



EDUCATION, EMPLOYMENT AND SMALL BUSINESS COMMITTEE

Members present:

Ms LM Linard MP (Chair)
Mr N Dametto MP
Mr MP Healy MP
Mr BM Saunders MP
Mrs JA Stuckey MP
Mrs SM Wilson MP

Staff present:

Mr S Finnimore (Committee Secretary)
Ms M Coorey (Assistant Committee Secretary)

PUBLIC HEARING—INQUIRY INTO THE DISABILITY SERVICES AND OTHER LEGISLATION (NDIS) AMENDMENT BILL 2019

TRANSCRIPT OF PROCEEDINGS

MONDAY, 29 APRIL 2019

Brisbane

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The committee met at 10.25 am.

CHAIR: I declare open this public hearing for the Education, Employment and Small Business Committee's inquiry into the Disability Services and Other Legislation (NDIS) Amendment Bill 2019. I would like to acknowledge the traditional owners of the land on which we are meeting this morning and also pay my respects to elders past, present and emerging. My name is Leanne Linard. I am the chair of the committee. Members present today are Mrs Jann Stuckey, member for Currumbin and deputy chair; Mr Bruce Saunders, member for Maryborough; Mrs Simone Wilson, member for Pumicestone; Mr Michael Healy, member for Cairns; and Mr Nick Dametto, member for Hinchinbrook.

The committee's proceedings are proceedings of the Queensland parliament and are subject to the standing rules and orders of the parliament. The proceedings are being recorded by Hansard and broadcast live on the parliament's website. The purpose of this public hearing is to hear evidence from stakeholders who made submissions as part of the committee's inquiry into the Disability Services and Other Legislation (NDIS) Amendment Bill 2019.

The bill was referred to the committee on 28 March this year. The committee will examine the policies the bill gives effect to and the application of fundamental legislative principles set out in the Legislative Standards Act 1992. The committee must report to parliament by 13 May 2019. The program for today's hearing has been published on the committee's web page and there are printed copies available from committee staff.

BURGESS, Ms Mary, Public Advocate, Office of the Public Advocate

CHAIR: I welcome the Public Advocate for Queensland. Thank you for making a written submission to the committee. Would you like to make a brief opening statement and then we will open for questions?

Ms Burgess: I would like to thank the committee for inviting me to speak today. As the statutory agency with legislative responsibility for systemically advocating to protect the rights and interests of people with impaired decision-making capacity in Queensland, one of my key roles at this point in the evolution of the NDIS is to ensure that any changes to legislation that will directly affect this cohort of people maintains all of the safeguards that we currently have in place to protect them and that there is no narrowing of those safeguards going forward. The amendments to the bill are intended to reflect how the disability sector will operate and how these safeguards will operate once we reach full rollout of the NDIS which is anticipated by 1 July but probably will not be in full practice until some time beyond that once all of the people get on board.

The concerns that I have with the legislation are specifically around the safeguards for people under the Coroners Act and the Public Guardian Act. The Public Guardian Act establishes a community visitor program where adult community visitors independently monitor different types of accommodation called visitable sites where these vulnerable people live, and the Coroners Act also provides for the deaths of people with disability in care to be reported to the coroner. Both those pieces of legislation use a similar definition for a site from which a disability death in care is reported or which should be visited by a community visitor. The Coroners Act currently defines a death to be reportable if it was in a place where the person was identified as having a disability under section 11 of the Disability Services Act and the person was residing in different types of accommodation that are defined in the act including a level 3 accredited residential service.

Disability accommodation is funded by the department specifically funding disability services, or a facility that is funded by a health or hospital service, or Queensland Health. More recent amendments in 2016 broadened the definition to include people receiving any NDIS funded services. Essentially, for the purposes of the Community Visitor Program, the Public Guardian Act has the same definition. It is consistent with the Coroners Act. Also, the definition of people with disability receiving any NDIS funded services was extended in 2016.

The current concerns relate to the new definitions of these visitable sites and reportable deaths in care. Under the new definition, a person receiving NDIS funded services will be only eligible for visits, or to have a death reported, if they are receiving a limited class of support under the NDIS. There are 37 identified classes of support under the NDIS. Only four of them are used in the Brisbane

amendment to identify those people who would be eligible for a community visitor visit or for their death to be reportable to the coroner. Those are the high-level areas of support funded under the NDIS, which include high-intensity daily personal activity support, assistance with daily life tasks in a group or shared living arrangement, specialist positive behaviour support that involves the use of a restrictive practice and specialist disability accommodation that has its own quite special definition under the NDIS legislation.

