Submission

To: **Parliament of South Australia:**

Social Development Committee

By Email: sdc@parliament.sa.gov.au

Topic: **MENTAL HEALTH SERVICES & THE NDIS**

Date: **29 October, 2018.**

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Executive Summary

In 2010, mental health and substance use disorders accounted for 183·9 million DALYs (disability adjusted Life years) globally, accounting for 8·6 million years of life lost and 175·3 million years lost to disability. Mental and substance use disorders were the leading cause of years lost to disability worldwide. The impacts of mental health disorders are substantial and for most people there are paths to significantly improved quality of life.

Recognising adverse impacts of a range of disabilities, The Australian Government asked the Productivity Commission to carry out a public inquiry into a long-term disability care and support scheme, in 2010. The National Disability Insurance Scheme (NDIS) was the end result of this inquiry with the National Disability Insurance Agency established in 2013 in the initial launch jurisdictions of South Australia, Tasmania and the Australian Capital Territory on 1 July 2013. South Australia now has 5 years of experience of the NDIS.

Uniting Communities considers the NDIS to be an excellent scheme in the making, but as a market based scheme, it is an incomplete market. We show that a majority of criteria generally accept as pre-conditions for effectively competitive markets do not apply to the NDIS and mental health services in South Australia, at the moment. This is part of the context for this Inquiry and we state that the current market failures mean that additional government intervention is crucial, at least in the short term, to mitigate the impacts of market failure, particularly for more vulnerable consumers needing mental health services.

Access to the NDIS should be a positive experience and for some people it is, however accessing the NDIS is also causing harm/distress for other individuals. Specialist staff who understand and support people with a psychosocial disability in addition to appropriate access and planning pathways are needed.

The data suggests that currently less than a half of eligible people, with mental health needs have a plan and only about 55% of plans are being activated in South Australia.

Since July 2017 no services have been available for people who are ‘new presenters’. In addition to this startling gap. We note the following observations:

- In Uniting Communities’ MHR:CS (Mental Health Respite: Carer Support) program about 10% of people who have applied have been unsuccessful in obtaining a service, another 10% have not engaged and not applied.
- PHaMs (Personal Helpers and Mentors services) services are not available to new applicants.
- There is no program where people with mental illness can self-refer without going through a clinical pathway.
- IPRSS (Individual Psychosocial Recovery Support Service) is the only psychosocial recovery program available

Ongoing funding is critically needed for the following mental health services.

- IPRSS / MHS linked psychosocial programs. Uniting Communities provides IPRSS for people over the age of 65. The NDIS is only available to people under the age of 65

however the state government has committed all of the available IPRSS funding. There has been no formal response to this as yet and Uniting Communities seeks an explanation and/or commitment from the State Government that people over the age of 65 will not be worse off under the NDIS and that psychosocial services will continue to be available for people over the age of 65.

- Fill the gaps of people not eligible for NDIS
- People who are subject to Section 55 who automatically transitioned over because they were under DHS, may not continue after the first annual review, so NDIS will cease in some cases
- There is also a need for programs where people can self-refer

While ongoing dialogue is clearly needed between the Commonwealth, States and consumers, we urge the State Government to ensure that immediate funding is available to ensure that these gaps in services are met during the transition to full NDIS

There are a number of impacts on South Australians with mental health issues who struggle with the application process for NDIS, these impacts include:

- People not wanting to engage with the system because it is too complex, too daunting or people do not expect they will get the service they need, are being pushed to apply in order to satisfy continuity of support (CoS) requirements, if not eligible for NDIS, or otherwise be left without a service altogether when transition is considered to have been finalised.
- People who are deemed unsuccessful in applications are required to reapply which can be exceedingly stressful and exacerbate existing conditions.
- As a service provider, we see the onerous nature of obtaining and producing reports and recognise that they are very costly to produce when there is considerable opportunity to streamline report production.
- Many people are dropping out of the process or not activating the NDIS plan when it is approved, this needs to be further investigated by National and State governments
- There is need for more support by agencies than is currently available, but such support is unavailable for people not currently in a program and some people with mental health needs are not currently able to be considered for services through NDIS.

Access to the NDIA is difficult and creates a major barrier, increases frustration and results in disappointment and distrust of the scheme. The 1800 number is not an accessible pathway for transparent and easy communication. Having local contacts who are easy to contact via phone or email is vital to ensure improved outcomes of the scheme. Poor accessibility for the National Disability Insurance Scheme is in contradiction to everything that it is supposed to stand for.

In summary, there are insufficient services available for people with mental illness who are accepted into the NDIS, particularly in regional locations and for people with bespoke needs.

There is also substantial variability in the terms and quality of the services provided through existing plans with support and specialist support coordination not being consistently included in funding for plans.

The following are the priority recommendations that Uniting Communities makes to this Inquiry:

Priority recommendations

Recommendation 1
That a provider of last resort is urgently appointed and resourced to ensure that in the short term people needing mental health services in South Australia who are not receiving them through the transition to NDIS, receive the services they need.

Recommendation 2
That clients currently receiving mental health services, including services under Commonwealth programs transitioning to the NDIS, namely Partners in Recovery (PIR), Personal Helpers and Mentors (PHaMs), Day to Day Living (D2DL, and Mental Health Respite: Carer Support (MHR:CS), should not have to apply for the NDIS to have guarantee of continuity of supports and access services.

Recommendation 3
The SA Government should continue to act as support coordinator of last resort to ensure that services are available for people who need them.

Recommendation 4
That the SA Government urges the NDIA to provide direct assistance to support coordinators who are struggling to navigate “thin markets” and to support people with complex needs.

Recommendation 5
The SA Government should highlight to the Commonwealth Government and NDIA the shortcomings of application of market model assumptions for thin, emerging and transitioning markets and develop policies and practices that respond to market failures.

Recommendation 6
That the SA Government work with the NDIA to enable contingency funding to be immediately accessible when crises arise. This approach would require designated liaison and emergency contact points and procedures within the NDIA (or authorised agencies) which are responsive during and outside of business hours.

Recommendation 7
That clients currently receiving mental health services, including services under Commonwealth programs transitioning to the NDIS, namely Partners in Recovery (PIR), Personal Helpers and Mentors Services (PHaMs), Day to Day Living (D2DL) and Mental Health Respite: Carer Support (MHR:CS), should not have to apply for the NDIS to have guarantee of continuity of supports and access services.

Recommendation 8
That the SA Government encourage the NDIA to develop an approach to build flexibility in plans to respond to the fluctuating needs of participants with a psychosocial disability, including allowing minor adjustments to be made without the need for a full plan review.

Recommendation 9
That the Complex Needs Pathway incorporate a range of safeguards regarding plan implementation. These should include a requirement for support coordinators to provide regular, periodic implementation reports to the person, the NDIA and, where applicable, the person's plan nominee and/or guardian. As well as detailing funds expended, such reports should incorporate participant views and feedback and address outcomes and progress towards goals.

Recommendation 10
That the SA Government commit to funding so that people over the age of 65 will not be worse off under the NDIS and that psychosocial services will continue to be available for people over the age of 65 years.

