

Good Start to Life – Co-designing optimal maternal and infant nutrition resources for and by Maori and Pacific Islander families living in Queensland, Children’s Health Queensland

We have Michelle Moss, Daniel Flynn and Peter Gurr. Michelle, if you'd like to come up, has worked in human services for the past 25 years. She has worked across disability, health and domestic violence. Done direct support work and counselling, behaviour support, consumer and community engagement, so that's quite a CV Peter Gurr holds several volunteer positions for the Queenslanders with Disability Network, including at the Townsville coconvenor, the board director, an NDIS participant readiness peer facilitator. That is quite a lot of work, Peter. Congratulations. Finally, Daniel is the coconvenor of the Townsville local support group which is by and for people with a disability. Daniel I've got a little bit of information about your condition, but perhaps you'd like to share that yourself when you get the chance. Daniel has extensive experience with the disability sector, he's been the facilitator of many local support groups. Please join me in welcoming our next presenters to the front.

NEW SPEAKER: While we're getting the other bits of technology working, I will get started to introduce ourselves and what we're going to talk about today. We're all part of an organisation called Queenslanders with Disability Network. I'll hand over to Peter, who's going to talk about what QDN does and what we do.

PETER GURR: I'm Peter Gurr, a Townsville local and used to be a business owner here in Townsville. I'm also an MS person, diagnosed six years ago, so I had to close my business down and take it a little bit easier to try and get myself right, which is not going to happen unless some health people come up with a miracle. QDN, or Queenslanders with Disability Network, they are for people by people and run by everybody

in QDN has got a disability, or a family or partner, member with a disability, so we're all in it together and we all know what each other's... not disability, but that we're all on the same level of communication and everything about our problems and everything else. Statewide, we have 1500 members now. When I first started at QDN we only had 800. So we've grown, nearly doubled and it's our 15th year anniversary this year, so it's a bit of a bit year and a bit of a milestone. We've got 12 staff, but that could be changed by today, who knows? They change staff pretty regularly, because we've got casual staff and they move on and we get another casual staff person in to help us out with all sorts of stuff that we do. The seven people as I said on the board and basically we're now around the State, plus a few in Brisbane. We're spread far and wide in the State. Our motto is, nothing about us, without us and we work with each other and we try to change policy within government the way they look at people with disability and how we go about that is up to Michelle, because she's at that system change, that's why we pay her the big bucks, I guess.

MICHELLE MOSS: Just to give an overview of the work of QDN, we are funded as an information referral service and we're funded to undertake systematic policy to be the voice of people with disability and that's across a range of policy areas depending on what our members and our local support groups tell us about what's important to them. We also are funded at the moment to undertake quite a bit of work in the space of National Disability Insurance Scheme, the NDIS. I think an important part of the work of QDN is it lives to the motto of nothing about us, without us and it's very much about a codesign working, that it's informed by people with lived experience. I guess we wanted to talk to you about the work of the disability support organisations, which is where the local support groups fit and to set the scene in terms of disability we're in the biggest moment of transformational change in the disability sector. We've got the rollout and implementation of the National Disability Insurance Scheme, which I think is a great example and really shows the power and the passion of people and what can happen when people come together about something that's important to them and to bring about that change. For the first time ever in the his-

tory of the disability sector, we saw people with disability, families and carers and service providers unite around a common vision that we needed to do things differently to deliver support and services to people with disability and I think you would have all seen the evolution of the NDIS in that space. The NDIS gives people with disability choice and control and it's a different way of operating and a different way of doing business, so in the wisdom of the National Disability Insurance Agency, they thought it's really important they start to build the capacity of people with disability and their families and carers to be ready for how that new scheme's going to work and to be able to navigate as we've heard, a very complex system and to be in a place of being empowered to do so. So the initiative that they funded is the disability support organisation and that was to establish networks of people with disability, or networks of families and carers to be able to connect each other and provide that support, information and an opportunity to work out how they were going to prepare for the NDIS. Queensland, we only got funding for one DSO, so that was Queenslanders with Disability Network, there's another 18 across the country, most of which are in Victoria and NSW. Just briefly in terms of QDN's role as a DSO, we've had the job to establish 25 local support groups across the State. They're in various locations. We're going to talk to you today about Townsville, but we also have a local support group in gnaw Manton, we have one in Charters Towers about to establish in Cairns and then ranging across mainly the east part of the coast and South East Queensland. We had a request from our group members that there was to be some groups specifically for people with intellectual disability, they're led by people with intellectual disability for people with intellectual disability and we've got a couple of virtual networks. There's some information up there about the work that we do to provide support, training and the things that all of our volunteers and support group need to undertake the very complex job of bringing together groups of people and sharing information and supporting each other. Peter, I'm going to hand over to you to talk about what a local support group is and what they do and how Townsville got started.