Under this definition, the places where people are receiving these classes of support will still be entitled to these protections. Issues arise with this definition due to the way the listed classes of support are defined and applied in practice under the NDIS. The NDIS has not developed strong working definitions of the services that are included under each class of support and it leaves them open to variable interpretation, meaning that one NDIS recipient could potentially receive a support under a particular class of NDIS support and another receive that same support but it is categorised differently, depending on who their planner was. Potentially, one person could be visited by a community visitor and another not, even though they are potentially receiving the same supports. This is those bedding-down problems that you get with a new system—just waiting to see where everything lands.

The definition also creates a situation where a community visitor may visit a residential facility where multiple people with disability live, but it is classified as visitable only due to a class of support provided to a limited number of people there so that only some people at the facility are likely to be individually visited while others there will not. That kind of arrangement feels clunky.

We are also concerned that the process of conducting a visit gets difficult because you are not sure who is getting what class of support. All of that has to be clarified. Also, the process associated with deaths in care is likely to create confusion so that you do not get the right people visited. Also, of more concern to us, is that appropriate deaths in care may not be getting reported. We already know that we have a problem with reporting deaths in care. My predecessor did a report on the deaths of people with disability in care in Queensland in 2016. One of the key issues identified was that we do not think that providers are really clear on their reporting obligations and what death in what kind of accommodation gets reported. The situation is also compounded by the possibility that a proportion of people who might previously have received the benefit of the safeguards included in the legislation may not be eligible under the NDIS now. We are hearing that people who were getting supports for whatever reason—perhaps they did not get enough support with their planning or they did not frame it appropriately—are not all getting supports like they were in the past. Some people who were in may well slip out.

We also have concerns about the level 3 accreditation that is remaining in the definition—whether there will still be incentives for accommodation providers to maintain that accreditation when they will be able to get funding from the NDIS without it. We are not sure what the incentives are for people to maintain that kind of accreditation. Therefore, they can slip out of the visiting and reporting net if they do not maintain their accommodation accreditation. At this point, we do not know where it is going to land. It is more a precautionary approach that we are suggesting, because we know that people with disability die preventable deaths at a very high rate. Our report found that 53 per cent of the deaths that were reviewed were identified as avoidable and preventable. That is a really high rate of death. We should be seeing this as an emergency. I am concerned about the way this may pan out. As the NDIS beds down and people in the market decide whether they will continue accreditation or how they will continue to deliver services to earn an income, that is going to shift and we are not sure where it is going to land. People will potentially shift in and out of definitions, depending on the way people move within the market and we cannot anticipate that. Our view is that, only after the NDIS is fully implemented and the market adjusts to this new environment, will we know the true coverage of the amended legislation and its impacts.

We generally support the retention of a broader definition of 'visitable sites' at this point. The unknowns associated with the number of people who will receive NDIS funding who will also be covered by the protections under the legislation and whether this will include all of those people who previously had the benefit of the protections means that the ultimate impact of the amendment will take some time to know and understand. For the first two to three years it will be critical to closely monitor how the changes are impacting people and ensure that the safeguards continue to be in place to protect this group of particularly vulnerable people. That concludes my submission.

CHAIR: Thank you very much, Ms Burgess. We appreciate that. Thank you for the added comments that you have provided to your written submission. We will now move to questions. I invite the deputy chair to open for questions.

Mrs STUCKEY: Thank you and thank you so much for coming.
Brisbane

Ms Burgess: Thank you for having me.

Mrs STUCKEY: Like many, we are all very keen to see the NDIS happen in Queensland. We realise that it has happened in other states. Thank you for pointing out where you feel some of those gaps, or concerns, will be. I was keen to know whether you have been happy with the response that you have received from the department. Have you seen the response to your concerns?

Ms Burgess: Yes. We have had ongoing discussions about this prior to the legislation being brought to the parliament. We recognise that the department has tried very hard to identify those services that they believe people were getting in level 3 accommodation and line that up with the classes of support that they think fit the classes of support that people were receiving before in these services. Our concern is we think that there are people in other forms of accommodation that are getting levels of service probably at this level and are not in the system now and probably should be.

We know that people getting this level of service that we are focusing on are the most vulnerable. I notice that the responses are, 'We are only really wanting to focus on the most vulnerable here,' but when we are talking about the most vulnerable, we are seeing 53 per cent of their deaths being avoidable and preventable. I think we have set the bar a bit too high. We are not doing all we could or should. Now, with open eyes—when we have this kind of research and we have it from interstate as well; New South Wales and Victoria have recently produced very similar reports about the rates of avoidable death—I think it is a little more than just, 'We'll just maintain what we have' because what we have is not necessarily achieving the best outcomes for people. Even with saying, 'We're going to maintain what we have,' I am not convinced that it is not ultimately going to result in a narrowing of the people getting benefits, because we are not sure where the accommodation providers are going to land in terms of this accreditation process. If they can continue to be funded to provide disability services to people without having to remain accredited—and we are not sure about that; it is not clear to us—if you are running a business and your profit margins are very slim, why would you be seeking another form of accreditation, another administrative barrier to jump over if you could avoid it? I think the market will find its place.

