



Inquiry into the implementation of the National Disability Insurance Scheme and the provision of disability services in New South Wales

One Door Mental Health



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Executive Summary

As a grass roots community mental health organisation and an NDIS service provider for people with psychosocial disability, One Door is well placed to provide feedback on the implementation of the National Disability Insurance Scheme and the provision of disability services in New South Wales.

In Australia and New South Wales, mental health – psychosocial disability – has been, and continues to be, grossly under-funded despite the clear economic and societal benefits of investment. The NDIS is one of the most important social reforms in Australian history alongside the introduction of Medicare with the great potential to address the critical unmet need to support those with a psychosocial disability.

The experience of One Door Mental Health suggests that the National Disability Insurance Scheme has proven to be a heavily qualified success in providing choice and control for people with psychosocial disability. Whilst many people with psychosocial disability occasioning severe and permanent disability have benefited from support under the scheme, there are currently an unacceptably high number of people who are eligible for the scheme and are not getting adequate support. Reasons for this problem include administrative breakdowns at the National Disability Insurance agencies, financial and institutional problems arising out of the privatization of the disability and NDIS sectors and the complex needs and challenges facing those with psychosocial disability. There are also significant concerns that adequate supports are not, and will not be, in place for people with psychosocial disability who are *not* eligible for the NDIS. This all has significant implications for the implementation, performance and governance of the NDIS and the disability sector more widely.

One Door would welcome the opportunity to present our experiences in the appropriate forums to inform improvements to NDIS implementation and psychosocial disability supports.

Yours sincerely,

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About One Door Mental Health

One Door Mental Health is a specialist mental health recovery organisation, with a 33 year history, committed to improving access to services and the circumstances of people living with severe and complex mental illness. One Door currently delivers trauma-informed recovery-oriented support through the NDIS for people with psychosocial disability.

In the past One Door has provided psychosocial community mental health programs, specialist mental health Disability Employment Services (DES), care coordination, housing, clinical and peer supported services. One Door has delivered services and coordinated community psychosocial care for people across silos of sectors, funding and policy through the building of relationships and trust with other providers, funding bodies and most importantly, individuals and the communities in which they live.

The experience One Door has in delivering this support for psychosocial disability under the NDIS, as well as One Door's extensive experience in the psychosocial disability sector, position us well to comment on the implementation of the National Disability Insurance Scheme and the provision of disability services for people with psychosocial disability in New South Wales.



Some welcome news

Whilst the thrust of this submission is critical of psychosocial disability services both within and outside the NDIS, there is some positive movement in the sector that should be acknowledged.

In the context of disability generally, One Door Mental Health welcomes the NSW Government Transitional Advocacy Funding Supplement announced this year that will provide up to \$26 million in disability advocacy funding until 2020, with a key focus on activities and support inclusion of people with disability in their communities. However, there does not to date exist Transitional Advocacy Fund specifically designed for people with psychosocial disability. This is a serious problem, as many of the advocacy issues that arise around psychosocial disability vary significantly from issues arising around general disability.

In the context of psychosocial disability, One Door welcomes the additional \$82.5 million pledged to mental health in the last NSW budget, including the \$42 million of which will be invested in community based services and supports. One Door welcomes the \$100 million recurrent investment per annum to implement the NSW Government's mental health reforms, including strengthening early intervention and specialist community mental health teams, enhance psychosocial supports, and transition long-stay patients into the community. One Door also welcomes the NSW Government supporting the value of lived experience by announcing \$2.7 million to fund an additional 30 mental health peer workers across NSW for 2017/18 in November last year. As part of the \$100 million in recurrent funding to deliver the NSW Government's mental health reforms, One Door understands that 265 full time equivalent mental health worker positions will be created in 2018/19.

Administrative issues in the NDIS

The experience of workers and clients at One Door Mental Health suggest that there are currently a number of administrative issues facing the NDIS that impact negatively upon the ability of the scheme to provide choice and control for all eligible people with psychosocial disability.

