Chapter 7

Mental health services and the NDIS

The NDIS is fantastic. There are plenty of people with disability who have fluctuating needs. It is not just a mental health issue. But there is certainly a completely different approach to assessment when you are talking about people with an intellectual disability and people with physical disability than when talking about people who have experience of mental illness. It is very different. ¹

Mr Jeffery Cheverton, Deputy Chief Executive Officer Brisbane North Primary Health Network

Introduction

- 7.1 The National Disability Insurance Scheme (NDIS) represents a fundamental reorientation of the disability support arrangements for Australians with a permanent and significant disability.
- 7.2 In one sense the underlying approach of the NDIS and the Commission's recommendation are the same. Both envisage support services that are organised around an individual's needs.
- 7.3 As discussed in Chapter 2, there is a substantial range of mental illnesses experienced across the Australian population—ranging from mild and moderate to severe and persistent.
- 7.4 For people with a permanent disability arising from a severe mental illness, the NDIS will provide effective, person-centred non-clinical support. In terms of overall numbers, this cohort represents a relatively small proportion of the overall population—in the order of 60 000 Australians.
- 7.5 However, there are other groups whose mental illness does not fit neatly under the NDIS because of the episodic nature of their condition.
- 7.6 This chapter examines these issues and focusses on the potential service gaps which may emerge under the NDIS. The chapter also looks at the progress of the NDIS rollout to date in the trial sites of the Hunter and Barwon areas.

Commission's view

7.7 The Commission's report identified the benefits that may flow from the transition to the NDIS for people living with acute mental illness:

There is potential for the NDIS model to be an empowering one for people living with severe mental illness, because it gives a level of choice and control over funding and support which generally is not currently available.

¹ Mr Jeffery Cheverton, Deputy Chief Executive Officer, Brisbane North Primary Health Network, *Committee Hansard*, 18 September 2015, p. 8.

The NDIS also has potential to enable people to access educational, recreational and social opportunities which they otherwise may not have.²

7.8 The report goes on to note the difficulties posed for mental health by the definition of 'disability' under the *NDIS Act 2013*:

Under section 24 of the *National Disability Insurance Scheme Act 2013*, a person with a mental health disorder meets the disability requirements if the person has "one or more impairments attributable to a psychiatric condition", "the impairment or impairments are, or are likely to be, permanent" and "the person is likely to require support under the National Disability Insurance Scheme for the person's lifetime" (among other conditions). This potentially is problematic for people with severe impairment but with episodic illness, particularly where the emphasis in mental health is not on permanent impairment but rather on recovery and leading a contributing life.³

7.9 The Commission identified 'potential gaps' that could develop during the implementation of the NDIS:

There are serious concerns about the potential gaps which might grow under the NDIS. While those who are eligible for the top tier (Tier 3) in the system are expected to be provided with better, wrap-around supports (in non-clinical areas), people currently supported by mental health services may be left significantly worse off if they are not assessed as having a 'permanent disability' and therefore do not qualify for Tier 3. There needs to be a significant Tier 2 package in place to ensure people are supported and do not end up falling back on the mental health system. There also are related issues about support for carers of people who are eligible for the NDIS.

The unanswered questions about mental health and the NDIS cannot wait until the scheme is implemented. Re-engineering to fix the problems will be too difficult and ineffective, and for too long, people with a mental illness have borne the brunt of patch-up jobs. At a minimum, support for people who currently access existing programmes must be maintained until this issue is resolved.⁴

7.10 While positive about the impact the NDIS would have on access to support for people with acute mental illness, the Commission ultimately recommended that urgent clarification be provided for people with a mental illness under the NDIS:

National Mental Health Commission, *Contributing lives, thriving communities – Report of the National Review of Mental Health Programmes and Services*, 30 November 2014, Volume 1, p. 62.

National Mental Health Commission, *Contributing lives, thriving communities – Report of the National Review of Mental Health Programmes and Services*, 30 November 2014, Volume 1, p. 62.

⁴ National Mental Health Commission, *Contributing lives, thriving communities – Report of the National Review of Mental Health Programmes and Services*, 30 November 2014, Volume 1, p. 34.