Mrs STUCKEY: You have raised some really good points. I am really interested in whether you have any statistics. The statistics of 53 per cent of avoidable deaths is staggering and shattering. Do you have any statistics on how many people you think may no longer be eligible? There are obviously people who have not even been on the radar yet as well.

Ms Burgess: Yes.

Mrs STUCKEY: If I could just preface that: I am married to a GP who has a lot of concerns about the implementation of this. He deals with a lot of people with mental illness as well as disability, so it is coming from a very compassionate place.

Ms Burgess: Yes. We would love to be able to say that we have the statistics. The whole system is struggling with finding the people who are in the at-risk groups. I can see from the submissions that a lot of people are saying, 'Anyone with a disability living anywhere should be getting this kind of protection.' The problem is that we do not know how to identify and find all of those people. You need to have some kind of definitions for people to be able to be identified.

The problem is that all of these calculations, or assumptions, have been made with the best intentions but with not much in the way of figures and also not understanding how the market is going to change. For us, that is the big unknown here. Governments have no end of stories of where they planned something and the market will do something entirely different from what was intended. From our point of view, it is a particularly vulnerable group. We are just concerned that, to move this quickly, may not be the best option in terms of adjusting the definitions at this time—whether it is a narrowing or not. It is a narrowing on what we have currently, but that was expanded in 2016 at the beginning of the rollout of the NDIS when everyone was a little unsure what it was going to involve.

I think the broadness of definition has been challenging for those agencies that have had the responsibility for providing the Community Visitor Program and investigating reportable deaths. I am aware of the impacts of these kinds of things on their operations and resources but, at the same time, I am here to be advocating for the rights of those people who will be impacted. It is a weighing exercise.

The numbers are not readily obtainable. As I was saying, we also are aware that deaths were not being as accurately reported as they should have been. I am optimistic, though, that we are going to get much better data with the NDIS. It is an all-encompassing system. We will get data on the deaths of every person who is NDIS funded which, of course, will not allow us to do any sort of continuity in terms of tracking of trends, because they will be different—unless, of course, we can get data about the supports that they are receiving to be able to compare it with where we are now and

where we will be in the future. I feel pretty optimistic about the kinds of data that potentially will be available once the NDIS gets to full rollout and the commission is operating and collecting this data. How we respond to that and how the NDIA responds to those challenges is a whole other question.

Mrs STUCKEY: That is going to be incomplete data, from what you are saying. If we are worried about a narrowing of people being able to access the services, some people who are eligible may not be.

Ms Burgess: Exactly. There will be people missing out still. The problem with the system being very self-driven is that choice and control is a wonderful concept, but it is very difficult for people with impaired decision-making capacity to fully exercise that. The risks are greater for that cohort of people because, if they do not have the supports around them to be actively engaging, they end up with no plans or lower quality plans and supports and not as much active checking because they are expected to exercise choice and control and make complaints. We have raised these issues at the national level. It is difficult for most people to make complaints. Only very low percentages of members of the community complain about services, but we know that you get even lower rates among people with disability. Relying on a complete complaints driven system is not ideal. These community visitor programs are a critical complement to that. That is why it is important from our point of view to keep things like that in place.

Mrs STUCKEY: How important is it to have engagement from GPs with your clients?

Ms Burgess: Well, that is one of my things.

Mrs STUCKEY: You know why I am asking!

Ms Burgess: We think there needs to be a deliberate program linking the primary health network GPs with people with disability and complex health issues and also linking that into our public health system where most of these people ultimately turn up in emergency. Instead of just releasing them with a discharge summary, they should be released and referred to a GP who is prepared to take this particular type of patient and who should get paid at a higher level to be engaged in providing support and care for these people. We should have proper health plans that are annually checked and revised. The system should be working in a complementary way, as well as disability service providers being expected to maintain engagement with the systems. We need to have triggers in those systems, including being connected to the NDIS, that identify when people are missing their medical appointments and key specialist appointments that are so critical to people with, say, epilepsy. A lot of people we are talking about here have these conditions—

Mrs STUCKEY: They have multiple conditions.

