Mental Health Coalition
OF SOUTH AUSTRALIA

Submission:

SA Parliament Social Development Committee: The provision of services for people with mental illness under the transition to the National Disability Insurance Scheme (NDIS)

Mental Health Coalition SA (MHCSA)

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Introduction

The Mental Health Coalition of SA (MHCSA) values the opportunity to make a submission in relation to the provision of services for people in SA with mental illness under the NDIS transition. We would appreciate the opportunity to appear before the Committee to discuss our submission further.

The MHCSA has over 20 organisational members and provides a unified voice for the Community Managed Mental Health (CMMH) Sector in South Australia. The CMMH Sector comprises non-government organisations that deliver mental health services and work with people with mental illness and their families and carers across the state. The MHCSA work includes a strong focus on supporting and growing the Lived Experience Workforce and promoting positive messages that support people to improve their well-being and reduce stigma and discrimination.

The MHCSA Vision is that all people with mental illness in South Australia and their families will receive the mental health support they need when and where they need it. The MHCSA promotes a recovery approach meaning the goal of support is to assist people living with a mental illness to build a contributing life in the community including social and economic participation.

Context

There are approximately 230,000 people in Australia who need individual support in addition to the 64,000 people who are the target for NDIS support due to psychosocial disability. For South Australia this equates to 18,400 and 5,120 respectively (based on 8% of Australian population) We know that prior to NDIS, the combined Commonwealth and State investment in psychosocial support was supporting only a small proportion of this total number. We also know that 50% of successful applicants to NDIS with primary psychosocial disability are new to the system (Eddie Bartnik, NDIA 2017). To assume that the health system currently knows everyone who needs psychosocial support is incorrect. The numbers transitioning from existing mental health programs is only a small proportion of the total number of people who need psychosocial support. So, to plan to reduce funding for mental health programs in proportion to numbers eligible for NDIS supports is not good mental health policy. Maintaining investment in existing mental health services as NDIS rolls out is an appropriate policy

response as this would maintain capacity to provide more people with the psychosocial support they need. This is the prudent approach that the SA Department for Mental Health and Wellbeing is taking. Unfortunately other agencies are not and this is adding to the pressure and stress that was evident in the feedback we received.

What we need is a comprehensive, integrated mental health system that includes community supports in addition to NDIS, primary and tertiary care to adequately support South Australians living with mental illness. Any service re-design should focus on the social determinants of health and incorporate co-design with people with lived experience of mental illness and carers.

The NDIA recently announced the new Psychosocial Disability Stream as part of the Complex Needs Pathway[1]. The announcement stated that many of the recommendations of a report by Mental Health Australia "National Disability insurance Scheme: Psychosocial Disability Pathway, May 2018"[2] would be taken up. Several of the recommendations in this submission are reflected in that report and the NDIA response. The MHCSA is gratified to see that some issues are being addressed. We remain concerned, though, that other critical issues such as pricing remain unaddressed. The NDIA response has a heavy emphasis on skilling internal staff to redress Access and Planning issues. Given NDIA staff caps and the cost of internal staff, timeliness will remain an issue.

Summary of Recommendations

Each Terms of Reference has a list of recommendations. Some are repeated, with slightly different focus. The list below reflects the recommendations combined.

Commonwealth Programs Transition and the Gap in Estimated Percentages

The Commonwealth Programs Transition process is creating significant gaps. These recommendations are proposed as a way for the State to seek better outcomes from the Commonwealth both during and after full Transition.

1. Seek clarity about the accurate number of people transitioning from Commonwealth programs into the NDIS
2. Advocate that both CoS and NPS be re-calibrated to reflect accurate numbers and funded accordingly.
3. Advocate that funding for CoS within Commonwealth funded programs continues until the CoS measure is fully operational through PHNs and program participants can transition across without losing a service.
4. Advocate that Carers continue to receive support through the MHR:CS program until the Integrated Carer Support Service (ICSS) is fully operational and support for Carers is available through that service.
5. For rural and remote areas, consider an integrated State/NDIS strategy to address thin markets.