Urgently clarify the eligibility criteria for access to the National Disability Insurance Scheme (NDIS) for people with disability arising from mental illness and ensure the provision of current funding into the NDIS allows for a significant Tier 2 system of community supports.⁵

Witness perspectives

7.11 Many witnesses welcomed the NDIS for the benefits it could provide to individuals with severe and persistent mental illness. The comments from witnesses echoed the findings of the Commission in calling for urgent clarification around the implementation of the NDIS, in light of the issues which had been raised through the NDIS trial sites.

Concerns regarding transition of mental health programmes to NDIS

7.12 Mr David Meldrum, the Executive Director of the Mental Illness Fellowship of Australia (MIFA) explained the extent of the 'gap' in mental health services that may result in the transition to the NDIS:

I want to concentrate...on the several hundred thousand people who will not be eligible for that scheme [the NDIS]...

So we are talking about well over 400,000 people—by the most conservative estimate; some people would say the figure is something like 600,000—who access services because they need them desperately from time to time, maybe not continuously in the way that that last 56,000 people do, but from time to time they and their families need them desperately. They currently access a range of clinical services, but I am particularly concentrating here on the funding for the services in the non-clinical area—things like Partners in Recovery, Personal Helpers and Mentors, day-to-day living programs, respite care for carers, a whole range of programs that are funded by the Commonwealth and a whole range of programs that are funded by every state and territory. In the case of the Commonwealth, all of the dollars for all of the programs I just mentioned have been rolled into the NDIS. The problem is that the majority of the clients of all of those programs will not get a service under the NDIS... ⁶

7.13 Mr Meldrum went on to state that 8000 of the 10 000 clients receiving mental health support through MIFA members would be excluded under the NDIS:

For the people we are trying to assist—and across our MIFA membership we are dealing with about 10,000 people at any given time—we think about 8,000 of those 10,000 will find the door closed next 1 July... but we also want it to be recognised that if we leave things standing as they are and we do not find some way to maintain the current programs while implementing

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National Mental Health Commission, *Contributing lives, thriving communities – Report of the National Review of Mental Health Programmes and Services*, 30 November 2014, Summary, p. 16.

⁶ Mr David Meldrum, Executive Director, Mental Illness Fellowship of Australia, *Committee Hansard*, 26 August 2015, p. 18.

the NDIS we are actually cutting several hundred thousand people out of the existing services from next 1 July.⁷

7.14 These sentiments were echoed by Mr Ivan Frkovic, the Deputy Chief Executive Officer of service provider Aftercare:

People are really concerned that existing services, such as Personal Helpers and Mentors and Partners in Recovery, which are helping them to maintain lives in the community to some level and degree, will disappear [with the introduction of the NDIS]. Some of them will qualify for an NDIS package... Our estimate is that probably between 70 and 80 per cent, particularly Personal Helpers and Mentors, potentially will not qualify.⁸

7.15 Mr Frkovic told the committee that he was not confident in the NDIA's estimation that 80 per cent of people from some PHaMs programmes would become participants in the NDIS:

...we have something like 40 to 45 PHaMs programs across the country, so we know that population very well. When you look at the definition of severe and persistent mental illness and complex psychosocial disabilities we can clearly see about 20 per cent of them fit that characteristic. That was the way that program was designed. It was not designed to be totally that very challenging group; it was designed to be a wider cohort. So in a sense we are saying it should not be more than 20 per cent of them fitting. That is the way the two programs have been designed. It is a highly contested space. A lot of people in the National Disability Insurance Agency say, 'No, we are enrolling up to 80 per cent of people from some PHaMs programs.' I am yet to see the proof of that but if they were I would be alarmed because that is dramatic mission creep. They should not be going out to people who are coping well most of the time and giving them small packages of care. That is not what the NDIS is about.⁹

7.16 In particular Mr Frkovic expressed concern over the number of participants included in the NDIS trial sites, particularly the NSW Hunter region:

All I can say is that we keep on looking at our PHaMs programs and keep on seeing the same results. I am very up to date with what is happening in the Hunter, which is the most advanced area in terms of transition. I was talking to people there only last week and they said it is something like 25 per cent at the moment of people in PHaMs programs are being found eligible, so we know we are in the ballpark.¹⁰

8 Mr Ivan Frkovic, Deputy Chief Executive Officer, National Operations, Aftercare, *Committee Hansard*, 26 August 2015, p. 19.