Ms Burgess:—multiple conditions that all will contribute to the deterioration in their health if they are not actively managed. That was certainly the case for the people we saw in our deaths in care report. That is something I continue to work on. I keep engaging with the HHSs about it. There is no lack of care or concern. It is a very process driven system and it is not as good at responding to the needs of individual people who need some individualised attention and care.

Mr HEALY: Thank you, Ms Burgess, for your very detailed response and for your good submission. It is appreciated. Following on from my learned colleague in relation to engagement with doctors, can you elaborate on that a little more?

Ms Burgess: What we know is that people with disabilities have often a lot of associated health problems. They may have cerebral palsy. They often have heart conditions. They do not necessarily eat very well and they are not necessarily very active, so they have weight issues, diabetes, hardening of the arteries—that kind of thing. They may even have behavioural issues. Many people with disability also suffer from depression and other psychological conditions or psychiatric conditions. A lot of the medication for those conditions actually causes its own health problems for people. As a consequence, they are complex to manage health-wise. They will be potentially seeing or needing to see three different specialists, but no-one is necessarily coordinating that care. They may not have a regular GP. Their service providers do the best they can, but they are not very well trained in terms of anticipating health issues, looking out for problems. They do not do obs like they do in hospitals and check their temperature every day. A person might be ill and getting worse and until they are quite ill they are not going to pick it up because they will not realise they have a temperature and they might have had it for three or four days. It is really difficult.

What we have been trying to suggest is that there needs to be a partnership between the primary health system of GPs and our public health system in order to ensure that they are getting access to the right specialist care, that someone is coordinating that, that GPs are getting reports back and that the people are getting to see their GPs. That is an obligation that we think has to be

imposed on the service provider. It is complicated because you have different systems trying to work together which generally do not work together very well. There is plenty of will. It is difficult to get people from these different services in a room to talk about working together. It is not exclusive to Queensland. This is a problem across the country. In New South Wales they have a much more organised campaign around this and the rights of people to access equitable health care, but it is a problem across the country.

Mrs WILSON: You have mentioned that the full transition would likely be longer than 1 July. When do you or your organisation anticipate or estimate that the scheme will be up and running properly to ensure that our most vulnerable have access to the services they need?

Ms Burgess: This is really complicated. People keep talking about how the NDIS is like Medicare when it first came in. I cannot remember what Medicare was like when it first came in, but I suspect it was a bit clunky for several years. When we look at Medicare, we see that it is constantly evolving. It has been tinkered with. At different points in time government have stopped increases in terms of the amount that doctors are paid and different things provided by Medicare providers have been included in the codes. My view is that the NDIS is going to be like this. It is going to be an iterative social program that will get better and better over time. That is what we all want anyway. It will have to change as the community changes. Certainly the disability community will change the more people view themselves as being entitled to have access to services and to demand equity. Over several generations we will see a change in the way people with disability choose to engage with government services and they will be expecting more—more than they do now. Up until now people were given what they were given and they were meant to appreciate it. I think that is going to shift.

Personally I think we are talking three years before we have any idea how it is going to look in the longer term. We are going to have these periods of providers either coming into the market or dropping out because they cannot make a living. On the weekend I was talking to a friend who runs a mobile physio service. She was telling me that every service they provide is currently costing them \$70 out of pocket. They are hoping that they are going to streamline and refine their services and maybe fees will be increased or they are pulling out. They have other business avenues. She is a good business operator. She knows her margins. She does a lot of planning. If she is telling me that then there is going to be a lot of shift and movement in this market.

Also, the big problem will be making sure that the NDIS Quality and Safeguards Commission is on to those people who are in it for the money and who are not properly skilled and do not have the right motivation to be doing their jobs well and professionally. There is going to be no shortage of those people because these big government programs attract a level of that kind of dishonesty. We are going to have to watch this for a while and see where it all lands. Those who have the right business model will ultimately thrive, but there will be plenty of people come and go before that gets settled. People then have to keep changing providers as that occurs. There is a lot of instability for people during that time. When providers suddenly stop doing business, we do not really have a clear safety net in place yet for all of that. It is going to be difficult and more challenging before it gets better I expect, but we are very optimistic. It is a good thing.

Mr DAMETTO: Personally I am very interested in this. My sister-in-law is receiving care from the NDIS and my mother-in-law is her full-time carer. She is in a very lucky situation. She has somebody who manages her multiple conditions, as you have highlighted in your evidence today. Like you said earlier, some people are not that lucky and they are in full-time care. The adjustment of the definitions is narrowing the people who are protected by these safeguards. You highlighted that you had concerns about how this would work when it goes out to market and this legislation transpires in real-world scenarios. Would you be able to give us an idea of what you think some of those real-world scenarios could look like—where the rubber hits the road?