PETER GURR: A local support group is like all local support groups that get started. They're usually about somebody that wants information or a group of people that

wants information. In this case, it was people with disabilities coming together wanting information about the NDIS and how they were going to navigate that system. Now, everywhere we went, there was not enough information given on how we were actually going to do that. Some seminars we went to were very good and we were able to find that information quite easily. Other organisations or seminars that we went to sort of counteracted that information that we just got from the last seminar. So it was very confusing for people with disabilities, so we had a product that was given to us by the government and by the NDIS straight from them, so we were able to sit there and think about how we were going to develop this and do it. So what we did here in Townsville was we sort of followed the same lines as what had happened in other cities and Brisbane and elsewhere in Queensland where it was already running. So we run them guidelines, but not every had fits every head so we had to adapt it for the Townsville area even though the disabilities never changed. CP L doesn't change from here to Brisbane and everything else, nor does MS, nor does other things, but the people changed and their wants were different. It was rolling out in Townsville first, so the wants were information and we want it right this very minute, because we're going to roll out and what we did was I went to my individual groups and we had only four people that wanted to be in the local support group and we thought, is this worth it? Then, okay, we will do it, we'll just try it. So we got together, all of the city's leaders from around the area and we said "We're going to have a meeting, QDN's going to come up here and have a meeting", and QDN came up, the staff and myself as a board director, and we sat down in a room at the local PYC and we talked to the city's leaders and straight after that meeting, we told them what we were all about and when I say "the city's leaders", it was the city's mayor, the city's councillors and other people that were right up the very top echelons of Townsville, plus the service providers, and we needed them to be in the room so we could get their support, as well. Because they were the ones that had the participants that were going to be going into the NDIS and staying with them, and all we wanted to do was give them the information. We weren't trying to steal them, we just wanted to give them the information that they needed to be able to go on in

a peer-led setting and it's amazing how well it worked. We only had I think in that first meeting, eight people and four of them I think were made up of staff from QDN, so there were only the four people that turned up. The next meeting, I think we still had eight, but there was four new ones with disabilities, and the second meeting, the third meeting we slowly grew. I started going away a lot to Brisbane to do other work with the board and with QDN that I decided that I was going to make a precedent here in Townsville and I talked to QDN and said "We need to have coconvenors in all of these groups and we need to bring other people along and nurture them along and give them a go at taking a more senior role in the groups in a like "you do it one month and then Johnny, you do it the next month" and have that turnover of people so they all got a go, and they all got a chance to be heard and also, to give their information that they thought was crucial to them that might be crucial to somebody else. I got a convenor which was Daniel, I brought him online and it has worked out very well since that day and we've been going a bit over a year and a half or something. So we started at a really good time, where we had 12 months before we were rolling in and it was into the NDIS, we were able to share a lot of information that people needed and wanted and we were able to go back to the NDIS and the leaders like QDN, to get the information from government on the needs and wants that we had in our local community and our group grew to 25 in no time, because of that and that it grew further from there. I'll hand it back to Michelle, and she can ask the next question of us both, I guess.

MICHELLE MOSS: And I think what Peter's been talking about is that we know for all groups there needs to be a purpose for people to come together and the NDIS was certainly that driving change for people with a need and desire to want to get the best out of the NDIS that they could. So Daniel, you went about that in a particular way of meetings and how you met and what you focussed on. Do you want to tell people about that?

DANIEL FLYNN: Sure, thanks, Michelle. So I came into the local support group fairly early in the piece and I think within 6 months or so of joining, Peter asked me to share the load and I at that stage had spent some decades working in the disability sector in

various different roles with facilitating support groups, advocacy, working with different levels of government and so forth. We looked at basically... I think when I came on board we had about seven or eight months before we were expecting to roll out for the NDIS here in Townsville and it was expected that the lion's share of the people in the room would transition fairly soon thereafter. So we broke down the task of how do we get ready, and what do we need to know so that we get the most out of the scheme the first time around? Because we had heard many, many times from many, many sources that it's really quite important to get this right the first time, because after all, it is your life and if you have to wait another 12 months, then that's 12 months where things may not be as good as they could be. So we spent six or so months with Peter, mostly in Brisbane at times due to his other duties, going through lots of planning around what does it take to have a good life and what does it take to actually be included and be a welcome and participating part of your local community? I think in terms... actually, I might leave it there and come back to that in a moment.