Section 1: Introduction

Uniting Communities welcomes the opportunity to contribute to this inquiry. We are a major provider of community services in South Australia, including a number of services to assist people dealing with Mental Health needs.

About Uniting Communities

Established in 1901, Uniting Communities' mission is to create a compassionate, respectful and just community in which all people participate and flourish.
Uniting Communities works with South Australians across metropolitan and regional South Australia through more than 100 community service programs.
We are made up of a team of more than 1,500 staff and volunteers who support and engage with more than 20,000 South Australians each year.
UC offers programs for young people, families and children and older people, around mental health and wellbeing issues, disability support, respite for Carers, housing and crises, alcohol and other drugs intervention, counselling and rehabilitation, medical issues, and financial and legal services issues.

Our input is driven by specific comments from a number of people who have received services from us and from staff who provide services. We also add the distilled experiences of thousands of individuals, families and communities with whom we work through services, including financial counselling, aged care services, disability services, homelessness support services, Lifeline and many more.

Our specialist mental health services include:

- Family Mental Health Support Service

  Family Mental Health Support Service provides information, support and counselling for families who have concerns about the mental health and wellbeing of a child or young person through an early intervention approach.

  The service assists and supports children and young people aged up to 18 who may be affected by a mental health issue. We aim to increase understanding and awareness of mental health issues, and support children and families to improve their mental health, resilience and confidence.

- Headspace Mount Gambier

  Headspace is a network of centres across Australia that give young people access to health workers. Uniting Communities is the Lead Agency that operates headspace Mount Gambier.

  The service provides support across a range of issues including mental health, education, employment, alcohol and drugs.

- Support for older people experiencing mental illness

The Southern and Northern Individual Psychosocial Rehabilitation and Support Services (IPRSS) helps older people who are experiencing mental illness to increase their independence and enhance their quality of life.

- NDIS Psycho-social disability services

  This service provides recovery support services for people experiencing long-term mental health issues who want support to live the best life that they can.

  This service is available in regions where the NDIS has commenced

- Mental Health Carer Support and Respite

  People caring for a person with a severe mental illness may need respite and support from time to time. This service offers support for Carers living in the north-west metropolitan, north-west country and south-east country SA areas.

Other services supporting people with their mental wellness include:

- Lifeline
- Bfriend (LGBTIQ Service)
- Youth and family counselling
- New Roads Alcohol and Other Drug service (Counselling and Residential alcohol and other drug Rehabilitation)
- Financial counselling
- Homelessness Gateway Service, the first point of contact in seeking help for many people with nowhere to sleep.
- Streetlink Youth Health Services

Terms of Reference

The terms of reference for this inquiry are copied below. We consider each of these in turn in Section 5, after providing some case studies and broad observations that are germane to the review. The terms of reference are:

1. The gap between the Federal Government's predicted and realised percentages of mental health clients receiving NDIS support;
2. The reduction in funding to the Personal Helpers and Mentors program and Mental Health Respite Carer Support program and the impact this will have on people with mental illness;
3. The ongoing requirements for block funded mental health services provided by the State Government after the NDIS transition;
4. The effects on South Australians with mental health issues who are deemed ineligible to receive NDIS funding;
5. The sufficiency of services provided to people with mental illness, accepted into the NDIS;
6. The effects on South Australians with mental health issues undertaking the application process for the NDIS;

7. Any other relevant matters.

Section 2: Case Studies from Uniting Communities

The following case studies have been documented by Uniting Communities staff who work with people with mental illness. Names have been changed to de-identify individuals. Comments in the first person refer to the staff member who has written the case study

Ted

Ted is a 61 year old man with severe anxiety.

Ted as a young man was a surf lifesaver, won a scholarship to the Elder Conservatorium of Music and was employed as a forensic imaging technician. Ted enjoyed scuba diving, sailing and crewed on several Maxi yachts. He was a director of a Company helping his younger brother organize wildlife tours.

In 2007 Ted suffered a mental breakdown due to extreme bullying and pressure at work. Ted became withdrawn, angry and had a sense of failure. He became suspicious of everyone and everything including his family and ended up being found after disappearing for five days, in a different state in a psychiatric ward.

Ted has since relied on his elderly mother for support on a daily basis. Ted is supported to attend medical appointments, undertake house hold tasks, shopping and although Ted drives he often finds himself relying on his mother to transport him due to his high anxiety.

Ted sees his Doctor and his Psychologist on a regular basis.

Currently Uniting Communities supports Ted for 2 hours once a fortnight.

Working with Uniting Communities Ted submitted an access request to NDIS and was denied access. Ted stated that the process of applying for access was extremely traumatic for him having to relive and face up to his loss of a positive and productive life.

Currently Uniting Communities is working with his mother to reapply for access to NDIS with the permission of Ted, however he does not want to have any input during the process as he has stated that he does not want to re-live the trauma of applying for NDIS again.

Susan

Susan started an application for access to NDIS however when confronted with reliving the trauma associated with the circumstances surrounding her diagnosis of Bi- Polar and her story, she stopped the process and now refuses to continue with application.

Paul

Paul is a 57 year male who has a diagnosis of schizophrenia and a history of substance use. He is being cared for by his 93 year old mother who he lives with. His mother provides meals and does all house hold tasks including washing and cleaning. Paul is socially isolated and finds it difficult to engage well with other people.

Due to his paranoia Paul struggles with allowing strangers into the house therefore his mother does not receive cleaning or support service through MYAGEDCARE. Uniting

Communities Peer Support Worker maintains contact with Paul's mother however the mother is in a constant, highly stressful and unpredictable environment. She feels she cannot leave the house for respite or have safe conversations whilst her son is in the house.

Paul was receiving 1.5hrs of support a week however this has decreased due to an increase of inappropriate and threatening behavior towards female support workers and not enough male workers to work with client.

Paul has been denied access to NDIS.

It is clear that Paul's permanent, severe and persistent psychosocial disability (schizophrenia) is having a significant functional impact on his daily life, his informal and formal support networks. Paul would benefit from a higher level of support to improve his functional capacity to undertake activities of daily life and increase his social and community participation and maintain his existing support networks through the NDIS. It would be beneficial for Paul's plan to include Specialist Support Coordination to ensure that services are in place and that Paul's plan is implemented. The development of a Positive Behaviour Support Plan that would assist workers supporting Paul to engage with him in a respectful and positive way to ensure sustainability of the support and therapy supports would provide Paul with support to develop alternative communication strategies.

Given the age of Paul's mother and the reliance on her for activities of daily living and his only social support there is a significant risk of Paul's mental and physical state declining and associated negative behaviours increasing. This will put him at greater risk of being involved with either inpatient or forensic mental health services.

Adam

Adam is an Aboriginal man, father of 3 with a diagnosis of Foetal Alcohol Syndrome, anxiety and depression. He and his 3 children are being cared for by his adoptive mother. Due to Adam's high and complex needs, that have a significant impact on his daily functioning, he finds it difficult to engage with services and therefore is not actively engaging with the NDIS.