These issues include conflicting or changing indications from the National Disability Insurance Agency (NDIA) about such issues as how plans work under the NDIS, how and when plans can be reviewed, how self-management works, and what particular supports may be "in" or "out" in terms of service provision. There has been lack of clarity about reviews of plans under the NDIS, with requests for unscheduled plan reviews being confused with requests for internal reviews of a decision to approve supports. In some cases the NDIA has not given sufficient and clear information to applicants for key decisions. There has been a lack of communication about plans and reviews and slowness acknowledging requests and responding to enquiries. There have been inconsistent plans issued for people facing similar challenges and issues.

There have been reports of very long wait times between the time of application with the NDIS and the time of acceptance. There have also been reports of very long wait times between requests for plan reviews and reviews taking place, with the NDIS suffering a severe review backlog. These wait times effectively leave people with significant psychosocial disability challenges in “limbo”, without the supports they desperately need and not knowing when the NDIS processes may work for their benefit. These situations are exacerbated by a lack of triage processes within the NDIA to sort more urgent from less urgent requests for review.

One Door has knowledge of a significant number of cases that illustrate problems of access and review for people with psychosocial disability. For example, one consumer with an acquired brain injury required a change of circumstances on his NDIS plan as he needed extra support with commencing a TAFE course; he needed help with transport due to the occurrence of seizures that made him unfit to drive a motor vehicle. A Change of Circumstances form was submitted for the consumer on 22nd February 2018 and as of 17th July the NDIS review has still not occurred. Problems of access and review are further illustrated in a number of case studies summarized in [Appendix A](#), [Appendix B](#) and [Appendix C](#) of this document and in a Commonwealth Ombudsman Report¹. More broadly, NDIA processes have been slammed by Gary Humphries, Deputy President of the Administrative Appeals Tribunal. Mr Humphries described NDIS decision-making processes as slow and difficult to interpret; leading to an “unsatisfactory state of affairs”. He stated that:

“[i]t seems to the Tribunal entirely inappropriate that a Participant, working with finite resources and coping with the added burden of a disability, should need to be left in doubt as to the status of decisions made affecting his or her entitlement to the benefits conferred by the legislation, yet this is precisely the situation many applicants to the Tribunal have found themselves in recently,”²

There have been further reports that a significant number of NDIA staff are not sufficiently informed about the nature of psychosocial disability, and this can have a very negative impact upon the application and review outcomes for people with psychosocial disability otherwise eligible for the NDIS.

Workforce issues

One Door experience suggests that there is a significant paucity of skilled, qualified and eager people to work in a mature market for psychosocial disability support under the NDIS. In the context of the NDIS, quality-of-workforce issues are being exacerbated by low cost estimations

¹ Commonwealth Ombudsman (2018) *Administrative Reviews under the National Disability Insurance Scheme Act 2013: Report on the National Disability Insurance Agency's Handling of Reviews*. Online at http://www.ombudsman.gov.au/data/assets/pdf_file/0029/83981/NDIS-NDIA-Final-report-on-administration-of-reviews-under-the-Act.pdf; accessed on 9/7/2018.

² Gingold, S. (2018) The AAT Slams the NDIA's “Unsatisfactory State of Affairs”. Online at <http://www.disabilityservicesconsulting.com.au/resources/aat-slams-ndia>; accessed on 18/7/2018.

being used by the NDIA to reimburse service provision. With these low rates of reimbursement there are insufficient funds for service providers of the highest relevant qualification to provide the best quality of service to clients. For example, many One Door employees working in the NDIS with the SCHADS qualification at 4-7 have been replaced by employees with SCHADS at 2-3.

There has also been a de-skilling of the psychosocial disability workforce caused by drift out of the sector. Of 25 redundancies made recently at One Door adapting to NDIS, all but 1 person found work outside the mental health sector. In many situations, these employees are those in whom One Door has invested significant time and money training.

Privatizing government disability services and market readiness for the NDIS

The process of privatizing government disability services is a complex, often fraught issue. Organisations are undergoing fundamental transitions from assured block funding to fee-for-service financial models; transitions which have challenged established institutional cultures and behaviours. This process of privatisation reflects issues around wider market readiness for the NDIS. Again, One Door experience suggests that a number of mental health service organisations are struggling with the transition from the traditional block funding model to a sustainable fee-for-service model. Their internal established practices have often proven antithetical to a market-based model, and a number of organisations previously providing psychosocial disability services have had to close due to inadequate funding through the NDIS system.

