area if we ever needed it, which which was put in post us getting the complex, so people are thinking about it. Then we have a kitchen that's accessible for wider access kitchen and the whole of our main shed is, is set up with things kept out of the road, things towards the edges, so it is accessible. So those little decisions which make life a little easier, part of the original thinking. Our woodwork area and our blacksmithing area - woodwork is still very much able to take in people who have disabilities. Our metal work area, our blacksmithing area, although we have people with disabilities in there, it's pretty tight. It used to be, apparently it used to be a toilet block in the fifties and was a boys toilet block. So there's not a lot of space in there. But but, but we've had people with disabilities in there working.

Other things... So we have this policy that basically sets out and we get to new people who are coming to the... what do you call them, the NDIS person who contacts us originally and then the support worker needs to know these things. But the NDIS person who gets in touch with us to say, can this person join your shed? We will give them a copy of our support worker policy so they can read through it and, and basically it says we're going to do everything in our capabilities to make sure your person is safe and they enjoy what they're doing. And we so from that, we've had we have a number of people. We have currently, we've got a lovely 40 plus year old Down syndrome man who comes in, who plays piano accordion in the music group, and he's blind and he has the best time. And it is just a wonderful experience. But you know who the winners are? We, the old men, are the winners. Many, many people in our group have probably never experienced people with disability on a regular ongoing basis. This man brings such joy to his life and our music playing that it's just a wonderful experience. It's he's really enjoying it. And we are, too.

So how do we make it? We do the normal mandated things: We make better spaces. We have places where you can get in and out of easily. We have ramps and blah, blah, blah, all that sort of stuff. But we have we also have people who... Yeah, we just treat everybody is everybody else. And that's not your disabled well... we do take care, though. We're vigilant. We acknowledge if people wanted to work in the woodwork room particularly and then we are vigilant, we where they have to go through an induction process more often than not be accompanied by their support worker. Some people with disabilities come without support workers and we're okay with it. They're more able to say to us, look, this might be a bit difficult for me or this might be, you know, a little bit challenging, but we can support that just by our interactions with them. And we do that.

00:25:12:02 **Tracy**

So Phil, in the past, your shed hosted a workshop for young people with autism. Can you tell us about that particular workshop program?

00:25:20:00 **Phil**

Yes in fact I've spoken to three different men's shed gatherings now about that program because again, the person who came to us, the provider who came to us, said she'd been to a number of other sheds and they said, no, that's too hard for us to do. We've hoped to do it again. We're yeah, we're not having as much success with getting it off the ground again for a variety of reasons. But nothing really to do with the shed or whatever, it's been slow progress.

00:25:55:02 **Tracy**

It's wonderful the work you're doing there. Just finally today, Phil, in what ways could men's sheds support each other to further include people with disability in their local shed?

00:26:07:20 **Phil**

Well, I think you could go on visits to other men's sheds, and I think that's a wonderful thing for our members to do, is to go and look and see how other sheds work. But the reality is we just have to acknowledge that we need to be inclusive and we just need to say so this is, this person had some issues, problems, disabilities, whatever you like to call it... what are we going to do to solve a problem at our shed and how are we going to overcome this? What steps are we going to put in place? What things are we going to do to make it possible for people with divergent needs to attend our shed?

We have a couple of members who are visually handicapped that have assistance dogs and they come from the Gold Coast to our shed because other sheds wouldn't take them because they didn't have the room for the dogs. Well the dogs can sit under a table. We can put a nice warm mat down for them because we've got concrete floors or whatever, it's winter. They're just simple things.

00:27:16:02 **Tracy**

Phil you said 'simple things' and do you think that that is often the case, that it's really not that difficult to make these changes and then inclusion can happen?

00:27:26:06 **Phil**

I think it's very easy for inclusion to happen in that there's far greater problems that men's sheds have then how to get a wheelchair from point A to point B or you know what activities can we now promote that will that a person, any person will enjoy? Our music group is a great example. We now have a drawing and a photography group and a pool group. So they're easy access activities. A lot of men's sheds are particularly focused on woodwork and timber and we have an extension to that in terms of the blacksmith shop, there's no Men's shed that has a blacksmith shop as far as I know, besides us. And but, but again, if, if there was any fact we had a person come in last weekend because her 20-year-old autistic son is keen to do blacksmithing. And so she came in on a visit with him to the shed. I've now emailed her yesterday and today to say, how did you go? We're open over Easter apparently, that's okay, but I've emailed her to say, well how did you go, you know? Did it suit his needs rather than... it's not the environment that you might put somebody in with difference. You know. It's about the person's needs. Did he like what he saw? Will he be able to enjoy what he what he's doing? I think our sheds need to, and I'm certain all sheds do that, because we encourage all us senior aged gentlemen to come in and do those sorts of things. But we need to look further. We need to look further at including all. I'm not certain it's an option, in fact I'm certain it's not an option.

00:29:14:16 **Carers QLD announcement**

LAC Connect. It's a new way to stay in touch with your Local Area Coordinator, Carers Queensland, with everything you need right here on your device. It's a handy app to keep track of your LAC appointments, browse workshops and events, check out information and support and get the latest news stories and podcasts. It's available on Android and iOS, so whatever device you have, you can stay in touch. Head to our website to sign up at carersqld.com.au and look for LAC Connect.

<https://carersqld.com.au/lac-connect-signup/>

00:29:48:07 **Tracy (voiceover)**

And that was our final interview in this episode. For more information on some of the other great community organisations working in this space - follow the links provided in the episode transcript.

Thanks for joining us at Choice and Control, a Carers Queensland podcast. If you've enjoyed this podcast episode, please take a moment to leave a rating and review and share it with your community. For more information about the National Disability Insurance Scheme or Carers Queensland, contact us online at www.carersqld.com.au or call us on 1300 999636 or head to Facebook and look for Carers Queensland NDIS.

LINKS

School to Adult Life Transition project <https://carersqld.com.au/ndis/inclusion-projects/school-to-adult-life-transition-support/>

Autism Queensland <https://autismqld.com.au/>

Raising Children <https://raisingchildren.net.au/autism>

Positive Partnerships <https://www.positivepartnerships.com.au/>

ARFID <https://edfa.org.au/about-index-edfa/about-eating-disorders-families-australia/>

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