

Day 2

Opportunities and gaps: the interface between health and disability under the NDIS

Paige Armstrong, CEO, Queenslanders with Disability Network
Introduced by Melissa Fox, CEO, Health Consumers Queensland

Melissa Fox: Now moving on to the next session, the Queensland Health Consumer Collaborative is a joint initiative between Health Consumers Queensland and Queensland Health. This strategic high-level collaborative is informing the embedding of consumer partnerships at every level of planning, policy, delivery, monitoring and evaluation of health services provided by hospital and health services and the Department of Health. The Queensland Health Consumers Collaborative is chaired and the secretariat is provided by Health Consumers Queensland. So earlier this year, the collaborative identified one of the key issues of importance that they wished to focus on this year is the interface between health and disability services, with the roll-out of the NDIS and maximising opportunities for consumers to benefit from the NDIS. So as such, Health Consumers Queensland facilitated a breakfast forum on this topic last month.

We brought together the eight consumer and carer representatives that sit on the collaborative from across the State and the eight high-level Queensland Health representatives and we put together an additional attendance list and an agenda with assistance from Queenslanders with Disability Network or QDN. With the focus on the consumer carer members of the collaborative and representatives of key consumer groups and NGOs, we asked them to share what the key issues are currently that they're hearing or they're personally experiencing from the patient and carer perspective around those interface issues, what's being provided, what's falling through the gaps and how is this affecting people? Senior representatives from Queensland Health, the Department of Communities and the National Disability Insurance Agency were in attendance to hear first-hand these consumer concerns and to then have an opportunity to respond to that

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feedback and share some of the work already being done to identify and remedy gaps. A group discussion then explored the next steps of how to continue to work together to ensure that consumers and consumer organisations are kept informed as the NDIS roll-out continues across our State. The overwhelming feedback from the collaboratives consumers and carers was that there are profound challenges to accessing the new system and to undertake effective preplanning and planning in order to implement appropriate packages.

So to speak on this topic, I would like to invite someone that is very special to Health Consumers Queensland, Paige Armstrong was our executive director whilst we were within government as a ministerial advisory committee. She's now CEO of Queenslanders with Disability Network, and I would like to invite her to the stage to share with you her organisation and members' perspective on the opportunities and gaps, the interface between health and the disability under the NDIS. (APPLAUSE).

Paige Armstrong: Well good morning everyone and it's wonderful to be with you today. As I've been introduced by Melissa I'm Paige Armstrong and I'm with an organisation called Health Consumers Queensland. I'm going to play around with the button, I'm a little bit dyslexic. If we start going backwards it means I'm stuffing up moving through the slides. I'll let you know that beforehand. What I want to talk with people today about is to give you a bit of an idea about the organisation I come from, Queenslanders with Disability Network, who we are, what we do, why we're in the NDIS, National Disability Insurance Scheme space and a Queensland context around that, and then talk a bit about those interface issues and what we see as some key themes. If I also start by acknowledging the traditional owners of the land on which we stand and the leaders past, present and emerging before I go on. And can I also acknowledge that there are members of my organisation Queenslanders with Disability Network that have been here over the last couple of days. We were at a budget breakfast and the three or four people from Queenslanders with Disability Network who were here yesterday told me that the presentations were excellent, the company was great, they absolutely loved engaging with both other health consumers in the room, but also with a number of people from the

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hospital and health services and the primary health care network and Melissa, they think the food is great. So just take that one on board. Always a winner at events, I find.

So, who we are. My organisation is made up of, it's a State-wide network. It's made up of people with a diverse range of disabilities. That covers people with physical, intellectual, psychosocial, cognitive, sensory, that full range of disability and the organisation's been in place for about 15 years. We have besides a broad network of members across the State, we also have a very broad supporter network as well which includes families, volunteers, community organisations, government agencies who join up to find out what we're doing and how we do it. Very much the way that our funding is we do work that sits us in that thing around what we call systemic advocacy to get change. We've been quite successful in recent years in running campaigns in relation to things like changes that occurred in public housing, that disadvantage to people with disability who were public housing tenants. We've just run a campaign last year around the taxi subsidy scheme and the fact that people with disability when they went into the NDIS were, their taxi subsidy scheme was excluded, because it was a State-funded program or it was rolled into their NDIS package and people were a lot worse off as far as transport went, especially in the regional and rural parts of this State.