Indeed, there appears to be a lack of market readiness throughout the NDIS psychosocial disability sector. There is significant instability and change in the economic and institutional parameters of the market. There has been a lack of clear indication from governments or the NDIA about the nature of the emerging deregulated market for psychosocial disability support services. Although estimations have been made, it is still unclear how many people with psychosocial disability will participate in the NDIS; the kinds of functional impacts relating to psychosocial disability that participants will have; and the location and nature of thin markets.

Specific issues for people with psychosocial disability eligible for the NDIS

People with psychosocial disability eligible for support from the NDIS typically have complex care and support needs. This can make it difficult to develop, act on and review suitable plans. We have already noted that some NDIA staff are not well informed about the nature and needs of people with psychosocial disability. People with psychosocial disability, and their families and carers, very often do not understand what the NDIS is and how its processes work. People with psychosocial disability will generally rely heavily on carers or advocates to do the background work of gathering reports and statements about the client's specific needs, which may require some travel and cost.

With the severity and complexity of service needs also comes increased risk and cost to service providers, which may not be wholly remunerated under the NDIS.

Another problem arises where a person with psychosocial disability may need coordination of support (COS) from the NDIS beyond the first year of their package; typically COS is only engaged in the first year of NDIS support. Ongoing need for COS may arise particularly in the context of episodic or fluctuating illness. One Door experience suggests that Partners in Recovery organisations across NSW are experiencing a high number of clients with a 2nd or subsequent individually funded package that includes insufficient levels of COS, compared to the level of supports provided in the previous year.

Issues also arise in the circumstances where a person with psychosocial disability is eligible for the NDIS, but does not apply for a plan - a failure to provide choice and control. This can happen for a variety of reasons, including not being "customer ready"; anosognosia; a symptom of this illness, such as paranoia or hallucination; not wanting to agree that they have or be labeled with a life-long disability; or otherwise impaired decision making ability. One Door statistics indicate that 88 clients from Partners in Recovery South-West Sydney (24% of the total) have declined to apply for NDIS. Of this number, 3 were not well enough, 57 were not interested, 7 were undecided and 21 were "other". Common reasons for "other" were homelessness or unstable accommodation,

Some people with psychosocial disability applying for NDIS may not have the executive skills or personal capabilities to advocate well for themselves, and may end up with plans that are less than adequate.

These problems are further entrenched in rural and remote, Aboriginal and Torres Strait Islander and culturally and linguistically diverse communities. They are also reinforced by situations where the person with psychosocial disability does not have a primary carer, where they are homeless or isolated, have drug and alcohol abuse problems, poverty, poor education and/or criminal justice contact.

It has been suggested that some of the emerging problems for people with psychosocial disability and eligible for NDIS could be addressed through the creation of a dedicated "psychosocial pathway" into the NDIS. One Door recognizes that the NDIA is currently trialing such an idea, but also notes that the results from the trial and follow-up trial will not be available for quite some time.

Issues for people with psychosocial disability ineligible for the NDIS

Whilst some people with psychosocial disability have been eligible for NDIS and received support plans, there is a very large residual category of people with psychosocial disability who are not eligible and are relying on existing support and care institutions or programs. Although it is unclear

just how many of such people are affected, estimations have been made of several hundred thousand. Statistics from One Door suggest that of 222 applicants with psychosocial disability from Partners in Recovery South-West Sydney, only 96 (43%) have been found eligible. 60 (27%) have been found ineligible, almost all because the NDIA stated that permanency of disability had not been established; 56 (23%) are pending and 10 (5%) are no longer contactable.

Unfortunately a number of the institutions or programs these people rely on are being wound back in order for State and Federal governments to finance the NDIS. Established programs such as Partners in Recovery, Personal Helpers and Mentors or Day2Day Living are in the sights to be defunded. Organisations like One Door itself have had government block funding severely curtailed, impacting hugely on service delivery capability. One Door is very concerned that the closure of programs and organizations like these will mean fewer services for those who desperately need it, and severe flow-on costs in time that are humane, financial, social and political.

