**00:04 Carers Queensland announcement:** If you or someone in your family is using the NDIS, you've probably already heard of the myplace portal. Time to level up, and make myplace work for you. Carers Queensland's myplace portal support sessions can help you find your way around and get confident accessing your plan information online. Charge up your phone, tablet, or laptop and bring it along to a free session near you. Find out more, check for events coming up near you and book your spot online at carersqld.com.au. You can also call us on 1300 999 636.

**00:40 Voiceover:** Choice and Control: a podcast celebrating people with disability, brought to you by Carers Queensland, NDIS Local Area Coordination Partner in the Community.

 Max Elliot has quite a history with the Brothers Rugby Club in Albion. He's working in the restaurant on a school-based traineeship, before that he started playing there in 2014 when his parents established the GingerCloud Foundation. Their modified rugby program is making sport accessible and inclusive for kids of all abilities.

 Max has autism and uses NDIS support to build his skills and independence. His mother Megan says that's how he decided he wanted to spend his career in the kitchen.

**01:24 Megan Elliot:** It was about December last year, we did speech therapy one day and he just turned around and said ‘Mum, I want to be a chef’. And we were just so, so excited. We've seen, particularly since he's been able to get out from school a little bit more, the chef at Ruggers is just an amazing person, Simon's a wonderful man, so Max has really come out of himself. So from this year he'll be doing what they call a school-based traineeship. So he will be at school, but he'll be at Ruggers two half-days a week. And in the kitchen doing kitchen and food preparation one day, and then front of house, you know, taking food out and talking to people and customers, on the Friday afternoon when it's quite busy at Ruggers. It’s been obviously as many families like ours experience, it's a marathon, not a sprint, this journey we're all on. B we have to say he's just a wonderful, wonderful, warm young man. So it makes all the hard work with it really worthwhile.

**02:31 Fiona Stutz:** That's great. And why a chef?

**02:34 Megan:** He loves food, so that's really good. He's always loved food, it's really interesting, but I think too, Max is interesting, he's such an intuitive young man. When he likes people, he really likes people. And I think he loves Ruggers, and there's a longer story around this in terms of what we did with GingerCloud Foundation and the modified rugby program that we'll talk about. We wanted to create a place where he could feel safe and secure, be understood, experience success and belong into the long term. And so, because Ruggers restaurant is in Brothers Rugby Club, which is where we started this program called the modified rugby program back in 2014, he's been there every week, twice a week, every year since then. So he was so comfortable in that environment. That's where we used to go and have pizza and drinks at the restaurant within the club, so for him to then be able to work there wasn't a stretch.

But I think also the influence of having the formalised work experience, but also a wonderful owner of the restaurant, ironically his son and Max were in the same year at school from when Max was in grade two, kind of on and off. Matt, Matt Moses who runs Ruggers, remembers when Max was totally non-verbal and would kind of sit in the back of the classroom. And for him, it's just extraordinary to see him now, being an apprentice chef in the kitchen, working in his business. So I think all of those things create this place where everyone is working towards Max’ success, because they see the value that he brings into that community.

**04:34 Fiona:** Is Max using any NDIS supports to help him on his chef journey?

**04:41 Megan:** Yes. So, the main things that we're focusing on, from an activity development perspective is, functional numeracy, functional literacy, and really good language development. So we're using that in terms of the capacity building. If you meet Max, now it's hard to imagine that at seven, we were told by a specialist school to be prepared that Max would never speak, never read, and never write. And we would just fortunate that, you know, we had this little bird on my shoulder that just kept saying ‘tough call at seven!’ Like, he was only seven, writing someone off at that age when we don't understand enough about the neurology of autism.

Max is quite tricky because he has autism and he has a very complex language disability that sits as a co-morbidity, so it's not just driven by the autism. And it took so many years to actually dig into that and identify, that the learning delay was so complex. It was coming from a lack of attention. So, you know, we had to have the medication sorted out. Then we found an incredible speech pathologist, and he was the one person who went ‘yep, I think I've got something that I can work with’. So when we had all the language assessments, every part of Max's language assessment was below profound, like, if you can imagine, there was nothing except this huge spike in meaning. And it was quite incredible from a science perspective, we worked with a speech pathologist who could basically attach language onto that one spike, neurologically, of meaning. And now he can operate in a group, e's got great receptive language, more complex concepts are tricky for him, but we can break that down and he can ask questions.

So if you think about that from the capacity building perspective, that's where a lot of our focus goes. We still have three hours a week of speech pathology, which is the only way that Max has this language that's really developed now, but also we use an amazing program called Ghotit. And, so we use that for any assignments and stuff for school for Max now. We use a lot of the funding also for touch typing, so we taught Max to touch type really early because of all of the motor planning issues, writing was just a nightmare. It took so long to write he couldn't get his thoughts out. And using Ghotit, which is a program that was actually designed adults with dyslexia, Max can now get the thoughts out and actually, you know, write his communication as well. So that's been really exciting.