Ms Burgess: This will be speculative, of course.

Mr DAMETTO: Hypothetical, of course.

Ms Burgess: You could have a person who is living in level 3 accredited accommodation—

CHAIR: Technically we cannot ask hypothetical questions, but we can ask questions that relate directly to the bill. Is there another way you can phrase that question in relation to the bill? Maybe you could give us the benefit of your expertise of those you have seen to date.

Ms Burgess: I could talk about possible risks.

CHAIR: Yes.

Mr DAMETTO: Thank you for your direction, Madam Chair.

Ms Burgess: A person with multiple conditions may have gone into emergency for some incident. They might have had a seizure while they were eating. They might have inhaled some food. They end up in emergency. It all gets sorted out. They maybe spend a week in hospital. They go back home. They are referred to other doctors for follow-up—perhaps with a neurologist to review their seizure medication. There are problems with people having seizures because they actually need someone to keep a record of the seizures that they have. They are meant to keep a seizure diary to stay on top of it. If you are having regular seizures, it is an indication that perhaps your medication is not appropriate and needs to be adjusted.

The person could come home from hospital, but on the day that they are scheduled to go to their next appointment one of the disability support staff is sick or the car ends up in the shop for repairs or something so they cannot get to the appointment. What often happens is that they will then get a follow-up letter some weeks later—probably from public health—trying to reset the appointment. These things drag on. These appointments take a long time to get. It can be months before the next appointment is scheduled and who knows what will happen the next time. Eventually it falls off the radar.

Unless that person has some sort of issue in the meantime that requires them to go to the GP, probably no-one is going to proactively pursue this. That is not because the staff are not caring. They are doing everything they can to feed them and look after them day to day, but this is just another layer. Unless it is clearly outlined in their policies and procedures and the sorts of things they should be doing, say, weekly and monthly—for each individual the need to be reviewing medical care or whether they need any follow-ups will vary. How frequently you need to do that will vary from person to person depending on their condition. Some people might need to have their lungs checked weekly or fortnightly because they have breathing and swallowing and eating difficulties in order to make sure that they have not aspirated food, whereas people who do not have those kinds of problems might only need a quarterly check-up or to get the flu vaccination once a year.

Most of the time we are talking about people with much more serious conditions that require much more proactive management. If that person was then to suffer some sort of catastrophic outcome, perhaps they did not get their flu vaccination, they get the flu, no-one can really tell because maybe they have got some respiratory and swallowing issues, a lot of those people cannot cough very effectively so you do not even know that they have got something wrong, they are just sort of filling up with mucus. They end up very sick and they end up in hospital. That may be a reportable death in care if that person dies as a consequence, but it depends on what those supports were classified as at the time, whether they meet the four very specific classifications of the 37 supports that the NDIS funds. It depends also whether the accommodation provider remains an accredited level 3 provider. If they were in a level 3 facility but over time the provider goes, 'Well, I am getting funded by the NDIS. I am registered with them, do I really need to maintain this accreditation?', they may have the same people who flow over but in the end their NDIS supports do not meet one of the four categories and they are no longer a level 3 service provider because they decide they do not need to maintain it, they are the sorts of things that we are thinking could occur.

Let us face it, we are talking really vulnerable people here. I found it a little bit discouraging and unsettling that everyone is wanting to focus on the most vulnerable when we have got lots of very vulnerable people with quite complex health issues out there who may not fall into this category of most vulnerable but are certainly very vulnerable to having their health issues suddenly take a bad turn. By the time you realise what is happening, they are very sick and it is very hard to turn it around for some of these people.

Mr DAMETTO: Thank you for giving us that example. I appreciate it.

CHAIR: Very quickly, because we are over time—I do apologise to Michelle Moss.

Ms Burgess: Michelle will understand.

CHAIR: I know. Everyone would understand. We appreciate the time with you and it is always short in these sorts of environments, but if I can ask a few quick questions. The community visitor program is constituted under your act, the Public Guardian Act.

Ms Burgess: It is under the Public Guardian Act. I am the Public Advocate. We all are recognised under the Guardianship and Administration Act as different statutory roles.

CHAIR: Thank you very much. The community visitor program, you obviously would be aware what skills those community visitors have and the training that they receive but obviously given your clarification there we can obtain that information separately so that we can provide additional information in our report because that is obviously a very important role.