Given the decrease in funding for services Uniting Communities is not able to undertake an assertive outreach approach to support Adam to the level that is needed for him to access the NDIS and obtain the support that he requires to improve his functional capacity. It is likely that he will fall through the gaps.

Steve

Steve has been diagnosed with severe paranoid schizophrenia, was extremely isolated and very rarely left the home. He engaged with Uniting Communities mental health support program and attended an art group on a weekly basis where he developed friendships with the other group participants. He also benefits from support to assist him with his daily living skills due to the functional impact of his permanent psychosocial disability. Steve applied for NDIS and was rejected on the grounds he uses marijuana and he was told he needed to do something about his addiction to drugs before they would look at funding him under NDIS. Steve uses marijuana as a way of coping with his mental health symptoms. Without

supports he will no longer attend the art group and will therefore become even more isolated than he already was and may be at risk of losing his accommodation.

Alcohol and other drug use should not be a reason for denying a person with a psychosocial disability access to the NDIS. Steve has a permanent psychosocial disability that is severe and persistent that has a functional impact on his activities of daily living and his access to social and community participation. Marijuana is a strategy that he has adopted to cope with the functional impairment that the psychosocial disability has created in his life. Access to the NDIS would provide him with the reasonable and necessary supports that he needs to live a quality life and to improve his functional capacity.

Access to the NDIS should be a positive experience and not cause harm/distress to the individual. Specialist staff who understand and support people with a psychosocial disability in addition to appropriate access and planning pathways are needed.

Jane – Changing support Needs

Jane has multiple severe mental health issues as well as Parkinson's disease. She is cared for by her husband who also suffers from mental health issues. In the last year since she received her first NDIS package we have had to submit a change of circumstances form 3 different times due to her change in support needs as well as there not being adequate or no funding in the original plan for essential supports such as Specialist Support Coordination. Each of these reviews of her plan have taken at least 3-4 months to happen from the time of submitting the change of circumstances form. On most occasions her needs have again changed during the 3 months whilst waiting for the review. Although client has been granted funding for Specialist Support Coordination they were advised by the agency supplying the Specialist Support Coordination that the client and her husband would need to register with the NDIS portal so they can see how much money they are using and how much they have left. This became a significant stress for the Carer and client as both of them have low literacy skills, are not computer literate and they do not have a computer or an email account. The client was also not able to go to a library to access a computer on a regular basis either as she cannot get into a car and needs to use an access cab to go places which they cannot afford to do often.

Positive Examples of NDIS Engagement

Brian: Adult male client diagnosed with Schizophrenia – affective disorder, Major depression, PTSD, OCD, Bi- Polar who lives with his wife and adult son. Was receiving 2 hours per week respite under DSS funding, currently receiving 5 hours per week to attend the gym, grocery shopping, pay bills and general tasks. Client is enjoying joining in social groups once a month for 3 hours and attending performances on the weekend as they arise. Client has become more socially engaged, physically fit and has become confident enough to be a guest speaker talking about his lived experience of mental ill health and his journey to becoming as well as he can be at a community event.

Fiona: diagnosed with Schizoid-affective disorder, acquired brain injury, PTSD and anxiety. Fiona lives on her own in her own home. Under DSS funding she was receiving 2 hours a week support. Fiona has an NDIS plan and is now receiving 4 hours support weekdays and 2 hours on a Saturday with Uniting Communities and attends groups 3 days a week including overnight camps with Skylight. Fiona is now connected with her community and seeing an improvement in her social participation and overall wellbeing.

Uniting Communities Observations and comment from staff providing services.

- "Since a large number of clients have applied and been denied access to NDIS, which in itself can be traumatic, to reapply is often more challenging due to the client not wanting to relive their mental health story a second time around. Carers often state 'what will happen to (client) if I am no longer here to care for them, who looks after them then if they don't get NDIS?' so often they are the people who push to reapply for the care recipient."
- "Due to doctors not having a good understanding of the language of NDIS I have written a template using the wording which NDIS requests which I share with Doctors suggesting this as a guideline for them to use. After a consent form has been signed by the client allowing me to communicate with their Doctor and/or psychiatrist I make contact with Doctor or psychiatrist either over the phone or by email. I have also developed a template for Carers to follow when writing Carer's letters and offer time to support Carers to write letters."
- "I complete LSP – 16 and WHODAS assessments with clients "
- "I write a support letter for all clients currently receiving respite which covers all areas of functional capacity to support their access request application."
- "A number of clients with severe mental illness are not willing to apply for the NDIS as they are paranoid about the whole system, they do not believe they have a mental illness and do not believe they need supports even though they have a carer who assists them on a regular basis as well as many clients and Carers find the application process extremely stressful and time consuming. These Carers are going to lose supports for themselves in the future if the person with the mental illness does not apply for NDIS. The Carers have major concerns about what will happen to the person they care for in the future when they are no longer around or capable of supporting them if the care recipient is not receiving NDIS funding. Other Carers who care for someone with anxiety or depression are also rarely receiving NDIS funding due to the illness being episodic in nature and not being considered life long and something they will never recover from. These Carers and care recipients can still go through times where the mental health client is so unwell that they may be suicidal or need to be hospitalized in a psychiatric ward but because they eventually start to make some improvements due to lots of supports they are unlikely to be eligible for funding.
- We have had several clients who have illnesses such as schizophrenia, Bipolar disorder or borderline personality who have been rejected for NDIS funding the first time they apply and have had to be supported to reapply. Some of these clients have

had multiple admissions to psychiatric wards over the last 5 years, suicidal thoughts, have regular psychiatrist, psychologist or GP support and one has had recent treatment using Electroconvulsive therapy but they were still rejected for NDIS funding as their illness was not considered to fit the NDIS criteria. Clients find the application process very stressful and when they are rejected they often do not want to go through the stress again of getting forms filled out and obtaining support letters from different specialists or organisations and therefore will not reapply."

Section 3: Significance of Mental Health Issues

In 2010, mental health and substance use disorders accounted for 183·9 million DALYs (disability adjusted Life years) globally, this being or 7·4% of all DALYs worldwide, according to the Global Burden of Diseases, Injuries, and Risk Factors Study from that year and quoted in the Lancet.[1] These conditions accounted for 8·6 million YLLs (years of life lost) and 175·3 million YLD (years lost to disability). Mental and substance use disorders were the leading cause of YLDs worldwide. Depressive disorders accounted for 40·5% of DALYs caused by mental and substance use disorders, with anxiety disorders accounting for 14·6%, illicit drug use disorders for 10·9%, alcohol use disorders for 9·6%, schizophrenia for 7·4% and bipolar disorder for 7·0%. We note that the highest proportion of total DALYs occurred for people aged 10–29 years. The burden of mental and substance use disorders increased by 37·6% between 1990 and 2010, which for most disorders was driven by population growth and ageing.

The following table compares the estimated HRQL (health related quality of life) utilities for various conditions from the 2010 Global Burden of Disease study, and some subsequent national level studies. This table was produced as part research funded by the Victorian Responsible Gambling Foundation in 2016[2] and so has heightened reference to gambling.