Regulation and oversight mechanisms for the NDIS and disability sector

One Door recognizes that the NDIS, and the disability sector more widely, require clear, transparent and effective regulation oversight mechanisms.

In the context of the NDIS the counters of an emerging market suggest that a financial oversight mechanism, or “market steward”, could be invaluable. This steward could monitor and inform price-setting, market flexibility and market failures. It could report on areas of thin markets needing additional incentive to be serviced. It could also monitor and regulate service provider organizations for compliance with relevant legislation and policies.

Outside the NDIS, The psychosocial disability sector currently has some oversight in State and National Mental Health Commissions. Reform of psychosocial disability regulation or oversight would do well to work through these existing organizations.

The disability sector more widely could also benefit from a more effective regulation and oversight mechanism. This benefit is all the more urgent in a context where from 30 June 2018 NSW will no longer have a dedicated Minister or Department responsible for disability issues, and there is significant reform to the Department of Ageing and Disability Home Care. It has been acknowledged by NCOSS³ that independent disability advocacy and information organizations have played a critical role assisting individuals with disability to solve problems and negotiate barriers and systems; identifying systemic barriers and working with Governments to build inclusive solutions and representing the voice of people with disability in policy development,

³ https://www.ncoss.org.au/sites/default/files/public/policy/2018%20ADHC%20gaps%20report%20-%20Final%20approved%20version_0.pdf

drawing on a wide range of experiences. A recent cost-benefit analysis has shown that investment in disability advocacy results in substantial cost savings to Government while creating benefits for people with disability across their lifespan.⁴

⁴ Daly, A and Baret, G (2017) "A Cost Benefit Analysis of Australian Independent Disability Advocacy Agencies". Available online at https://www.pc.gov.au/data/assets/pdf_file/0016/222136/subpp0371-ndis-costs-attachment1.pdf; accessed on 27/6/2018.

Appendix A: Case studies of poor NDIA access processes

This Appendix contains a number of de-identified case studies of people with psychosocial disability having poor experiences of NDIA access processes.

Date of Access Request	8-12-2016
Primary Diagnosis	Psychosocial disability
Other contributing diagnoses	PTSD
Evidence submitted <ul style="list-style-type: none"> • Letter from GP • Letter from psychiatrist • Functional assessment measures • Supplemental evidence 	Email sent from Dr B (psychiatrist) and Mental Health staff DASS21 Support letter from One Door.
Date of response	23/2/2017 Access denied 23/8/2017 review denied.
Any reasons given for access being declined	24 1 B C E 25 1 A C
Details and outcomes of any reviews	Declined after review of a review.
Why does this access decision trouble you, why does this decision appear to be inconsistent with other access decisions	The reviewer stated that the reason for final refusal is because participant has been able to access community activities independently. Support worker stated that all community participation has been achieved through assistance from psychosocial support services and not independently accessed. The participant's disability impacts on her daily life and is life long.

Date of Access Request	Dec 2016
Primary Diagnosis	Bi-polar disorder,PTSD, anxiety
Other contributing diagnoses	Epilepsy, depression, sarcoidosis, chronic pain, fibromyalgia
Evidence submitted <ul style="list-style-type: none"> • Letter from GP • Letter from psychiatrist • Functional assessment measures • Supplemental evidence 	<p>Two GP letters No as referral form from GP awaiting psychiatrist Dr A Psychologist report provided. WHO-DAS</p> <p>Support letter from Support Worker detailing the 5 functional aspects</p>
Date of response	22-02-2017
Any reasons given for access being declined	“Section 24of the NDIS act you must have a impairment which is permanent –you do not meet these requirements”
Details and outcomes of any reviews	Review of a review was also deemed ineligible. Administrative Appeals Tribunal process was put in place through People with Disability in August 2017
Why does this access decision trouble you, why does this decision appear to be inconsistent with other access decisions	<p>This client has complex needs and at times when unwell struggles to leave the house</p> <p>The participant also has two physical complaints that attack her immune system and leaves the participant in constant pain.</p> <p>This participant would benefit greatly from the NDIS and increase her enjoyment in life.</p>