So we had a campaign last year and managed to get some agreement from the Queensland Government that they would continue to fund people for the taxi subsidy scheme outside of the funding being provided through this thing called the National Disability Insurance Scheme. (APPLAUSE) Thank you. Very much the work that we do is informed by our members. We have 24 local support groups that operate around the State. They're anywhere from Gulf of Carpentaria stretching to the border, going inland. Our groups are run by volunteers, people with disability and attended by people with disability and their supporters. They're very much what we see as our eyes and ears on the ground. They let us know what's happening, what those key issues are so that we can actually look at any patterns that are occurring and make sure that we're able to raise those with the relevant government authority. Meanwhile those local support groups are also very assertive and active in their own communities in taking up local issues to actually

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improve the social and economic participation of people with disabilities within that particular community.

Now, I'm not sure of sort of how much knowledge people have about this thing called "the beast" that's called the National Disability Insurance Scheme. I'd be highly surprised if people in the room haven't heard of it, so can I ask for a show of hands. How many in the room have actually heard about the National Disability Insurance Scheme? Yay, that's fantastic. How many of you might be potential participants in the scheme going forward, or your family members might be participants? That is even better to see. And, it is really good to know that I'm talking to people that have some knowledge, because I wasn't sure about where people were coming from, I thought I'd give you a 101, like a basic introduction to the NDIS. It is a new way of providing support. It is as everyone keeps saying, it's transformational change. It's the largest social change in Australia since Medicare.

The key thing about the National Disability Insurance Scheme is that not only does it give people some choice and control over what you get, how you get it, when you get it, who delivers it, but most importantly in a Queensland context, there are 90,000 people to come into this scheme, 45,000 of which will be new people and I'll talk about that in a minute. Across Australia, the scheme's going to take in about 460,000 people. You need to be under the age of 65, an Australian citizen and you need to have a disability that results in a significant functional impact to actually register to access and I'll talk about that in a minute, as well. And it's administered by the National Disability Insurance Agency. The principles that underpin it reflect national, international and national human rights, but the rules and legislation of the scheme are underpinned by people having choice and control and most importantly, not just about what they get and how they get it, but funding is attached to the person, not to an organisation. For many people, that gives them a flexibility to do things in a way that they haven't done before and to actually have a bit of a shopping basket provided, of course, there are enough services to shop across.

If we have a look at the Queensland context and just before I move on to the Queensland context, perhaps if I just share a story with you about why we are working in

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this space and why at the moment we always say that we support the intent and the presentlies of the scheme. There are many, many issues around the interface and around interface issues, not just with health. But trust me, there are issues around a number of interface issues and you only have to pick up a State, your local or your State or a national newspaper, listen to the radio and you will hear one of the less than good news stories about the NDIS.

But the reason that we have remained involved in promoting the scheme and will continue to do so is because across the areas where it's rolled out and that's mainly rural and regional Queensland to date. Members that we have who have been waiting for years, not just 5, 10, 20, 25 years. I have a family member with a disability. We have been waiting for nearly 25 years to get an adequate support package. We are pinning our hopes on this scheme, because for the very first time we have a commitment that provided the person wants or has needs reasonable and necessary supports they're reflected in a thing called an NDIS plan, then those supports will be funded. They won't be funded next year and they won't be funded in sort of only for 20 weeks. It will be funding that's a commitment and ongoing. And to illustrate that, I'd just like to actually share a story about one of our members, John.