The data is sound and shows that three of the 'top 6' biggest impacts on reduced quality of life are direct "mental health" conditions, with schizophrenia giving the worst impacts of all health conditions that disrupt quality of life. Indeed, schizophrenia both acute and residual states and bipolar disorder have more adverse impact on the quality of life of people than moderate alcohol use disorder, amphetamine dependence, stroke, amputation and hearing loss, for example. This gives an insight into the substantial adverse impacts of mental health on the lives of people and we argue, consequently, the importance of ensuring that people giving with mental health issues have access to the best possible support and treatment available.

[1] https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(13)61611-6/fulltext

[2] Assessing gambling-related harm in Victoria: a public health perspective, Browne, M, Langham, E, Rawat, V, Greer, N, Li, E, Rose, J, Rockloff, M, Donaldson, P, Thorne, H, Goodwin, B, Bryden, G & Best, T, Victorian Responsible Gambling Foundation

Health related quality of life utilities for various conditions

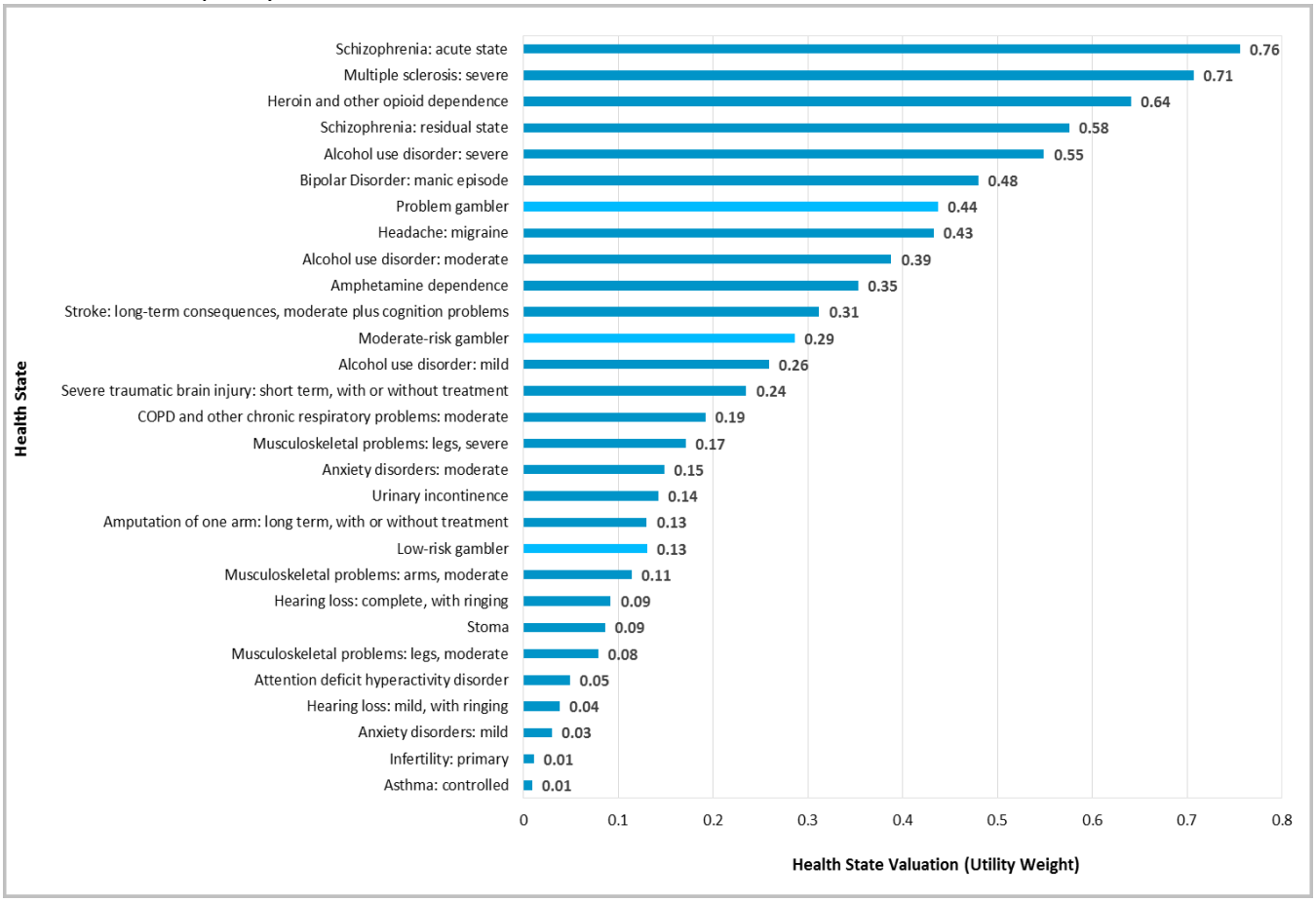

Figure 1, Source: Assessing gambling-related harm in Victoria: a public health perspective.

Section 4: Current State of Play, NDIS and Mental Health Services

In considering the current state of play regarding NDIS and mental health services in South Australia, we note the data presented in table 1 below which shows community mental health service contacts for patients and treatment days for selected states for the year 2016-17. When compared with national figures, given in the 'total' column, it is worth noting that South Australia has average service contacts per patient rates below the national level and significantly below largest states of New South Wales and Victoria, while average treatment days per patient is also two days below the national average in six days below the rate for New South Wales patients. South Australia also has a higher rate of both service contracts and patients per thousand of the population compared with national rates. This could suggest that while demand per capita is greater in South Australia, the level of service received by each patient in community mental health care services is less than the national rate

Community mental health care service contacts, patients and treatment days, states and territories, 2016–17

Count		NSW[7]	Vic[6]	Qld	WA	SA	Total
Number	Service contacts	3,217,760	1,579,185	1,976,246	921,395	682,162	8,905,942
Number	Patients	128,133	66,559	98,357	60,112	39,180	419,884
Number	Treatment days[a]	2,301,712	883,577	1,402,061	680,969	484,127	6,101,929
Number	Average service contacts per patient	25.1	23.7	20.1	15.3	17.4	21.2
Number	Average treatment days per patient	18.0	13.3	14.3	11.3	12.4	14.5
Rate[b](per 1,000 population)	Service contacts	412.7	252.9	404.7	358.8	397.3	365.2
Rate[b](per 1,000 population)	Patients	16.4	10.7	20.1	23.4	22.8	17.2

Table 1: Source, AIHW, Mental Health Services report[3]

Note: South Australia's data is combined from two separate databases with no data linkage or other method applied to remove duplicates. Past investigation has shown CMHC NMDS data – approximately 5 percent of consumers state-wide are duplicated across the systems.

Uniting Communities considers the NDIS to be an excellent scheme in the making, but as a market based scheme, it is an incomplete market.

We illustrate this in table 2 by considering criteria generally recognised (by economists) as essential criteria for competitive markets and in considering these criteria from the perspective of three demand-side participant 'sectors' and the service supply side.