Date of Access Request	05/12/2016
Primary Diagnosis	Treatment-resistant Schizophrenia
Other contributing diagnoses	Diverticulitis
Evidence submitted <ul style="list-style-type: none"> • Letter from GP • Letter from psychiatrist • Functional assessment measures • Supplemental evidence 	<p>GP Support Letter Psychiatrist Letter WHODAS</p> <p>Support letter from Community Mental Health Support Letter from PHaMs</p>
Date of response	18/04/2017
Any reasons given for access being declined	Participant could shower herself
Details and outcomes of any reviews	Have not received any information about the review
Why does this access decision trouble you, why does this decision appear to be inconsistent with other access decisions	The decision particularly in a psychosocial application should not be based on whether a person can or cannot shower themselves.

Date of Access Request	Phone access request by carer and participant 1/2/2017; letter dated 1/2/2017 requesting more evidence; full application submitted 13/4/2017 to NDIA
Primary Diagnosis	Paranoid Schizophrenia
Other contributing diagnoses	nil
Evidence submitted <ul style="list-style-type: none"> • Letter from GP • Letter from psychiatrist • Functional assessment measures • Supplemental evidence 	<p>Yes</p> <p>Yes</p> <p>Yes</p> <p>Yes</p>
Date of response	25/7/2017
Any reasons given for access being declined	Not eligible due to lack of significant impairment .Client said he was “ok” during a phone interview. Client not granted a planning meeting, assessor conducted phone interview despite documentation attesting to clients fixed delusions and severe paranoia. Apparently assessor deemed it appropriate to telephone client w/o regard to his condition.
Details and outcomes of any reviews	Complaint made re decision and method of assessing client on recommendation of NDIA officer after repeated failed attempts to contact NDIA Assessor. Assessor phoned CoS the day after the complaint was lodged by client’s sister, robustly defended her position and stated that it was correct, that the client could go for review. When asked who would review the decision, the assessor, (JD), stated that she would perform the review, despite there having been a complaint against her, and she could not see any issue with this. Assessor demanded more reports specifically from the treating psychiatrist, despite CoS having submitted all reports deemed necessary for access (from experience of other ARFs). Assessor stated that reports from long-standing case managers were not sufficient, unless they had mental health qualifications: i.e. psychologist/psychiatrist. CoS agreed to seek further evidence and advice.
Why does this access decision trouble you, why does this decision appear to be inconsistent with other access decisions	Inappropriate behaviour with regard to the needs of Mental Health participants. i.e. telephone call to a person with fixed delusions. No recourse to remedy except review by the person who made the contested decision.

Date of Access Request	March 2017
Primary Diagnosis	Manic depression, Asperger's syndrome, hoarding disorder
Other contributing diagnoses	bladder incontinence, Type 2 diabetes,
Evidence submitted <ul style="list-style-type: none"> • Letter from GP • Letter from psychiatrist • Functional assessment measures • Supplemental evidence 	<ol style="list-style-type: none"> 1. Psychiatrist 2. Clinical psychologist 3. GP 4. Evidence from Centalink establishing DSP 5. Support letters from recovery workers 6. OT functional assessment 7. Test establishing spectrum disorder 8. Evidence in photos regarding hoarding disorder 9. Statement from Mental Health Team
Date of response	End of August 2017
Any reasons given for access being declined	Permanent disability not established
Details and outcomes of any reviews	In a process of seeking review
Why does this access decision trouble you, why does this decision appear to be inconsistent with other access decisions	<p>Client submitted enough evidence proving his manic depression and spectrum including formal diagnosis and how much impact his episodes of manic depression and spectrum disorder have on his life.</p> <p>Client is struggling with hoarding disorder and without external help he is unable to manage his household.</p> <p>This decision is troubling our services because we are the only service this client is currently attending and without ongoing support client's mental health might <u>deteriorate</u> and might end with readmission to hospital.</p>