And then from the community capacity building, from the community side, so the social interaction side, we've got fantastic support workers who would do things like teaching him to catch the bus. A lot of cooking at home, two of our support workers are really fantastic in the kitchen and they love cooking, so they've really given Max a passion for cooking. And I think that's part of where the chef part comes through as well. But, if Max could have pizza all day long, Max would eat pizza. But it gives him a sense of, he can do these things by himself.

Last year also, there was a big chunk that helped Max and get his learners online as well. So there was a lot of practice that went in with that. We also use a fantastic tutor who is really helping build the functional numeracy. So that's things like, Max can start to make some basic assumptions about when you give people $10, if you spend five, how much money should you get back? So trying to give that sense of financial security. It will be very difficult for Max to really ever control his own money, but you know, we can put things in place around that. But as much functional literacy and numeracy as we can, and then really building up all the independent skills. This year he’s got a new bike, so he's going to be riding to and from Ruggers so that he's got that independence going to and from work as well.

This is our second plan. It worked so well for us last year, and we've got a great coordinator as well. And I think, when you've got a really clear vision about what you think your children can achieve and what your young people can achieve, then build a plan kind of based on that vision, if that makes sense.

09:35 (music)

**09:44 Megan:** We want Max to make as much of a contribution in the community as he can. That hopefully involves getting a job of some level, paying taxes, as well as getting all the support that we can. We want his life to be as normal as it can be in the capacity of what he has and being able to modify things and giving him support around him. Our children have the right to that expectation in life. We're a really, strong believer in contribution, because once communities start to understand what our children and what our young people contribute to community, they start getting turned on to, ‘Oh, maybe we can modify things a little bit because these people are amazing and they bring so much and they enrich our lives and teach our young people so much about disability’. And yeah, that's kind of always been our philosophy.

**10:39 Carers Queensland announcement:** Getting started with your first National Disability Insurance Scheme plan? Get off to a strong start with Carers Queensland's free workshop: Using Your NDIS Plan. Learn how to you use your funding, work with service providers, and use the myplace portal. Find out more, check for events coming up near you, and book your spot online at carersqld.com.au. You can also call us on 1300 999 636.

**11:10 Voiceover:** The family's relationship with the club where Max is now working stretches back to when he was eleven, when the seeds of what would become the GingerCloud Foundation were first sown.

**11:23 Megan:** For us, those years between five and 11 were pretty bleak. We got to 11 and Max was at school down the road, and there was a wonderful rugby coach, and we had a friend around the corner whose son had Aspergers. We started a little rugby thing called Max and Jake Rugby, which was basically about getting kids out on the field, being able to pass the ball, just to kind of get some sense of normality. We had a huge rugby club literally a roll down the hill, Max could ride his bike down the hill to a wonderful rugby club called Brothers Rugby Club.

Max was about 11 and he was doing Max and Jake Rugby, and we said to our coach at the time, ‘Hey, Dale, there's this incredible community of people down the road who we don't know, all of the other boys the same age as Max all play rugby, but Max doesn't know any of them, we don't know any of the parents, Lara our daughter doesn't know any of the siblings, how do we get involved in this incredibly vibrant community?’ Because we've lived that period of our life like a family, like a horse with blinkers on, literally just trying to get from day to day. And then once we had this bit of space to get light at the end of the tunnel, we went ‘OK, how can we get involved in the club?’ And that's kind of where it started.

What we realized was that, if we knew nothing about autism, which we didn't, how would we expect anyone else in our community to know anything about the challenges that we were facing? So we realized that if we wanted to get involved in the community, that it was also our responsibility as a family to help train the community and help build awareness about our kids. So the first thing is to create a place where our kids feel safe and secure, where they're understood, where they experience success and belong. And the second thing was to nurture a generation of young people for m disability is normalised, because a bit like the recycling concept, if you train the young people, I mean kind of 14 to 17 year olds initially, they will take that thought leadership back to their families and back to their group of friends. Because only by normalising disability will we be able to create this community where, when we’re not here anymore and I’m not able to support Max's life and his vision, that community needs to be ready and have the capacity to be able to go ‘Of course I'll involve Max and kids like Max. Why wouldn't I? We want the question to be “why not?” instead of “why?”

We realised that kind of social change was going to take a generation, really, so we needed to do that at the same time. So, GingerCloud, the name: ginger refers to the first time that Max came home from school and had enough language to ask for morning tea at tuck shop. And it was a gingerbread man and an apple juice, so that's where the ginger came from. And then the cloud, we see a cloud as being every milestone, a cloud in a blue sky is that stepping stone and celebration of every small success in Max's life to get you where, as a family, you believe that you can go. So that's what GingerCloud means. So for all of our families involved, it's about a celebration of every milestone towards a vision about what amazing lives we believe our young people can have. You know, if we set the bar low, our kids will achieve it every time. But if we set the bar high, our kids will work to that and our community will work to that. And we'll work together to be able to say, ‘what is the best possible life that our young people can have and what kind of contribution can they make to our community ongoing?’