Ms Burgess: We think it is a very important role. We value it highly. We occasionally ask for community visitor reports when we have concerns about a particular facility and want to have a look at them. Occasionally when we have ongoing issues we get them routinely from the Public Guardian who is always very helpful in terms of providing them. I do not know exactly what training they get. A lot of them are only part-time, casual employees. They do this work and that is certainly all the work that they do for the Public Guardian and they are paid according to the visit or the time the visit takes and the report takes and that is it.

CHAIR: We can obtain that. In your submission, on the last page in the conclusion, the second paragraph, you make the point, coming back to the definition, and you do seek a broader definition of visitable sites and deaths in care, that it should include all people receiving supports under the NDIS. It is very broad, obviously, and I appreciate your comment in regard to concerns over narrowing. Is there a compromise between the two, because essentially that is almost every person?

Ms Burgess: And we are talking a lot of people.

CHAIR: Some of those supports are not necessarily complex, they are quite minor. That has been provided.

Ms Burgess: Earlier on we had suggested a different identification of classifications of support to the department and we did not specify that here. I could provide something to you later that is our suggested broader categorisation.

CHAIR: That would be fantastic if you could provide that by close of business on the 30th, which I know does not give you a lot of time but obviously that is material that is already in place within the organisation. Finally, I do not think your submission did reference the report that you have commented on in regard to deaths being at 53 per cent. Can we have a copy of that report?

Ms Burgess: Yes, I can send that to you, absolutely.

CHAIR: It would be of benefit. My question is that you estimated those deaths of people with a disability at 53 per cent. What was the definition that you used in regard to all people with a disability?

Ms Burgess: It was people with intellectual disability who were living in these types of accommodation.

CHAIR: It would be great if we could have that as well.

Ms Burgess: I can also send you links to a recent report from the ombudsman in New South Wales on the same issue. Every two years they do a report about the deaths of people with disability in care. Late last year the Victorian Disability Commissioner also released a report on the same issue. The findings are very consistent across all of those reports.

CHAIR: That would be lovely if you could provide that additional link but I think particularly the report because you have referenced it in your evidence here today. On behalf of the committee I thank you for the role that you perform in Queensland. As you mentioned, this group is a particularly vulnerable cohort and when you are talking about people with reduced capacity to make these sorts of decisions I think we all appreciate that the NDIS is wonderful, we are moving from a supply to a demand driven program, but there will always be those who cannot fully participate in that and that is why we have agencies like yours.

Ms Burgess: Thank you very much for having me today.

MOSS, Ms Michelle, Business and Operations Manager, Queenslanders with Disability Network

CHAIR: Welcome Michelle and thank you for coming today. Thank you for your submission. Would you like to make a brief opening statement and then we will ask you some questions?

Ms Moss: Good morning and thank you for the opportunity to speak with the committee this morning. QDN is an organisation of, by and for people with disability. We have 2,000 members across the state. We operate 21 local support groups, which are led by people with disability for people with disability. We undertake a range of big picture policy work that is informed by our members, as well as direct project work funded by the Department of Communities and the National Disability Insurance Agency over recent years.

The Disability Services Act has been an important piece of legislation for people with disability since it was introduced into Queensland parliament. QDN believes that the fundamental rights and safety of all people with disability are central and it is critical that we have robust legislation, mechanisms and practices in place to deliver on this.

QDN has undertaken a broad range of work over the past five years in working alongside people with disability to get ready for the National Disability Insurance Scheme and we have worked with people to build their knowledge and capacity about the scheme as well as informing some of the big picture policy work that has been happening and the key interface issues with the state and Commonwealth government and mainstream services.

One of the critical things for Queenslanders with disability is the bilateral agreement, which is central to Queensland's implementation of this, that identified 90,000 Queenslanders with disability eligible for the scheme. We know that 45,000 of these are estimated to be people who have been in receipt of state or Commonwealth funded services and 45,000 of these are new participants, these are people who have never received funded supports before. Queensland's bilateral is the only one in all of Australia that has such a high percentage of new participants to enter the scheme.

As members of the committee would be aware, the entry of participants into the NDIS has been slower than anticipated in those bilateral arrangements and particularly the number of new participants to enter the scheme from our estimates and understanding is probably sitting at about one-third of those who we thought would be in. You would be aware that we are two months out from the end of that transition time. I think at the end of December the NDIS quarterly report talked about 35,491 Queensland participants with approved plans with six months left to go to head towards the 90,000 people identified in the bilateral agreement.

QDN acknowledges the hard work and efforts of the department and the NDIA in transitioning people, but we also know from our experience and the work we are currently doing that there are many challenges for participants to get entry into the scheme. That is one of the things in terms of our concerns around the definitions and who is covered and who is not, especially in this critical period of time post 30 June when this legislation is to be enacted.