The following criteria are generally accepted as those that are necessary preconditions for a market to be competitive:

- Large numbers of sellers and buyers: so that no one market participant can influence price.

[3] https://www.aihw.gov.au/reports/mental-health-services/mental-health-services-in-australia/data

- Product homogeneity.
- There are substitutes for both firms and products
- Supply-side participants (generally summarises firms) are profit maximising
- No external interference, including legislation or regulation by government
- Perfect mobility of factors of production
- Perfect information about prices and quantities is available for all market participants.

We now consider these criteria for the "market for NDIS and mental health services" from the perspectives of demand-side participants, specifically 'direct' consumers receiving or seeking a service, Carers of direct consumers and the communities in which service recipients live. From the supply-side we consider the perspective of service suppliers other than government, including for-profit businesses and organisations like our own.

	Direct Consumers	Carers	Community	Suppliers (not government)
Many buyers and seller	✗	✗	✗	?
Product Homogeneity	✗	✗	✗	✗
There are substitutes (goods and suppliers)	?	✗	✗	?
Profit maximisation	✗	✗	✗	✗
No external interference (eg regulation)	✗	✗	✗	✗
Mobility of factors of production	✗	✗	?	✓
Perfect information re price and quantity	✗	✗	✗	✗

Table 2. Source, Uniting Communities observations

The following comments apply to the rows in this table;

- Many buyers and sellers / suppliers: there are many registered providers but a number of these are not providing services or are only providing some of the services that they have been registered to provide. We also note that many regional markets are very "thin" in terms of supply of NDIS services, particularly for people with mental health needs.
- Product homogeneity: service quality is a major factor in provision of mental health and NDIS services, some services are exceptional, others are lacking. The crucial nature of service quality means that product homogeneity will never really apply in mental health and disability service "markets" where differentiated, specialist services are often needed to meet the specific needs of a person needing assistance.
- There are substitutes: particularly for mental health services within the NDIS as well is for NDIS services in general, bespoke services are needed to meet the needs of individual consumers, so the notion of a range of substitutes being available simply does not hold, nor is it desirable

- Profit maximisation: there is a price cap for NDIS services, so this severely limits the capacity of suppliers to seek to maximise price. We also observe that for consumers, price is not a good proxy for service quality. Some services provided at the prescribed price are very high quality, others are not. Price is not able to be used as a signal of service availability nor quality.
- Mobility of factors of production: suppliers can generally provide mobility through staff since staff is the dominant factor of production. Consumers, particularly in regional markets can have limited capacity to move to where the services that they need are available.
- Perfect information: there is considerable difficulty for many consumers and often their Carers as well to be able to gain the information they require about service availability, price and quality. Information failure is substantial concern for NDIS services in general and for those providing mental health support in particular.

Table 2 shows that a vast majority of criteria for effective markets do not apply to the NDIS and mental health services in South Australia at the moment. This means that additional government intervention is crucial, at least in the short term, to mitigate the impacts of market failure, particularly for more vulnerable consumers needing mental health services.

The previous section demonstrates that the impacts of mental health issues are substantial in terms of diminished quality of life for individual consumers their Carers and their communities. In this section we have shown a substantial market failure in the provision of mental health services through NDIS in South Australia due to undeveloped market structures and "thin" markets, particularly in regional locations and for some more specific service needs.

The recent report by the Joint Standing Committee on the National Disability Insurance Scheme is also significant and warrants consideration by this Inquiry

We note the following findings and recommendations of the report by the Joint Standing Committee on the National Disability Insurance Scheme: "Provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition"[4]
"As described by participants, both PIR and PHaMs programs support recovery in mental illness and psychosocial disability using a wrap-around approach that facilitates coordination of care and an integrated approach to treatment and support.

4.18 According to Woden Community Services Inc., the transition of funded services to the NDIS such as PIR and PHaMs "has left a huge hole in the service delivery continuum for people with illness. There are now fewer options for people and for service to refer to for support."

The Committee made the following observations about what they termed the "service landscape" which included consideration of transition problems and unserved people.

[4] https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/MentalHealth/Report

4.61 The committee is concerned that for people living with a psychosocial disability the service landscape remains complex and fragmented as services cross both sectors and jurisdictions. Clearly there is a complex intersect between psychosocial disability services and the mental health sector. At present, consumers, their families, Carers and service providers, face confusion and uncertainty about what psychosocial support programs will be available to people outside the NDIS, especially once the transition period has ended.

4.64 The committee acknowledges the particular role that Carers and families have in the support of people with psychosocial disabilities. The Committee supports the view that there is a need for greater clarity around the continuity of support for Carers under the NDIS. As the NDIS does not include direct provision of respite support for Carers, the provision of support for Carers appears to only be available if it is included in the participant's plan. Whilst the Committee acknowledges that elements of the MHR:CS fall within the ILC scope, it is not yet clear how some supports, such as recreational respite activities, will be funded and supported. It is too early to assess how this is affecting Carers but there is already anecdotal evidence suggesting that some Carers will no longer access the level of support they require and had been provided with through the MHR:CS program.

4.65 At systems levels, there is a lack of clarity on how LACs, PHNs and LHNs will ensure people with a psychosocial disability will access NDIS and/or other services. With PHNs not able to commission psychosocial services this may also create a gap in meeting the support needs of some communities, especially in regional, rural and remote areas. The Australian, state and territory governments should urgently clarify and make public how they intend to provide services and funding for ensuring continuity of support and services for people with a psychosocial disability beyond the supports provided through the NDIS. Finally, the NDIA should provide details about the arrangements it has put in place for ensuring a provider of last resort services is available for all NDIS participants unable to find a suitable service provider."

We highlight recommendations from this report which we also believe are germane to this Inquiry and we have included some as part of our recommendations in section 6 of this submission.

Section 5: Responses to Terms of Reference

The following provides some brief responses to the terms of reference for the Inquiry

1. The gap between the Federal Government's predicted and realised percentages of mental health clients receiving NDIS support;

The following data is taken from the recent NDIS, Disability Reform Council quarterly performance report for SA, 30th June 2018. The figure shows the percentage of potential or active participants with a plan approved for various categories of disability.