Date of Access Request	March 2017
Primary Diagnosis	Client has been diagnosed with Bipolar Affective Disorder and with Schizophrenia and experiences some of the “negative” symptoms such as reduced emotional expressiveness and reduced motivation and would benefit with more individual support, such as psycho-education and behavioural support
Other contributing diagnoses	Depression
Evidence submitted <ul style="list-style-type: none"> • Letter from GP • Letter from psychiatrist • Functional assessment measures • Supplemental evidence 	<ol style="list-style-type: none"> 1. Support letter from GP 2. Support letter from psychiatrist 3. Support letter from Partners in Recovery program staff 4. Support letter from recovery workers from ODMH 5. Documents from hospital regarding admission and readmission
Date of response	May 2017
Any reasons given for access being declined	Permanent disability not established
Details and outcomes of any reviews	Reapplying to NDIS in June 2017 with more evidence including functional assessment, new letter from psychiatrist and GP. Provided extended support letter from PiR and ODMH. Several follow up phone calls to NDIS without outcome, told NDIS has a backlog and client needs to wait.
Why does this access decision trouble you, why does this decision appear to be inconsistent with other access decisions	Client has some of the “negative” symptoms of mental illness such as reduced emotional expressiveness and reduced motivation and would benefit with more individual support, such as psycho-education and behavioural support. Client is currently attending our service 4 times a week from 9am till 5pm. Client is socially isolated from his family. He requires a psychosocial support services program for one-on-one support to build his communication skills.

Date of Access Request	25/01/2017
Primary Diagnosis	Somatic Symptom Disorder with Fatigue
Other contributing diagnoses	Bipolar 2, Generalised anxiety disorder, dyslexia and social anxiety disorder.
Evidence submitted <ul style="list-style-type: none"> • Letter from GP • Letter from psychiatrist • Functional assessment measures • Supplemental evidence 	<p>Access Request Form completed by treating psychiatrist and included CAN Scale Level 4 Assessment Support Letter –PIR</p> <p>At review further supporting documentation was submitted – more detailed letter of support from PIR, Carer Statement and OT Assessment.</p>
Date of response	To initial application – March 2017 To request for review – 30/08/2017
Any reasons given for access being declined	Does not satisfy Section 24 (1) (c). Decision upheld at review.
Details and outcomes of any reviews	Currently scheduled for AAT review.
Why does this access decision trouble you, why does this decision appear to be inconsistent with other access decisions.	It is clear from our PIR work that this client needs support to manage her personal affairs (medical, financial, educational and vocational) and to make and maintain connections to meet her social needs. The client also has a goal to live independently and to do so will need significant capacity building and ongoing support.

Date of Access Request	Original 20/10/16 Review 18/11/16 rejected 1/2/17 2 nd ARF 12/9/17
Primary Diagnosis	Complex PTSD, Borderline Personality Disorder, Depression, Diabetes, depression, Chronic pain, panic attacks & fatty liver
Other contributing diagnoses	As per above
Evidence submitted <ul style="list-style-type: none"> • Letter from GP • Letter from psychiatrist • Functional assessment measures • Supplemental evidence 	Original – Treating Doctors report, Psychologist, psychiatrist, specialist reports 2 nd ARF -Mental Health Assessment, PIR Support Letter, Report from Treating Psychiatrist (Dr I), Report from GP, CANSAS and In-Kind Fact Sheet.
Date of response	15/11/17 awaiting result of 2 nd application
Any reasons given for access being declined	1st application Does not meet criteria as not permanent Review came back that DBT Therapy should be considered first.
Details and outcomes of any reviews	Declined
Why does this access decision trouble you, why does this decision appear to be inconsistent with other access decisions	What do the NDIS consider long term? Consumer is in her late 50s and the PTSD was from trauma as a child most of the other diagnosis was from her late teens. Nearly 40 years with mental illness and it isn't considered permanent. DBT therapy is not readily available in the region for free and psychiatrist indicated it wouldn't work