Now John's typical of many blokes in regional Queensland. Hard worker, he was a builder, spent many years building up a business and he and his wife decided to retire when she developed a range of health issues and he felt it was time to start becoming an early part of the grey nomads. Late 50s decided, he sold his home, invested in his son's business, let's travel around Australia and let's have a look at the world. That was really good except just after he started, John was diagnosed with MS. Multiple sclerosis, and whilst he was travelling he became progressively worse, so he progressed from being able to drive a car to being in a wheelchair with a wife that already had chronic health conditions becoming his carer. John returned to his home town, because he'd already invested in his son's business. They had nowhere else to live but in that caravan and so we had a man without any funded support, a wife that was supporting him and doing a fantastic job, but it impacting on her overall well-being and his well-being, because he had no support workers to help with lifting, transferring, all those things that might happen

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around your personal care and he was also virtually crawling around a caravan, because he had no aids, equipment or modification. He had a little bit of equipment, I should say, I should apologise that he got, but it was very limited.

John has now accessed an NDIS package. He has decided he self-manages his own money, his own funds and he self-manages his own plan. John has hired support workers, he just attended a family wedding in South Australia. He is a leading member in his community, he's an honorary member of the cricket club and he runs one of our local support groups as well as being on a number of national bodies that are working around NDIS implementation. John is but one story of many QDN members with disability across this State that have benefited from the funding that has come with this scheme and the fact that he's had a bit of flexibility about how that funding's used. That, in essence, is why we promote and support this scheme. (APPLAUSE) Thank you. So, some key messages around interface, because I know I'm going to run out of time very quickly. A key message, there are 45,000 new people to get funded support for the first time in this State under the NDIS. Trust me, if you are a person who has been waiting for support, it's a game-changer. It's a game-changer provided you can get over the line, access the scheme and then get a decent plan. And I'm jumping to show you that we work with people from marginalised communities.

We've been doing work around NDIS access, so this is an example of some of the things that we do. I must apologise, I jumped a couple of slides. That's the thing about the buttons and myself, but there are 45,000 new people to access the scheme in Queensland and health is a major connector around enabling especially new people to come into the scheme. What we've identified and what our members are telling us, what other people know is that there are real challenges in registering to access the scheme. There are challenges around the planning and the preplanning. People think that it's an easy thing to register, to access the NDIS. They're told just to ring a 1800 number, but for new people coming into the scheme, you need to complete an access registration form and one of the biggest challenges around completing that form is around general practitioners and Allied Health professionals and getting appropriate information in the right way and getting

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signoff for that. We've recently done some work in this space that I'll just leave to the very last part of my presentation to talk about.

Before I do that, I'd also like to touch on some other interface issues. Some of the interface issues that we're facing are issues around Allied Health and nursing care. They relate to wound care, catheter management, equipment and issues to do with MASS and the interface with the medical aids assistance scheme. We were pleased to note that the Queensland Government has just announced in the State Budget an additional \$10 million over the next financial year to support allied nursing and health care to address these issues whilst things are being ironed out through a national working party with the Commonwealth and with other State and Territory governments also involved in the NDIS. I spoke about people getting access, registering the scheme. Some of the things that people are reporting to us is that to actually register to access, depending on the type of disability you have, you will need to have some detailed assessments or you'll need to have assessments. They are costly, they may be a neuropsych assessment. It may be another particular assessment that relates to your health condition and the subsequent disability you have. That is something that isn't an easy thing for most people who do not have spare cash. Many people with disability in our State are people who are on Disability Support Pensions or they work part-time simply because of a range of other related issues.

So the ability to have upfront cash to pay for assessments is often a challenge. And at the moment, although there is goodwill and intent across hospital and health services and work occurring across GPs, hospital and health services and primary health care networks, it is still a tricky issue about how that's going to happen. I spoke because I think I'm going to run out of time, I am going to move on. The video that I played, which I think I need to move past Jo, was to demonstrate the work that QDN does, our work is always co-designed with our own members and it's co-delivered by members. Obviously people with disability that have some life experience around the various projects that we run. We've had a particular focus in the last 12 months around what we call "hard to reach people", because we think they are a key group that could be supported through this scheme and we're very much worried that they will miss out, because they don't engage

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well with community or mainstream services. If I'm going forward, the last thing I just wanted to talk about.