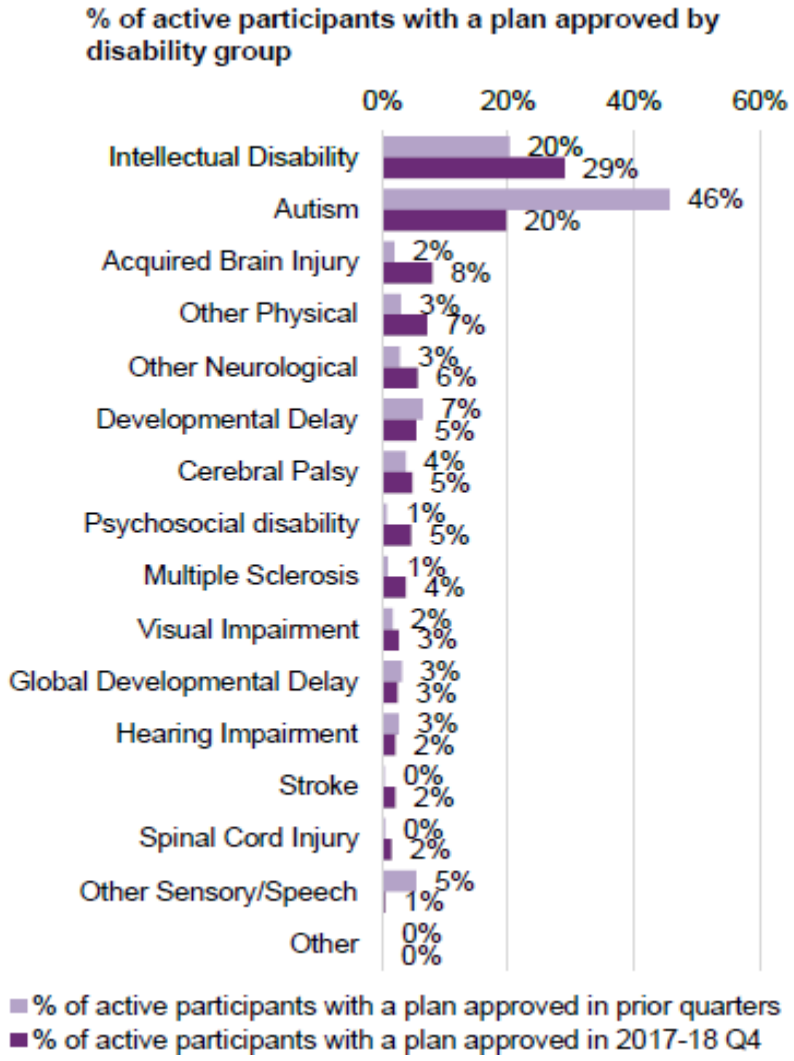

Figure 2, Source NDIS, Disability Reform Council quarterly performance report for SA, 30th June 2018

As of June 30th 2018, 49% of people with an intellectual disability who are likely to be eligible for a plan, actually had one, being 20% of people approved prior to April 2018 and 29% approved during the quarter April to June 2018. This means that 51% of people with an intellectual disability who would be likely to be eligible for one, did not have access to the services that a plan would permit as of 30th June 2018. The rate of plan approval for this

group of people for the June quarter 2018 is encouraging, however the reality that about a half of eligible people were not on a plan is alarming.

For People with Autism the situation is better with 75% of likely eligible people having a plan by June 2018, however, 25% of people with Autism who are plan eligible still did not have access to the services that an approved plan affords. The situation is much worse for people with an acquired Brain injury for whom 10% have a plan, meaning that 90% of likely eligible people do not have a plan, it is a similar situation for people with other Neurological disabilities, for whom only 9% have a plan, and 91% do not have a plan.
This data illustrates the significant gaps between the potential number of people receiving the services that they need though having an approved plan and the actual number of people with approved plans.

A second issue of concern relating to accessibility of plans is activation rates for plans. The data in figure 3 shows the "utilisation of committed supports" in March and June 2018.

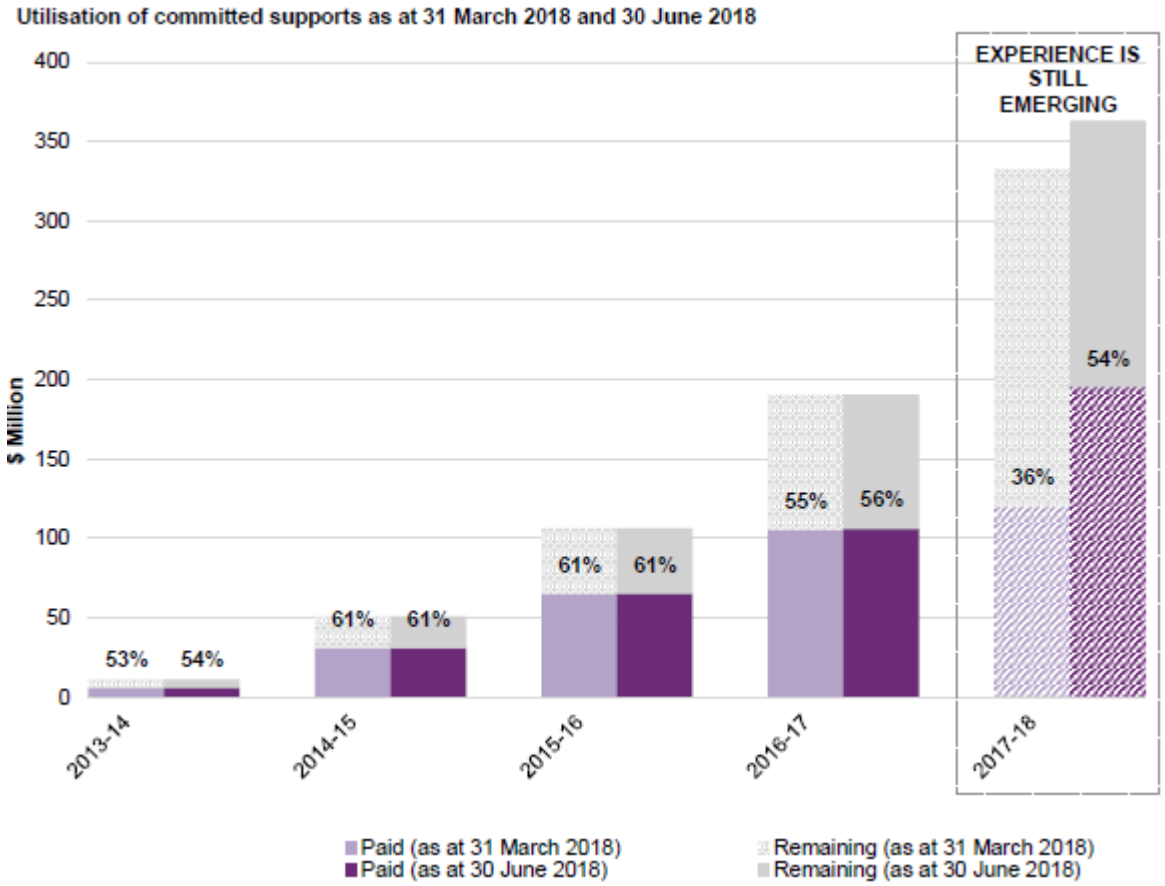

Figure 3, Source NDIS, Disability Reform Council quarterly performance report for SA, 30th June 2018

The data suggests that currently only about 55% of plans are being activated. When coupled with consideration of the percentage of likely eligible people with mental health support needs who have a plan, it is apparent that well below a half of eligible people have a plan that is being utilised.

Since July 2017 no services have been available for people who would be new presenters. In addition to this startling gap. We note the following observations:

- In UC's MHR:CS program about 10% of people who have applied and been unsuccessful in obtaining a service, another 10% have not engaged and not applied.
- PHaMS – not available to new applicants.
- There is no program where people with mental illness can self-refer without going through a clinical pathway. (also Metro Options Uniting SA)
- IPRSS is the only psychosocial recovery program available.