[1] https://ministers.dss.gov.au/media-releases/3691

[2] https://mhaustralia.org/sites/default/files/images/ndis_psychosocial_pathway_consultation_project_-_final_report_-_may_2018.pdf

Block Funded Services Provided by the State after the NDIS Transition, for South Australians not Eligible for NDIS

Mental Health Services have always been underfunded relative to need and the most underfunded area is in community supports. NDIS aims to support a small percentage of people with mental illness. State funding for community support will be even more important after the Transition to help people with mental illness to stay well and build a better lives in the community. The evidence is clear that this will also reduce their reliance on emergency and acute services. The following are recommendations that are largely within State control.

1. State use the NDIS Taskforce chaired by the Chief Psychiatrist to develop an accurate picture of who needs psychosocial supports in SA and what their service needs are, thinking beyond known consumers. For example considering services that will reduce ED presentations and hospitalisation. Fund accordingly, considering the economic and social benefits.
2. For rural and remote areas, consider an integrated State/NDIS strategy to address thin markets.
3. Co-design services with people with lived experience of mental illness and Carers.
4. Reinstate programs that have known positive outcomes, such as crisis respite.
5. Ensure that Commonwealth CoS and NPS measures integrate with the State mental health services.
6. Ensure clear, timely and accessible entry points to services.

State Funded Programs Transition, Including Housing Considerations

State funded programs were designed and funded to solve particular problems in our mental health system. There is no analysis to suggest that these issues will disappear with the introduction of NDIS. There is no evidence to suggest that there is lessening demand for the current services with our data showing over 40% new clients in NGO services in the 2017/8. Ensuring good coordination of housing and support remains an important component of mental health services. Some people currently supported in State programs have come from highly institutionalised settings and some have complex illness, co-occurring conditions and/or behaviours. For some of these processes of deinstitutionalisation, such as Returning Home, families were promised by the State that their loved ones would receive continued support. There is high risk that defunding State programs will lead to higher levels of insititutionalisation and homelessness as our capacity to support people in the community declines.

1. Continue to fund State programs at the current level for at least another twelve months beyond 1 July 2019, to give time to properly quantify need and design services for the future.
2. Maintain transparent communication about the transition process and make reports public.
3. Measure impact for people found ineligible for NDIS. This could be done in partnership with the NDIA.
4. The State considers the implications of housing specifically relevant to mental health and devise a plan to address including a housing and support program (HASP or similar).

The Access and Planning Process

The changes announced by the NDIA should lead to some improvements in this area. Our feedback proposed the following recommendations.

1. Advocate for flexible pathways to test eligibility for people to access NDIS, with shared strategies to connect with people who have no natural or planned supports and cannot or will not apply. Alternative gateways could be through service providers working in partnership with LACs or NDIS if that works best for clients.
2. Block fund supports to help people access NDIS – through the access and planning processes.
3. Work with people with lived experience to modify NDIS language so it is accessible to potential participants, rather than expecting people to learn NDIS language.

Sufficiency of Services in NDIS

The NDIS is broad and covers a wide range of disabilities. It was not designed specifically for people with psychosocial disability and has generic requirements for service provider skill levels. This means that our current appropriately skilled and experienced workforce is too expensive to deliver the bulk of the support in NDIS plans.

1. Advocate that NDIA co-design a reference package (or several) for psychosocial disability with consumers and carers. The package should be flexible enough to meet the individualised needs of participants and include provision for Capacity Building supports, case management if needed and episodic needs that can be instigated in a timely fashion.
2. Advocate that NDIA re-evaluate the need for case management that should be provided by a service provider that the participant has rapport with and trusts. This could be a modification of Complex Support Coordination, and require experience in case management along-side Certificate IV in Mental Health or Certificate IV Mental Health Peer Work.
3. Advocate for a review of the Price Guide to cater for skilled mental health and peer support workers at SCHADS level 4, with adequate training and practice supervision – packages may well cost less to deliver or are likely to decrease over time as participant become more skilled in managing their own recovery.
4. Up-skill LACs and/or employ mental health specialist LACs in each region.
    a. ***Note:*** this has recently been announced as part of the Psychosocial Disability Stream included in the Complex Needs Pathway[3].