MICHELLE MOSS: I think that's a nice segue too, because the group has been about supporting people at an individual level, but it's also been a great change agent at a community level and at a systems level and I think that's something else we wanted to share of that impact that the power of people coming together can support at the individual level, but it also can have impact on changing community. We know that the NDIS is just an enabler in people's lives and that the real issues that members talk to us about are how to get affordable and accessible housing, how do I get good health care that meets the needs of me as an individual? How do I access the community through transport that supports me? So these are all the things that people across the groups across Queensland were talking about, it's the interface issues with those mainstream services, and how do we drive that change to get better outcomes for people? So Peter, do you want to talk about some of the community level work we've done?

PETER GURR: At a community level here in Townsville, I'm also part of through my work at QDN I got offered a position with QCOSS as an emerging voices speaker at different events and QDN and QCOSS got together and got to talking to the Townsville City Council and a few other leading organisations here in Townsville in government, and we got the NDIS involved and we just had one yesterday and the day before. It was the annual QCOSS, QDN, NDIS changing lives, changing community conference. Now we had 12 months ago and I'm one of the organisers on both and it was such a success the first time round that we decided that we'd do it again, so that's something that we did just as a trial thing 12 months ago that brought the entire community of people with disabilities and carers, community leaders, everybody together all to work as one for two days, and some of the information and some of the work that we've seen yesterday and the day before around systems change in government and change of thinking through people with disabilities and without was nothing but amazing from a person that is a tradesman, a building contractor, still licensed in Queensland and a business owner and now a person with a disability I am just sheer amazed at some of the things that I've seen in the last two days and I've seen over the period of time with the DSO and different things that we've done here in Townsville. But we've also, Daniel and I, done a lot of conferences and other things that QDN has opened up to us, including this, what we're doing today has only been available to us because of our association with QDN and the work that we do with those guys and their knowledge and their commitment to us and to the community. So it's very important that all people with disabilities can access you by accessing us and getting your knowledge by being able to be here with us, and I'm privileged to be here.

NEW SPEAKER: Michelle, we have 10 more minutes, so if we can wrap it up, we can have questions.

MICHELLE MOSS: I'm going to hand it over to Daniel to do I guess a bit of final information at that systems level, the role of the groups has been at that grassroots, what is happening on the ground and that has informed lots of really big picture policy change and I'd just ask Daniel to share a story about transport.

DANIEL FLYNN: I'd like to say that one of the wonderful things that we have seen is amazing personal growth in the group, but we've had some really positive systematic changes. A couple of very quick ones I think of was there was an individual whose equipment had been cut off and that potentially due to that person's condition could have had extremely dire health impacts and due to the work that Peter and I were able to do with the assistance of QDN in Brisbane and interface with the agency here in Townsville, the NDIA who administer the NDIS we were able to see that situation rectified very rapidly. Also with CAPS, which is the continence aids, or something to that effect. With the NDIS rollout in Townsville, many people who were in receipt of that Medicare funded system were told they were going to have to wait possibly up to 6 months while they roll out on the NDIS, because that had been cashed out into the new program and many people couldn't wait. Again, we were able to feed that back into the system and people received those payments on time, or almost on time to tide them over until they were moved into the NDIS. Finally, the probably big systematic change that we've been working on now for many months and unfortunately yet to get quite the outcome we'd like and indeed need for many people here in Queensland is that of transport and the subsidy scheme the TSS. In Queensland when people move on to the NDIS currently, they are removed from the TSS program and so they lose their half price taxi card and unfortunately as the system exists currently, they're not in any way adequately compensated in their NDIS plan for that, which is having some rather dire effects in terms of people's ability to access their local communities. But we've been able to use, an absolutely essential service for anyone to be able to access their own community, absolutely. So we've been able to use our links with QDN and the NDIS and various different levels of government to work through this issue. We are still in communication with various levels of government at present to come up with both a short term solution and a permanent one, but watch this space on that one. We won't let it go quiet.

NEW SPEAKER: Maybe we could throw to questions and use that as a way to finish the session.

MICHELLE MOSS: I was just going to say and I think Daniel and Peter were being modest in terms of the power and the passion of the group around the taxi subsidy, because the minister actually has come to meet with the group several times, Mr O'Rourke to get that firsthand experience about what is happening on the ground for people with disability around the TSS and informing government in that way and that's a great example of the strength of the groups across the State to provide that lived experience to inform good decisions at a government level.

NEW SPEAKER: I'm not sure this one's working, I'm going to have to run around with this. We have a question here.