Date of Access Request	13/3/17
Primary Diagnosis	BPD, Bipolar
Other contributing diagnoses	Diabetes
Evidence submitted <ul style="list-style-type: none"> • Letter from GP • Letter from psychiatrist • Functional assessment measures • Supplemental evidence 	GP filled access request Specialist reports Letter from a friend
Date of response	28/3/17
Any reasons given for access being declined	Consumer has PIR and PHAMs support Consumer can access 10 sessions under a mental health care plan.
Details and outcomes of any reviews	Consumer was not well enough to complete a review at the time so has just requested a new ARF and we will be applying again.
Why does this access decision trouble you, why does this decision appear to be inconsistent with other access decisions	PHAMS and PIR are transitioning to NDIS and unless she gets NDIS will no longer get support. PHAMS and PIR shouldn't be a reason to deny her access. 10 sessions with a psychologist is not adequate to help a person with her diagnosis. Consumer also has functional issues, such as home care that have not been looked at.

Appendix B: Some more recent case studies of poor NDIA access processes

This Appendix contains some more recent, de-identified examples showing that flaws with NDIA processes are ongoing.

1. Submitted application – Feb 2018
Application approved – April 2018
Review submitted – May 2018
Still awaiting answer
2. Submitted application – Dec 2017
Application rejected – March 2018
Review submitted – May 2018
Still awaiting answer
3. Submitted application – April 2017
Application rejected – December 2017
4. Submitted application – Jan 2017
Application rejected – March 2017
Review submitted – March 2017
Still awaiting answer
5. Submitted application – Sep 2017
Received rejection – June 2018
7. Submitted application – May 2017
Application accepted – November 2017
Planning meeting – November 2017 (n plan received)
Application rejected – February 2018
Verbal review submitted – February 2018
Email review submitted – March 2018
Still awaiting answer

Appendix C: Article from The Saturday Paper

This Appendix contains the text of an article titled “Bureaucratising Disability” first published in the print edition of The Saturday Paper on Jun 30, 2018; online at: <https://www.thesaturdaypaper.com.au/opinion/topic/2018/06/30/bureaucratising-disability/15302808006482>

Bureaucratising Disability

Back in the day, before the National Disability Insurance Scheme arrived in our area, my son was supported by the community mental health system – a network of services focused on keeping people out of the acute hospital system. There was always someone I could contact when I saw him withdrawing into himself and becoming unwell again. A sort of safety net.

My son experiences severe and enduring depression and anxiety. He has been hospitalised several times when suicidal. There are some things a mother never stops worrying about and that is one of them. And it’s why the NDIS scares me.

I had faith in the community mental health workers who used to support my son. If there was a crisis, I knew his dedicated outreach worker had a process to follow and people to contact. They worked in teams and there was always someone who could be reached and would take responsibility. These were people with relevant skills and qualifications, who received ongoing supervision and training – they were invariably employed full-time on permanent or at least yearly contracts. In my eyes they were never paid enough, but hopefully it was a living wage.

Community mental health support workers have been replaced by disability support workers. I think that speaks volumes about stigma, de-skilling and the loss of a recovery approach.

These mental health support workers always seemed to have time to connect with their clients and develop an ongoing therapeutic relationship with a focus on personal recovery rather than disability. Vitally, they could advocate for clients struggling to speak for themselves. Accessing support didn’t require begging for help or spending months getting reports to prove you were “disabled enough”. Money was never mentioned.

Sadly, under the NDIS, that has all changed.

The NDIS promised independence, choice and control. For our family, it has had the opposite result. Navigating the system has been a crushing experience. I rarely sleep through the night anymore. I am so tired.

In our area, the state government transferred all community mental health funding to the NDIS more than a year ago. The organisation supporting my son moved out and the outreach worker he trusted was laid off. Although our son was one of the few people automatically eligible for the NDIS, 14 months later he still has no supports.

Just imagine what can happen to someone experiencing serious mental health challenges in 14 months.

I can't tell you how many times my son has fallen through the cracks after losing his outreach worker. Time after time, he's been forgotten – another name disappearing down the vortex of a database, where no one can possibly find it if they aren't repeatedly asked to look. This is a system where no one seems to have any sort of ongoing responsibility or connection to an individual. There's nobody you can follow up with. There were so many changes, all at once, and it's just too hard for anyone to navigate.