⁷ Mr David Meldrum, Executive Director, Mental Illness Fellowship of Australia, *Committee Hansard*, 26 August 2015, p. 18.

⁹ Mr David Meldrum, Executive Director, Mental Illness Fellowship of Australia, *Committee Hansard*, 26 August 2015, p. 30.

¹⁰ Mr David Meldrum, Executive Director, Mental Illness Fellowship of Australia, *Committee Hansard*, 26 August 2015, p. 30.

7.17 Similarly, Mrs Narelle Hand, a Program Manager at Anglicare raised questions about those current PHaMs programme clients being able to access help under the NDIS:

The Personal Helpers and Mentors program [PHaMs], which I feel is of such fantastic benefit, is a psychosocial support program. This program is at risk of being defunded and being represented under the NDIS. Our concern is that many people in our program may not be eligible for NDIS packages. We have been attending all of the consultations that have been rolled out in the Hunter region and the evidence that has come back is that at some stage it might be that only 20 per cent of the participants we currently have will be eligible for those packages. Our concerns are that the people who are not eligible will fall through the gaps. ¹¹

Concerns relating to confusion about the NDIS framework and funding

7.18 Ms Pamela Rutledge, the Chief Executive Officer of service provider RichmondPRA explained that a key issue in the transition to the NDIS was the sources of the NDIS funding:

...there is a major national systemic issue around the NDIS which is to do with where the money is coming from in each state and territory, so we are experiencing some unanticipated consequences of the fact that in New South Wales the money was historically disability service money, in Victoria it was historically mental health money and it is different in every state. It is part of the bilateral agreements. This puts the National Disability Insurance Agency in a very difficult position in trying to create a national framework of eligibility and support until we can get some greater clarity around that broader issue. The NDIS is intended to fund disability supports for people, including people with a psychosocial disability, but it grew out of the broader disability sector. There is a lack of definition about what is a disability support for a person with a mental health issue compared to what has traditionally been a health support for those people. That is the piece of work that many of us are trying to get engagement with. ¹²

7.19 A further issue for the NDIS is confusion around the NDIS framework and what it will fund for people with mental ill-health. Ms Rutledge explained that while the PIR programme will transition easily into the NDIS, there was confusion around other programmes and their recipients:

I think it is sort of clouding and confusing the whole framework about what it is that the NDIS will provide and fund for people with a long-term severe and persistent psychosocial disability and what will remain as a Health funded support. That is where I think we start to get into this confusion about: where will support for all the people who do not get tier 3 packages sit? We do see that the Partners in Recovery model is really well positioned to be reframed to go on being funded as part of the solution, not only for

¹¹ Mrs Narelle Hand, Program Manager, Anglicare, Committee Hansard, 26 August 2015, p. 42.

Ms Pamela Rutledge, Chief Executive Officer, RichmondPRA, *Committee Hansard*, 26 August 2015, pp 30–31.

supporting the tier 3 packages but also for trying to fund the level 2 and provide some block funding for ongoing support for people who do not get their tier 3 packages, but it is a very big, clouded picture at the moment, and there is a need for some really detailed and committed work. Many people are involved in it, but it is really hard to see how we are going to get traction in that space. I think the next year is really crucial about getting that traction. ¹³

7.20 Mr Jack Heath, the Chief Executive Officer of SANE Australia argued that the NDIS had started with good intentions and the mental health sector had embraced the policy in the hope that it would bring additional funding to support those with mental ill-health:

In terms of the National Disability Insurance Scheme, we see this as a highly problematic area when it comes to mental health. We started off in a very well intentioned way. We as a sector accepted an inadequate or improper policy framework that required people to go and plead their disability, which is completely opposite to a recovery model. We did that because we thought there were going to be huge amounts, billions of dollars, that would go to 56,000 people who have got very severe needs and who we desperately want to help. Our concern is that it is now looking like that additional support for those people is going to come off the back of potentially 625,000 people, as identified by the National Mental Health Commission, who themselves have very severe mental health needs. We thought there was going to be a huge bucket of additional funding for NDIS; that bucket seems to be shrinking and potentially disappearing. ¹⁴