Given I've had a bit of a focus on those 45,000 new people and issues to do about access, because if you're not able to actually register access, forget about the planning, there's a lot of focus in Queensland on planning at the moment. We think it is essential, it's very important. But without getting into the scheme to start with, then planning will be a bit of a moot point and there's many people. There's 8,000 people sitting in supported accommodation facilities across the south-east corner of this State. They're the old hostels and boarding houses, we would consider nearly 70 per cent of those people would be eligible for supports under the NDIS which would give them a better quality of life. At the moment, those people need to get through that registration process to access the scheme. They are but one small group of people that are a cohort that sits slightly outside of what would be seen as people that deal readily with mainstream services, whether they're community, health or any other government service. So recently, we worked with the Brisbane North Primary Health Care Network to develop a GP toolkit. The toolkit has application for general practitioners, Allied Health professionals and it's also something that anyone in this room could use. Any health consumer would be able to have a look at the toolkit and have a look at some of the work, examples in the toolkit and apply it to things that you might want to see in a access registration form that you might provide to the National Disability Insurance Scheme about accessing the scheme. We have copies of the toolkit on-line, we have a stand outside and I'll be around after this presentation, so we are more than happy to make sure that we talk to anyone and give you a link to the toolkit if people are interested in finding out more about it. I can't stress enough how important it is for Allied Health and general practitioners, and if you're from a HHS or a primary health care network in the room, can I just reinforce, it doesn't matter if you're from up north, Central Queensland or down here, or on the Queensland border, one of the key interface things that isn't spoken about a lot is at the moment this great thing called the National Disability Insurance Scheme of those so-called "new people", in every area where the scheme is rolled out, they have not found the 50 per cent new people that they need to find and we are convinced that part of that is not just lack of knowledge about the scheme, but part of it is the complexity around people having to register to access. So a plea I'll

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make is you're from a HHS or a PHN, is get the link to the GP toolkit that's been produced. It is a great product and it actually provides one of those talking points... I keep on banging that, so I'm moving it to the side, I apologise.

It provides one of those talking points from an important thing about how you might relate a person's health condition to a disability to filling in the right area in section F of an access form, and that section F is the crucial thing. If you don't actually fill that out correctly, there's administrators that sit in a national access team in the NDIA, they are administrators, they're not health professionals. They look at how those boxes are filled out. If you don't have the right things in the right boxes then you might get shunted along and I think there's a couple of people in the room today who have already had knockbacks as far as trying to register. So people, feel free to see us at the stand outside and it's wonderful to connect back with people today. Thank you. (APPLAUSE).

Melissa Fox: Thanks, Paige and thank you so much for the work that your organisation is doing and I hope that you're receiving the support that you need to listen to consumers and provide that important strategic advice. We've got such an exciting opportunity with the NDIS we've just got to make sure that it's accessible and useable for people. So we remain committed to working with Queenslanders with Disability Network. We want to continue to hear from you about your experience of trying to access or accessing the scheme. We find it mind-boggling that grey area exists that Paige was talking about, about access to nursing and Allied Health services. We're not sure why that wasn't worked out at perhaps the first scoping workshop that looked at this, but we remain committed to keeping the pressure on to make sure that confusion is sorted and that people can access the services that they need. So I hope that you enjoy the next two sessions of examples of engagement. We'll be starting them promptly after morning tea at 11. I then really look forward to welcoming you back in here for a panel that I'm going to facilitate with two health journalists. I'm hoping we can trim some of these plants so you can actually see me on stage. Then we'll be ending the day with our discussion with our board, where I look forward to you getting to know them and hearing from about you where you see the future of evolution of engagement going. Enjoy morning tea, and I look forward to seeing you soon.

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