My son's first NDIS plan, which he was never able to activate, was very limited. It only funded a tiny amount of basic support for skill development, such as public transport training. According to the NDIS, he needed help to use trams and buses – he didn't – but they failed to offer any support for him to put his plan into action, a process that involved not only finding service providers but also interviewing them and negotiating contracts.

When depression stops you getting out of bed and robs you of motivation, energy, confidence and self-worth, how are you meant to proactively seek support? When anxiety stops you from answering phone calls, speaking to people or even leaving the house, how do you interview service providers?

If you can't advocate for yourself, and you have no one else to advocate for you, then I don't know how you can possibly access the NDIS. Maybe that wouldn't be such a huge problem if the other supports weren't withdrawn, but that's what has happened to my son and so many others. Assertive outreach might once have changed the situation, but I haven't seen any sign of it under this scheme.

Our son was left alone to manage. But he couldn't.

Like many carers and families supporting loved ones, I was excluded from the NDIS process and didn't know what was happening. My son didn't live with us and he desperately wanted to be independent. I respected that and I wanted to be his mum, not his support worker. But I was also naive. It didn't once occur to me that he wouldn't have any help to navigate this new system.

I offered to step in when he became obviously unwell. He seemed to have given up hope and I was increasingly worried about his safety and wellbeing. With assistance from a local mental health

advocacy group, he finally received a new NDIS plan with more funding and support coordination. But that proved just the first hurdle. There are so few mental health providers left in his area that waitlists for support coordination have stretched to six weeks, and there is no equivalent to the youth mental health outreach worker he had before.

The lack of comparable supports to those provided pre-NDIS is really important, especially in light of recent funding announcements by Health Minister Greg Hunt focused on those who aren't eligible for the scheme. There is a danger that people with an NDIS package are excluded from other programs on the basis that they might be double dipping, when in fact supports are not comparable. This has happened with respect to other disabilities.

Given next to no practical information by the NDIS, I've watched its rollout as any interested spectator would – reading position descriptions posted to job websites. Support workers are now employed on casual or short-term contracts with limited hours. Pay is close to the minimum wage, about \$20 an hour. Most positions don't require any qualifications, let alone experience working in mental health or with young people. It makes for a heartbreaking read, knowing what is at stake for so many people in the community.

Community mental health support workers have been replaced by disability support workers. I think that speaks volumes about stigma, de-skilling and the loss of a recovery approach. I can't tell you how much damage can be caused by someone who doesn't understand the impact of mental illness and the need for hope.

There are practical issues, too. NDIS support workers are expected to use their own cars, creating issues around safety, privacy, insurance and who pays for mileage. This is just one way in which it feels as though, under the NDIS, the focus has shifted from people to numbers. These interactions have been reduced to financial transactions. Every conversation, email and minute of travel is charged at an hourly rate. But when everything is about money, what happens if you have little funding?

At the moment, I can't see any safety net for my son, and it scares me.

All I'm left with is a swirl of questions. Under the NDIS, will there be anyone to call if I see my son becoming unwell again? Will anyone have the skill, or even the time, to develop a trusting and therapeutic relationship with him, and be able to recognise when his mental health is declining? Will support workers communicate with one another, or will they be siloed – clocking on and clocking off, going their separate ways? Will anyone be accountable?

My family is not alone in this. A report just released by Mental Health Victoria found about 91 per cent of the 150,000 or so people experiencing severe mental illness each year in Victoria won't be eligible for the NDIS. But funding for community mental health services continues to roll into the

NDIS, leaving many people without alternatives for crucial psychosocial supports. I dread to think what will happen to them.

The decision to share my fears publicly was a hard one, but I'm doing this because we cannot overcome a problem that can't be seen or acknowledged. However, I don't want to throw blame around. Without exception, every single person I've contacted while attempting to advocate for my son has tried their best to make things work. But they are stymied by bureaucracy that can be overwhelming.

I understand that the NDIS is wonderful for some people but, in my family's experience, it hasn't been designed for mental health. Something has to change, and we need to talk about it. People's lives depend on it.

Anonymous (Mother of person on the NDIS)

This article was first published in the print edition of The Saturday Paper on Jun 30, 2018 as "Bureaucratising disability".