7.21 Ms Susan King, the Director of Advocacy and Research at Anglicare Sydney agreed with Mr Heath's comments:

We are also very concerned that with the growth of the NDIS there may well be defunded mental health services. We want to be assured that national systematic and adequately funded early intervention approaches remain, because we understand the depth of the problem, particularly in the areas in which we operate. ¹⁵

7.22 Mr Frkovic told the committee that the uncertainty and confusion surrounding the NDIS implementation was having consequences for those trying to access services:

This is creating uncertainty at the moment and increasing anxiety and levels of relapse amongst people... A lot of these programs are due to finish in June next year: 'What happens beyond June? Where do I go?' So, it is creating problems for the participants themselves—the individual

14 Mr Jack Heath, Chief Executive Officer, SANE Australia, *Committee Hansard*, 26 August 2015, p. 39.

¹³ Ms Pamela Rutledge, Chief Executive Officer, RichmondPRA, *Committee Hansard*, 26 August 2015, pp 30–31.

¹⁵ Ms Susan King, Director, Advocacy and Research, Anglicare Sydney, *Committee Hansard*, 26 August 2015, p. 42.

consumers—families and carers. They are saying, 'What do we do in this situation?'...we have staff who are really struggling in terms of what happens to them. When you think about it, we have 450 staff, and a lot of people are wondering what happens beyond June next year. That whole system that is currently working is being unravelled from a whole range of perspectives, which I think is causing us some major challenges in terms of ongoing support for people with mental illness, and their families. ¹⁶

7.23 Mr Quinlan of Mental Health Australia advocated for mechanisms to be put in place to assist users of services and programmes to navigate the transition to NDIS, and to ensure that there was no barrier to people seeking to access help. Mr Quinlan explained by way of example:

If Sebastian, who is on the PHaMs program at the moment, comes into my NDIA tomorrow for assessment and is refused—I say, 'Sorry, Sebastian; you can't have the NDIS service and, by the way, your PHaMs service has been enrolled'—he walks out the door entitled, under the current agreement between state and federal governments, to a continuity of service, a guarantee of service. Governments have agreed that Sebastian is entitled, but Sebastian walks out the door with no mechanism to tie him to that guarantee. A very simple process, in my view, would be for the NDIA not to say, 'Good luck, Sebastian; you're on your way,' but to say, 'Here is the state or the Commonwealth program to which you are now entitled.' That would be a very simple mechanism to turn that guarantee of service, which governments have happily committed to, into some sort of concrete action on the ground, because otherwise I fear there are going to be a lot of people falling through the cracks. ¹⁷

7.24 Similarly, Dr Gerard Naughtin, the Chief Executive of Mind Australia told the committee that there was confusion amongst consumers and their families about what the NDIS entailed for them. Dr Naughtin suggested that the communication around the benefits of the NDIS for those with mental ill-health was not being made clear:

...we are not at this stage really effectively marketing to this particular group within the NDIS the real positive advantages that the NDIS will deliver. There needs to be more thought in relation to more effective marketing for specific population groups and particularly the groups that are potentially eligible due to mental ill health...many people are not getting that message—and then starting to think constructively about how they might engage and use that.¹⁸

17 Mr Frank Quinlan, Chief Executive Officer, Mental Health Australia, *Committee Hansard*, 26 August 2015, p. 31.

Mr Ivan Frkovic, Deputy Chief Executive Officer, National Operations, Aftercare, *Committee Hansard*, 26 August 2015, p. 19.

Dr Gerard Naughtin, Chief Executive, Mind Australia, Committee Hansard, 28 August 2015, p. 28.