2. The reduction in funding to the Personal Helpers and Mentors program and Mental Health Respite Carer Support program and the impact this will have on people with mental illness;

The Personal Helpers and Mentors (PHaMs) service assists people impacted by severe mental illness with workers providing practical assistance and helping participants to manage their everyday tasks.

With PHaMs services progressively transitioning to the NDIS, the Commonwealth Government is reducing funding for the program under the assumption participants will receive an NDIS plan to access the service.

The Department of Social Security (DSS) told Senator Siewert in Senate estimates, 2018[5]

"Transition to the NDIS extends until 30 June 2019 and further PHaMs clients are expected to transition over this period."

As of 30 June last year, 231 PHaMs clients had been found ineligible for the NDIS, for reasons including include age, residency and not meeting disability requirements.

A total of 158 PHaMS clients had withdrawn access requests, 162 declined to transition into the scheme and 35 failed to return their access request forms.

Community Mental Health Australia's (CMHA) 2018-19 Federal pre-budget submission called for NDIS and mental health reforms to ensure appropriate services were accessible for people living with mental health conditions.

We are also well aware that many PHaMS staff have been made redundant. This is a problem at many levels because not only has expertise be lost to the system where it is just been needed, establish relationships between consumers and services have also been damaged. Note at making it harder for consumers to engage with new services where they are available. For a service provider. It also means that contribute effort will need to be put into retraining the workers win funding again becomes available for services of this ilk.

[5] Sourced from Pro Bono news: https://probonoaustralia.com.au/news/2018/01/people-severe-mental-illness-struggling-ndis-transition/

3. The ongoing requirements for block funded mental health services provided by the State Government after the NDIS transition;

Ongoing funding is critically needed for the following mental health services.

- IPRSS / MHS linked psychosocial programs. Uniting Communities provides IPRSS for people over the age of 65. The NDIS is only available to people under the age of 65 however the state government has committed all of the IPRSS funding. There has been no formal response to this as yet and Uniting Communities seeks an explanation and/or commitment from the state government that people over the age of 65 will not be worse off under the NDIS and that psychosocial services will continue to be available for people over the age of 65.
- Fill the gaps of people not eligible for NDIS
- People who are subject to Section 55 who automatically transitioned over because they were under DHS, may not continue after the first annual review, so NDIS will cease in some cases.
- There is also an immediate need for programs and services to which people can self-refer.

While ongoing dialogue is clearly needed between the Commonwealth, States and consumers, we urge the State Government to ensure that immediate funding is available to ensure that these gaps in services are met during the transition to full NDIS

4. The effects on South Australians with mental health issues who are deemed ineligible to receive NDIS funding;

People with mental health issues who are deemed ineligible for NDIS funding should still be eligible for they are participants Continuity of Support if in a current program. Where this is not the case, for example for those people in PHaMS and MHR:CS who have chosen not to apply for NDIS or who have sought a service since programs in transition were capped, Continuity of Support is not available, and no psychosocial or respite options can be accessed in these mainstay programs. The Carers Gateway is not due until September 2019, so there is a long gap for people who are not currently in a Carer program. IPRSS is still available but is beginning to face transition pressures as well and it is not open to people who prefer to self-refer, anathema for a market based model where the consumer is supposed to be sovereign.

There is urgent need for new places to be available to meet new need during the transition period by augmenting MHR:CS and providing extra psychosocial options.

The Integrated Carer Support Service is not due until Sept 19, so there is a long gap for people who are not currently in a Carer program. MHR:CS has been capped and is essentially unavailable except for those in the program and not yet transitioned. There is urgent need for new place to be available through MHR:CS

5. The sufficiency of services provided to people with mental illness who are accepted into the NDIS;

The expertise of the NDIA planners when developing someones plan is critically important and planners must be qualified and understand the functional impact of psychosocial disability to ensure that appropriate levels of support are included in a person's plan, including support coordination or specialist support coordination.

While there are probably numerically enough service providers to provide supports needed in Adelaide there are not enough effective providers in regional areas, contributing to the thinness of these local markets.

In summary, there are insufficient services available for people with mental illness, who accepted into the NDIS, particularly in regional locations and for people with bespoke needs.

There is also substantial variability in the terms and quality of the services provided through existing plans with support and specialist support coordination not been consistently included in funding for plans.

6. The effects on South Australians with mental health issues undertaking the application process for the NDIS;

There are a number of effects on South Australian's with mental health issues who struggle with the application process for NDIS, these impacts include:

- People not wanting to engage with the system because it is too complex, too daunting or people do not expect they will get the service they need, are being pushed to apply in order to satisfy continuity of support (CoS) requirements, if not eligible for NDIS, or otherwise be left without a service altogether when transition is considered to have been finalised.
- People who are deemed unsuccessful in applications are required to reapply which can be exceedingly stressful and frequently exacerbate existing conditions
- As a service provider, we see the onerous nature of obtaining and producing reports and recognise that they are very costly to produce when there is considerable opportunity to streamline report production
- Many people are dropping out of the process or not activating the NDIS plan when it is approved, this needs to be further investigated by the Commonwealth and State governments.
- There is need for more support by agencies than is currently available, but such support is unavailable for people not currently in a program and some people with mental health needs are not currently able to be considered for services through NDIS.

7. Any other relevant matters.

Access denied explanations:

Clarification and communication as to why a person's access has not been met is required. Often it is due to them not answering the phone or their mail, having the wrong contact details in the system or another minor administrative issue. If additional documentation is required to support their access requirements then this is also needs to be explained.

Access to NDIA staff

Access to the NDIA is difficult and creates a major barrier, increases frustration and results in disappointment and distrust of the scheme. The 1800 number is not an accessible pathway for transparent and easy communication. Having local contacts who are easy to contact via phone or email is vital to ensure improved outcomes of the scheme. Poor accessibility for the National Disability Insurance Scheme is in contradiction to everything that it is supposed to stand for.

Section 6: Recommendations

There have been a number of reviews of NDIS and mental health service provision that are relevant to this enquiry, we have already identified the Joint Standing Committee on the National Disability Insurance Scheme and also recognise the report "the illusion of choice and control" by the Victorian Office of the Public Advocate. We consider both of these reports to be well researched, considered and to accurately reflect our experiences as a service provider.

Each of the recommendations from these two reports have merit for consideration by this Inquiry. We have reproduced the most relevant recommendations below, before concluding this section with our priority recommendations for this Inquiry. The following reproduction of recommendations uses the numbering from the original reports:

<u>Selected Recommendations from the Victorian Office of the Public Advocate</u>

Recommendation 1
The Victorian Government should work with the NDIA to finalise, pilot and roll out the proposed Complex Needs Pathway as soon as possible. Evaluation of the pathway must be outcomes-based and directly informed by the experiences of participants. The evaluation report should be a public document.