**15:48 Fiona:** And so now the modified rugby program’s played in numerous rugby clubs in Brisbane, the Darling Downs, North Queensland, and even in the ACT. Where do you actually see this program going?

**15:58 Megan:** Well, hopefully nationally. So we're looking at expanding in the ACT this year and we'd like to get into Victoria. We've had some interest out of WA as well. I’ve actually also had six countries say that they'd like to get involved in the MRP.

We were very lucky in 2016. World Rugby is like the global overarching body that runs rugby around the world, and we came second in their character award. They award that for groups around the world who make a really significant contribution to rugby. So we're looking at setting up a licensing model with the MRP where people around the world can access the drills. And the big thing that makes the modified rugby programs so different is we have a really specific allied health framework that sits in the backend. So, we profile each child when they come in, we ask parents to complete information about them, their needs.

So the modified rugby program has been specifically designed for children with autism, Aspergers, and learning and perceptual disabilities as well. They might have a secondary physical disability, but the majority of the modifications are cognitive. So it's things like sensory awareness, modified language, we have lots of visual supports, it's a shorter timeframe. It's a quieter time when we do it, so we generally always play first up, instead of having 600 under-sixes arrive at the same time. And we train and play on the same field as the clubs. Because a lot of our kids, if they've got balanced related issues, when they're younger, we're aware of vestibular issues, sensory issues. But also the thing is just the ability to be on a green pitch, with 15 other people, and have a coach and have someone who's in charge, is a big adjustment for a lot of our kids.

That’s why it was so important for us to get them so early, because to help children understand what a workplace is like, they need to start operating in groups, but in a really supportive, modified environment. So what makes the MRP so different is that every player with a learning or perceptual disability has their own player-mentor on the field. And, because we've got four divisions now, the young people with disability are from seven up to about 25 in the colts program, and then we have teenagers from 14 to 17, so it's school [ages], but now we have player-mentors who support our older children. Max is obviously now leaving school, we need to be able to support the older people as well, the, older young adults. So we've got university students who support them, and a lot of the uni students, a lot of them are doing OT or they might be doing physio, or they're doing teaching. They genuinely have a passion for inclusion and diversity. So they're getting to have this wonderful work experience whilst they're still at uni.

For the schools, a lot of the schools now do service and the kids have service obligations. So we wanted to allow those young people who haven't experienced, say children, young people like Max firsthand, to have an experience about what it's like to support a person with a disability. We train the player-mentors as well, so there's a program that we call the Disability Inclusion Leaders Program, where in those early years, it's really all about giving them a language of diversity and inclusion and giving them simple ways that rather than just being inclusive they learn how to actually do inclusion. Kids are worried about, what words should I use? How do I support this person? Can I touch them? What do I do if they don't understand me? What happens if I can see that they're getting anxious, what strategies do I put in place? So that's where our allied health framework comes in.

When we are no longer here to support him, he'll have had a lifetime of being able to be independent and start making decisions. And the fact that the NDIS will continue across Max's life, as a family that gives you an incredible sense that it's going to be okay. Because that's the greatest fear that all of that, all of our families have, you know, we can do so much when we're here, but what happens particularly when we're not here? And the big thing for us is we never wanted that pressure to sit with our daughter, we wanted her to be able to live her life, not to change her life to have to be there for Max if she didn't want to. She may still want to, but it’s her right to live her life as well.

I think this is, in terms of understanding the NDIS support ongoing, it gives families the ability to be normal. And when you haven't had normal, the value of normal is an incredible thing, to think that life will be okay. It will be okay for him. It'll be okay for Lara. We'll still do all the things that we do, but we know that we are working to create the best opportunity for Max's life that he can possibly, possibly have, and still for him to be able to make as much of a contribution in the community as he is able to within his capacity. And gosh, if we can have that, that's a pretty special outcome.

**22:14 Voiceover:** To find out more about the program head to Facebook, look for the GingerCloud Foundation or the Modified Rugby Program MRP. You can also check out what's on the menu by looking up Ruggers Restaurant.

Many thanks to Fiona Stutz for the interview in today's episode.

Thanks for joining us at Choice and Control, a Carers Queensland podcast. For more information about the National Disability Insurance Scheme or Carers Queensland, contact us online at carersqld.com.au. You can call us on 1300 999 636 or head to Facebook and look for Carers Queensland NDIS.

**Mentioned in this episode**

[GingerCloud Foundation](http://gingercloud.org/)

[GingerCloud Foundation on Facebook](https://www.facebook.com/gingercloudfoundation/)

[Modified Rugby Program (MRP) on Facebook](https://www.facebook.com/modifiedrugbyprogramMRP/)

[Ruggers Restaurant](https://www.facebook.com/ruggersrestaurant)

[Carers Queensland website](https://carersqld.com.au/)

[Carers Queensland upcoming events and workshops](https://carersqld.com.au/events/)

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