Response from the Department of Social Services

7.25 In response to these concerns about the continuity of service for existing clients who are assessed as not NDIS eligible, Dr Nick Hartland, the Group Manager of the National Disability Insurance Scheme within the Department of Social Services explained that continuity of service had been a part of the intergovernmental agreements for the NDIS trial stage. This means that:

If they [a client of a service or programme being rolled into the NDIS] are receiving a program at the moment and their program gets rolled into the NDIS and they are not eligible for the NDIS—or, alternatively, they do not get the same service offer—the government is committed to providing, outside the NDIS, continuations of service. We keep working with our colleagues in health and watching our own programs to make sure that happens. We have not yet heard of cases where that commitment is not being met... Also, it is relevant that for many of these people the reason they do not get an NDIS package is that their needs are not high enough to get into the scheme. They might have a need but it is not the type of need that is best addressed by an individually funded support package. ¹⁹

7.26 In additional to the continuity of service arrangements, Dr Hartland told the committee that the NDIS has the capacity for funding outside of the individually funded programmes, such as PHaMs:

In addition to the continuity-of-support guarantee, as you would be aware, there is capacity in the NDIS to fund programs outside of individually funded programs. We have toyed with various names for this. We have called it tier 2—which, of course, meant nothing to anyone who did not know what tier 1 and tier 3 meant—so we have now tried to call it 'information linkages and capacity building'. Unfortunately, that is about as opaque as tier 2. We move forward gradually into these policy areas and we hope we are making progress, but there is capacity for the scheme to fund support for people who do not get the individual package.²⁰

7.27 Mr James Christian, the Group Manager of Disability, Employment and Carers in the Department of Social Services told the committee that, contrary to what other witnesses had said, the Victorian and NSW trial sites had shown high eligibility rates:

Mr Christian: ...it may be a little more reassuring to know that in Barwon [in Victoria] and the Hunter [in NSW] of those PHaMs clients who are currently eligible it has been assessed that 80 per cent of them are eligible for NDIS.

Senator McLUCAS: That is very important. So 80 per cent are eligible from the PHaMs client group.

Dr Nick Hartland, Group Manager, National Disability Insurance Scheme, Department of Social Services, *Committee Hansard*, 26 August 2015, p. 62.

²⁰ Dr Nick Hartland, Group Manager, National Disability Insurance Scheme, Department of Social Services, *Committee Hansard*, 26 August 2015, p. 62.

Mr Christian: Yes.²¹

7.28 Later Mr Christian clarified his answer by letter to the committee:

The clarification I am making is that it is "80 per cent of PHaMs **clients** who have applied to access the NDIS are being assessed as eligible". Not all PHaMs clients have made an NDIS access request. 22

7.29 Dr Hartland could not provide a precise answer when asked about what work had been done to identify the number of people who will fit into that Tier 2 group but not get a Tier 3 package and will need to be able to be in touch with the NDIA or with mental health services on an ongoing basis:

...there is a group of people who have a disability and have a support need, and then a smaller group who need an individually funded package, and the difference between the two is about 200,000 people. Mental health would be a part of that cohort. We have not gone much further than that at this stage. To some degree we would be relying on the finalisation of the planning framework to get a feel for the actual numbers outside of that, and we would also be relying on where we think we are going to get to in relation to numbers of people with a mental illness who have an individually funded package. The NDIS was budgeted for on the basis that basically 57,000 to 60,000 people with a mental illness would have an individually funded package. Whether it ends up at that we will, of course, still have to wait and see. We are on track for something close to that but perhaps slightly under, and I think we would need more information from the population planning framework to then make an assessment about the tier 2 effort. So, no: we do not have an answer. We have a feel for it but not a precise answer. ²³

7.30 In fact the work of the Department of Social Services to determine the number of those in Tier 2 may be made more difficult by the government's decision not to have an eligibility criteria for Tier 2, or as it is now called, Information, Linkages and Capacity Building (ILC). In answer to a question on notice, the Department of Social Services advised:

Tier 2 of the National Disability Insurance Scheme (NDIS) is now called Information, Linkages and Capacity Building (ILC), to reflect the range of support available. ILC will not have eligibility criteria, so there is no estimate of the number of people who will access this support. Both NDIS participants and non-NDIS eligible people with a disability may access ILC...²⁴

21 Mr James Christian, Group Manager, Disability, Employment and Carers, Department of Social Services, *Committee Hansard*, 26 August 2015, p. 62.