Recommendation 2
All services which interact with people with disability, including all places of detention such as prisons and mental health services, should adopt protocols to identify whether people entering their service are NDIS participants or potentially eligible to be so, and to facilitate access requests at the earliest opportunity.

Recommendation 4
The work with the NDIA to enable contingency funding to be immediately accessible when crises arise. This approach would require designated liaison and emergency contact points and procedures within the NDIA (or authorised agencies) which are responsive during and outside of business hours.

Recommendation 7
The Complex Needs Pathway should incorporate a range of safeguards regarding plan implementation. These should include a requirement for support coordinators to provide regular, periodic implementation reports to the person, the NDIA and, where applicable, the person's plan nominee and/or guardian. As well as detailing funds expended, such reports should incorporate participant views and feedback and address outcomes and progress towards goals.

Recommendation 8
The Victorian Government should urge the NDIA to publish, consult on and implement its Maintaining Critical Supports and Immediate Support Response policy and framework as a matter of urgency. This policy and framework should ensure that:

- multiple designated providers of last resort are clearly identified

- providers of last resort are adequately resourced to enable them to respond immediately in situations of market failure which includes having staff available on short notice
- the providers and their staff have specialised experience, skill and expertise that are relevant to the specific needs of participants
- clear procedures exist to guide planners, local area coordinators and support coordinators when the need arises for a provider of last resort to provide any approved support (not just 'critical' supports)
- participant plans have built-in flexibility for situations in which a provider of last resort is required, including the ability to access contingency funding
- as soon as possible, participants are transitioned back to support outside provider of last resort arrangements
- provider of last resort mechanisms continue to exist beyond full rollout of the NDIS (and are not just a temporary or artificial market artefact during transition).
-

Recommendation 9
The NDIA and Australian and Victorian Governments should publicly clarify who is responsible for ensuring that individual participants receive their funded supports. This responsibility must continue to be clear once the NDIS is fully rolled out.

Recommendation 10
The NDIA should provide direct assistance to support coordinators who are struggling to navigate thin markets and support people with complex needs.

Recommendation 12
The NDIA, in conjunction with the Australian and Victorian Governments, should adjust market mechanisms and policies (including the pricing framework) to stimulate and ensure the existence of sufficient numbers and diversity of crisis accommodation providers, and should also ensure that sufficient funds are provided so that Specialist Disability Accommodation provision is able to meet existing and future demand.

Recommendation 13
The NDIA should commission the provision of crisis and respite accommodation for participants who need accommodation at short notice.

Recommendation 14
The NDIA's Maintaining Critical Supports and Immediate Support Response policy and framework should specifically address and provide guidance in relation to Specialist Disability Accommodation and crisis accommodation providers of last resort. The framework should include a vacancy management strategy for providers to prioritise clients with the most urgent need.

Recommendation 15
The Australian and Victorian Governments should enact legislative and other safeguards to provide security of tenure and other rights protections for all forms of accommodation used by NDIS participants, including Specialist Disability Accommodation.

Selected Recommendations from Joint Standing Committee on the National Disability Insurance Scheme:

Recommendation 6
The committee recommends clients currently receiving mental health services, including services under Commonwealth programs transitioning to the NDIS, namely Partners in Recovery (PIR), Personal Helpers and Mentors (PHaMs), Day to Day Living (D2DL, and Mental Health Respite: Carer Support (MHR:CS), should not have to apply for the NDIS to have guarantee of continuity of supports and access services.

Recommendation 8
3.83 The committee recommends the Department of Social Services and the NDIA collaboratively develop a plan outlining how advocacy and assertive outreach services will be delivered beyond the transition arrangements to ensure people with a psychosocial disability and those who are hard-to-reach can effectively engage with the NDIS and/or other support programs.

Recommendation 10
3.85 The committee recommends the NDIA develops an approach to build flexibility in plans to respond to the fluctuating needs of participants with a psychosocial disability, including allowing minor adjustments to be made without the need for a full plan review.

Recommendation 13
4.67 The committee recommend the Australian, state and territory governments clarify and make public how they will provide services for people with a psychosocial disability who are not participants in the NDIS.

Recommendation 15
4.69 The committee recommends the National Mental Health Commission be appointed in an oversight role to monitor and report on all Australian, state and territory mental health programs and associated funding, including those delivered through the primary healthcare sector.

Recommendation 16
4.70 The committee recommends the Department of Social Services and the NDIA develop an approach to ensure continuity of support is provided for Carers of people with a psychosocial disability, both within and outside the NDIS.

Recommendation 17
4.71 The committee recommends the NDIA in collaboration with the Australian, state and territory governments develops a strategy to address the service gaps that exist for rural and remote communities."

Priority recommendations

Noting these recommendations and our comments given above, the following are Uniting Communities' priority recommendations for South Australia, for immediate implementation.

Recommendation 1
That a provider of last resort is urgently appointed and resourced to ensure that in the short term people needing mental health services in South Australia who are not receiving them through the transition to NDIS, receive the services they need.

Recommendation 2
That clients currently receiving mental health services, including services under Commonwealth programs transitioning to the NDIS, namely Partners in Recovery (PIR), Personal Helpers and Mentors (PHaMs), Day to Day Living (D2DL, and Mental Health Respite: Carer Support (MHR:CS), should not have to apply for the NDIS to have guarantee of continuity of supports and access services.

Recommendation 3
The SA Government should continue to act as support coordinator of last resort to ensure that services are available for people who need them.

Recommendation 4
That the SA government urges the NDIA to provide direct assistance to support coordinators who are struggling to navigate "thin markets" and to support people with complex needs.

Recommendation 5
The SA Government should highlight to the Commonwealth Government and NDIA the shortcomings of application of market model assumptions for thin, emerging and transitioning markets and develop policies and practices that respond to market failures.

Recommendation 6
That the SA government work with the NDIA to enable contingency funding to be immediately accessible when crises arise. This approach would require designated liaison and emergency contact points and procedures within the NDIA (or authorised agencies) which are responsive during and outside of business hours.

Recommendation 7
The committee recommend that clients currently receiving mental health services, including services under Commonwealth programs transitioning to the NDIS, namely Partners in Recovery (PIR), Personal Helpers and Mentors (PHaMs), Day to Day Living (D2DL, and Mental Health Respite: Carer Support (MHR:CS), should not have to apply for the NDIS to have guarantee of continuity of supports and access services.

Recommendation 8
That the SA Government encourage the NDIA to develop an approach to build flexibility in plans to respond to the fluctuating needs of participants with a psychosocial disability, including allowing minor adjustments to be made without the need for a full plan review.

Recommendation 9
That the Complex Needs Pathway incorporate a range of safeguards regarding plan implementation. These should include a requirement for support coordinators to provide regular, periodic implementation reports to the person, the NDIA and, where applicable, the person's plan nominee and/or guardian. As well as detailing funds expended, such reports should incorporate participant views and feedback and address outcomes and progress towards goals.

Recommendation 10
That the SA Government commit to funding so that people over the age of 65 will not be worse off under the NDIS and that psychosocial services will continue to be available for people over the age of 65 years.