NEW SPEAKER: I do have a question, if any one of you can answer. As you were saying before, you're okay to do all disabilities, no matter what the disabilities are. I am hearing impaired, how well are people with a hearing loss catered for? I might come to a place like this and I can't afford captioning. Does the NDIS provide captioning?

NEW SPEAKER: So that was a question about captioning for people with hearing impairment, who would like to answer?

PETER GURR: We do and yesterday and the day before, QDN and the National Disability Insurance Scheme... I'm not sure, but I do know that we do at QDN and we also for people with vision impairment, we use a lot of sign and whatever they need, as well.

MICHELLE MOSS: And Shirley, maybe we can have a talk to you later about who to talk to in the agency 'cause we're not the National Disability Insurance Agency unfortunately, but we can find out the answer to that question.

NEW SPEAKER: We have one question down the back and then I'll come to you, Kevin.

NEW SPEAKER: I'm a care partner of someone who has younger onset dementia and very strong advocate, as he is, as well. I'm a care partner of someone who has younger onset dementia and he's a very strong advocate, as well. What I was going to say is we still actually feel very isolated and I didn't know anything about the fact that your group existed. We don't actually, we're from Brisbane, but our connection

seems to be more national with Alzheimer's Australia and a lot of people don't even realise with dementia whether or not we fit into the disability area and I feel as if what we're trying to do is reinventing the wheel and I just wonder if somehow we can link up better. I organise a support group and people are asking me for the information. John's just going to miss out on the NDIS because of his age, but there's so many people out there who are still not getting any help.

NEW SPEAKER: I will hurry up to the front.

MICHELLE MOSS: More than happy to connect and talk to you at lunchtime and I think there are lots of wonderful things happening in the community. Lots of great peer support groups and peer networks and it is about how do we work more effectively together, recognising that different groups have different purposes and different needs and visions, but there's great work that we can do collectively to strengthen that.

NEW SPEAKER: Daniel, did you want to say something?

DANIEL FLYNN: No, I'm good.

NEW SPEAKER: Just a quick one. I've been hearing a few stories of late about young people with disabilities in age care homes who are getting kicked out of the age care home and there's even one just down the road from QDN at Lutwyche that were doing that and they've been moved into State housing which is not even disabled access. Because NDIS won't be coming on board until 2019, has QDN had any thoughts...? I haven't seen anything on my emails come through for a while? Has QDN had any thoughts on how to deal with those people?

MICHELLE MOSS: Just quickly, because I know I'm holding everybody between here and lunch. QDN has been a strong advocate throughout the whole of the implementation process about how do we make sure that those people who are vulnerable don't miss out on the NDIS and people with different needs, whether they're homeless or at risk of homelessness, exiting the criminal justice system, child safety, young people in nursing homes. So the NDIA, or the department of social services have just

funded four organisations in Queensland, QDN is one of them, to work in the south-east corner with people who are disadvantaged, experience additional disadvantage to accessing the NDIS. So we have started some conversations around young people in nursing homing. It is to work with people who are at risk of homelessness and all those other additional disadvantages that people experience. There are two organisations who are working in Far North Queensland to work with Aboriginal and Torres Strait Islander communities around supporting people and the community to access the NDIS if that's what they want, and also Imparo for culturally and linguistic diverse background.

NEW SPEAKER: We have one final question, if you can keep it quick, because everyone wants to go on lunch and we've got to prepare for the minister.

NEW SPEAKER: Hi, I did have two questions. One's really quick, are you coming to Rockhampton? Secondly, where do you see the carer's allowance and payment moving forward with the NDIS rollout?

NEW SPEAKER: I'm not sure if QDN can speak to the latter, but they can certainly speak to the former question.

PETER GURR: Under the NDIS, I had to find this out myself, because I'm a participant under the NDIS, my wife is on the full carer's payment. Under the NDIS, it doesn't affect your carer's payment. That's what we were told by Centrelink and that's what we were told by the NDIS. Now it is my payment for my care and my life. It is not my wife's. It is for me to get the care when my wife's not around, not my wife. So you've got to understand that, that it's the individual's package, not anybody else's and it only affects the individual for their entire life. That's another thing that people don't understand. Get it right first time, because it's for your entire life.

NEW SPEAKER: I think as you can tell from the questions, the NDIS is hugely complex, so please join me in thanking our wonderful speakers for shedding some light on that.

APPLAUSE

And also congratulate them for the great job they've done in setting up a really meaningful local support group that's making real change. So thank you very much for that work.

APPLAUSE