QDN is currently funded until 30 June to provide independent support and advocacy to people with disability to assist with their access to the scheme. To date we have worked with almost 1,000 people who have needed additional support to go to their doctor's appointment, to assist their doctor with the paperwork that needs to be completed, to help gather the evidence to prove their disability and functional impacts. We have worked with so many people who do not even know where to start and who are in desperate need of support. Some of these are people who have been in receipt of some kind of support before and many who have not and there are lots of people who have been denied access on their first attempt to access the scheme because of the challenges, barriers and administrative work that is needed at this time.

Based upon the amendments in the bill and QDN's experience as a member-driven organisation, QDN is concerned as at 30 June there is still going to be a significant number of Queenslanders who are not in the scheme. You asked questions earlier about the time frames for that and I think there is going to still be a significant number of people who are not in the scheme and it is really important that the legislation in those definitions, particularly around the reportable deaths in care and the visitable sites, is able to cover the people who may not have yet gained access. There may be people, who have had support and who have been denied access, going through a range of reviews and trying to get assistance to get their entry into the scheme.

QDN would have the position that, especially in this short-term post 30 June, there is a need to look at those people who may not yet be in the scheme and the definition of their NDIS support, particularly for the specialist disability accommodation and young people in residential aged-care. We

know that the market has not matured for funding of specialist disability accommodation. Our understanding is that there are very low numbers and very low numbers in Queensland, so noting that that is one of the criteria in the definitions around the types of support, that people have specialist disability accommodation. I think that is something that is going to take time to mature and what the market does and how it responds needs to be considered in the definition of how people are covered in different types of accommodation arrangements.

Similar to Ms Burgess's and the Public Advocate's position, there are a range of things where we do not know how it is going to land and what it is going to look like for participants and the way that they may be managing their plans. As QDN raised in its submission, the definition that talks about people partly receiving funded supports—sorry, I will grab the rest of my paperwork to name what that is.

CHAIR: We have read your submission, Michelle, so I might get you to wrap up there and then we can open to questions, unless there is something specific that you wanted to add in addition to your submission, if you are covering off on some of those comments?

Ms Moss: No. The only other things are that we do not know what the market will look like and the different arrangements that people will have in place. We would caution to make sure that the definitions include those, because, as Ms Burgess said, it is really critical that those reportable deaths are for the range of vulnerable people. We understand that there are people with high levels of vulnerability, but there is also a broad range of people who are not yet in the scheme and we do not understand, with a great deal of evidence, what that will look like.

CHAIR: Thank you very much for that opening statement. You have been talking about the key issue in your submission, which is the broader definitions of 'visitable sites' and 'deaths in care', on the last page of your submission. I note that you are commenting about Queenslanders with disability who may be ineligible for NDIS supports but who should still fall within that. That is a fairly all-encompassing definitional range that you are proposing. Do you have a basic threshold that you feel people should meet to be captured in that, so that the committee understands what you are suggesting there?

Ms Moss: We are suggesting that the people who might not be eligible for the NDIS but have previously had some type of support or maybe some kind of direct community care support—they may be ineligible for the NDIS or may not choose to make application to enter the NDIS—would still be afforded some safeguards and protections.

CHAIR: It is anyone who is deemed eligible under the NDIS and receives support or anyone who previously received state support under a package? Okay, thank you very much for that.

Mrs STUCKEY: Michelle, this might sound like a very simple question: are children included in your organisation?

Ms Moss: No. Our organisational membership is adults over the age of 18. However, we do have a range of supporters and family members who have children. They are not ordinary members of the organisation under our constitution, but they are supporters and have a different class of membership.

Mrs STUCKEY: Were you satisfied with the response you received from the department to your concerns?

Ms Moss: Yes, in terms of the department's response and the key issues that they responded to. The areas where we think there needs to be that consideration are around the definitions that, particularly in our understanding and our reading of the proposed amendments, might preclude people who are self-managing their plans or who have family members who are self-managing their plans to be captured under 'reportable deaths'. They might be people who are living in community in dwellings with other people with disability, but essentially they are self-managing. They might be employing staff who do not sit under an NDIS registered provider status and they can have different contractual arrangements with their staff.

We would be concerned that at the moment in that reportable deaths area, clause 51, 'Amendment of s 9 (*Death in care defined*)', states—

- (i) paid for wholly or partly from funding under the NDIS; and
- (ii) provided by a registered NDIS provider that is registered under the NDIS Act, section 73E to provide a relevant class of supports; and
- (iii) within the relevant class of supports.

That definition may preclude people who are self-managing their plans and engaging staff directly themselves in an employment arrangement.