Mr James Christian, Group Manager, Disability, Employment and Carers, Department of Social Services, letter of clarification, 3 September 2015. Original emphasis reproduced.

Dr Nick Hartland, Group Manager, National Disability Insurance Scheme, Department of Social Services, *Committee Hansard*, 26 August 2015, p. 66.

²⁴ Department of Social Services, Question on Notice from the 26 August 2015 public hearing.

Committee view

- 7.31 The committee supports the NDIS and the benefits it can deliver for those afflicted by severe and persistent mental illness. The committee notes the progress of the rollout in the trial sites, and the issues which have come to light as a result. The committee thanks witnesses for their insightful comments about the NDIS and the implementation to date, and notes that witnesses have been able to advise the committee based on their collective expertise and experience.
- 7.32 The committee believes that the NDIS has the potential to provide significant support to those with mental illness. Already, programmes such as PIR and PHaMs make a large difference in the lives of those suffering from mental illness. Part of the evidence provided by Anglicare Sydney included a powerful example of the difference that the right support can make to someone living with mental ill-health:

...one case study that we have permission to disclose today. The participant is a middle-aged single lady. She was admitted to hospital with severe depression and anxiety. Leading up to this she had lost her job. She was not able to pay her rent. She became homeless and lived with different friends. She was discharged from hospital and tried to find support. She found out about our PHaMs program and referred herself. That is another benefit of this program—you can refer yourself.

Her goals were to find stable housing and to finish her university degree. She had been enrolled for some years but, due to her mental health, she was unable to complete the course. During her involvement with PHaMs, she received intensive support in managing her anxiety and depression and addressing issues related to finances and housing. She was able to access stable housing, which was a major breakthrough for her. Our PHaMs workers offered weekly support and later fortnightly support in managing anxiety in relation to social situations and the completion of her university degree. Initially it seemed impossible for this participant to be able to complete her degree and the PHaMs worker employed different strategies to help improve motivation and structure so that she could finish her work.

She experienced regular major depressive episodes, including suicidal ideation, but with the support of the PHaMs worker and her psychiatrist she managed to get through the crisis and did not require any hospital admissions. Her depressive episodes became less regular with time and, in consultation with her doctor, she stopped her medication.

The participant was able to complete her university degree, which improved her confidence, and following on from this she began to reconnect with friends and relatives. PHaMs played a major part in supporting this participant when she was not able to manage most aspects of her life due to severe depression and anxiety. She has achieved a much improved quality of life, which she deserved, and her mental health has been so much more

stable. This is just one of...thousands of stories from PHaMs that have been achieved.²⁵

- 7.33 Examples such as this leads the committee to conclude that the impact of programmes like PHaMs and PIR cannot be underestimated. These programmes are the embodiment of the findings of the National Mental Health Commission's review: that community-based, targeted, early-intervention allows an individual to live with mental illness and actively contribute to the social and economic life of the community. Without such programmes, the result for the individual can be dire, and the cost to the health system can increase exponentially if the individual is forced to access acute care or income support.
- 7.34 The committee believes that the testimony from witnesses and the insights of the Commission demonstrate that there is an urgent need for the government to clarify the support available for people with a mental illness, whether under the NDIS or through an external programme or service. The confusion and uncertainty needs to be alleviated as it is already impacting on both service providers and access to services for those seeking help.
- 7.35 The committee urges the government to respond positively to the findings of the Commission, and to the committee's evidence.

Recommendation 13

- 7.36 The committee recommends that the government immediately clarify how Tier 2 or Information, Linkages and Capacity Building (ILC) will be implemented and how many people it will support.
- 7.37 The committee recommends that the government share available information on the workings of Tier 2 or ILC in order to quell the disquiet in the community and ensure that individuals do not lose access to much-needed services.

Senator Deborah O'Neill

Chair

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²⁵ Mrs Narelle Hand, Program Manager, Anglicare, *Committee Hansard*, 26 August 2015, pp 42–43.