Mrs STUCKEY: You were talking about a number of people being denied access due to challenges with paperwork and things like that. How much of a barrier is that? How could it be simplified?

Ms Moss: It is a significant barrier. Certainly in the project that we are currently doing called NDIS peer to peer advocacy, we are seeing a significant number of people who are challenged with that. We are working with a range. We have worked with doctors, psychiatrists and allied health professionals. We have developed a GP toolkit that was funded by the Brisbane North Primary Health Network in response to this issue. We know that the NDIA is promoting that and using it nationally to assist GPs and other health professionals to understand the requirements that the NDIA have in their access request forms, because it is a barrier for people in gaining access. It is a significant issue and I think one that needs continued dedicated work.

Mrs STUCKEY: Finally, we have all acknowledged that a number of adults and children with disability do have complex needs. They rely on a number of prescribed medications, as well. Risperidone is one that springs to mind. I am referring here to your desire to eliminate restrictive practices, which includes chemical practices. Is that the sort of thing that you would be wanting to eliminate?

Ms Moss: From the QDN's perspective on the basis of people with disability, I think it is about working towards the reduction and elimination of restrictive practices, noting that, in some circumstances, there may be a need for a level of restrictive practice for some, but with the ultimate goal of looking at how the systems and things can be put in place to work well with people. We have certainly seen over the years the effect of reduction and, for many people, the elimination of the use of restrictive practices that maybe 20 years ago the staff who supported that person could never have imagined that that could happen. I believe that the NDIS is a great opportunity for people with disability to get access to the right supports, and for many for the first time in their lives.

Mrs STUCKEY: Do you concur that that does involve a lot of medication for various complex needs?

Ms Moss: Yes.

Mrs STUCKEY: I wanted to check that one. Thank you.

Mrs WILSON: When we are looking at the new disqualified offences, do you think any other disqualified offences should be considered?

Ms Moss: At this point I would not be able to make comment on that from an informed place.

Mrs WILSON: Could you take that on notice?

Ms Moss: I can take that on notice and give something by close of business—

CHAIR: On 30 April.

Ms Moss: That is tomorrow.

CHAIR: I am sorry; we have short time lines.

Mrs WILSON: Why do you think there are so many new participants wanting to get involved in this scheme in comparison to past years?

Ms Moss: In terms of Queensland, there has been a consistent and historical underfunding of disability services across decades and decades. The Productivity Commission did the modelling on the numbers based upon the types of disability and the range of supports that people would need. There are other new participants out there. In our work on getting on the NDIS grid project, QDN worked with people who were marginalised across the level 3, boarding houses, people who have been living in caravan parks, homeless people, community housing providers, Child Safety, juvenile justice and criminal justice systems. There are a lot of people engaged and supported in those mainstream service systems who have a need around their disability and a need for support. I guess it is some of the challenges that they experience. As Mrs Stuckey was mentioning, there are challenges with paperwork and the administrative application of that. Actually getting in is one of the barriers for people.

Mr DAMETTO: At the moment in Queensland 45,000 people have been identified and are on the NDIS. With a 50 per cent increase in that, looking at the current quality providers in Queensland, do you think we are ready for this rollout when it comes to the care that will be needed?

Ms Moss: In terms of our working partnership with National Disability Services and the other peak bodies that work with community organisations, I think we are certainly at a point where there are a broad range of quality providers in the market. However, it is certainly not to the level of what is needed to meet market demand at full scheme implementation. Certainly in all our submissions

around workforce, market stewardship and market readiness, we have highlighted key points around the need for the market to develop for the role of people with disability as customers in that market. That also needs a range of support and development, because this is a new way of operating. People are going from being passive recipients of care to being into that place of choice and control. With that goes a range of different roles and responsibilities.

As the need for the market to develop, there is also a really important role for the customer to be able to develop and grow their skills in this area, particularly for people with impaired decision-making capacity, on whom the amendments in this bill are primarily focused. Certainly, there is the need for supported decision-making, and involving people in the decisions that affect them if they are considered to have impaired decision-making for the matter. There is still a lot of work to be done.

Mr DAMETTO: Do you believe there is a role for state government to get involved in helping support new businesses and new providers to be market ready?

Ms Moss: Yes, definitely. There is a role for state government to continue to explore what that innovation looks like and how to respond to opportunities that, in this way of operating, we have not had in place before. That is very exciting, but with it goes some challenges around how we safeguard people within that.

Mr DAMETTO: Thank you very much for your answer.

CHAIR: Ms Moss, thank you very much for coming today and for giving us the benefit of your expertise. For everything that you are doing in this space, thank you.

The committee adjourned at 11.28 am.