Any other relevant matters

Other matters raised in our feedback included the need to develop a specific State plan to address housing. Our feedback also called for advocacy to the Commonwealth for a higher hourly rate to enable appropriately skilled workers to provide Capacity Building services. There are a range of issues and problems raised regarding planning wait times and process. Improvements should follow the NDIA

[3] https://ministers.dss.gov.au/media-releases/3691

announcement of the new Psychosocial Disability Stream and our feedback called for ongoing monitoring and public reporting of progress.

Recommendations:

1. The State considers the implications of housing specifically relevant to mental health and devise a plan to address, including a housing and support program (HASP or similar).
2. State supports the addition of a new Capacity Building rate paid at SCHADS level 4, to take in Mental Health Support Workers and Peer Support Workers.
3. Advocate that the new Psychosocial Disability Stream be reviewed at regular intervals, engaging with participants, carers and service providers. Results should be transparent and made public.

Specific Terms of Reference

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

The original Bi Lateral Agreement was silent on mental health and yet Commonwealth programs attempted to transition from 1 July 2017 at the same time as disability programs in SA. The second Bi Lateral agreement assumed all South Australians in specialist disability programs (which apparently includes Commonwealth mental health programs) will be transitioned by June 2019. 104 people with a primary psychosocial disability entered the NDIS during the quarter to 30th June 2018 (SA Performance Report, P10)[4] and there were 227 people in total with active plans. The evidence suggests we are unlikely to meet Bi Lateral targets.

MHCSA has collected data for the past three years and in FY18 we asked the 10 participating organisations to tell us how many people were in their programs, where they exited to, how many made Access requests; were successful in their application and also exits to NDIS. With a sample of 3,511 participants across 14 programs at the end of June 2018, 34% had submitted an NDIS access request, and 12.7% had been found eligible with 1.7% had exited to NDIS. The difference between the 'eligible for NDIS' figure and the 'exits to NDIS' figure is explained by a number of steps (which take time) between achieving eligibility for the NDIS and actually receiving support via the NDIS. The exit to NDIS figure represents the point at which the mental health service provider is aware that support is being received via the NDIS.

There have been about 40% new clients in programs in FY18 – meaning about 40% of participants have exited the programs during the year. The exit destinations are diverse including to GP care, commonwealth and/or state psychosocial programs and Community Mental Health. Some were exited to no ongoing care indicating that for many people the short-term psychosocial support was effective and long-term support is not required.

DSS had originally indicated that 80-90% of PHaMS participants would be eligible for NDIS. This has dropped to about 70% in more recent DSS/NDIA presentations. The quantum of funding allocated for Continuity of Support and the NPS measure appears predicated on outdated Commonwealth estimates. In total, CoS and NPS measure funding will total less than 10% of previous Commonwealth spend across

[4] https://www.ndis.gov.au/medias/documents/sa-performance-aug-18/SA-Performance-Report.pdf

mental health programs. A 2017 Senate Estimates response indicated that nationally about 32% of applicants were deemed eligible[5] for NDIS from PHaMS programs that had transitioned in the 16/17 year and the MHCSA sample indicated 26% as at 30th June 2018. We expect that 26% to rise, but we don't know what the final percentage will be, however it is likely to fall well short of the original estimates from the Commonwealth. In this context, the National Psychosocial Service (NPS) and Continuity of Support (CoS) funding appears inadequate for the number of people likely to need supports other than NDIS. Funding for CoS and NPS is to go through Primary Health Networks and for the most part services are not yet defined in South Australia, while funding for PHaMS and Mental Health Respite: Carer Support will cease at 30th June 2019.

We must also consider that about 50% of entrants to the NDIS with a primary psychosocial disability are not previously known to the mental health system. With the end of Commonwealth mental health programs, we are likely to see a greater pressure on mental health services in the state For this reason, MHCSA believes that the Commonwealth should provide reassurance to SA that it is willing to re-calibrate funding for CoS and NPS appropriately.

Feedback from NGO Providers and people with lived experience:

- Eligibility criteria is still not clear and interpreted differently by different Assessors, LACs and Planners. This is affecting the proportion of people deemed eligible for the Scheme.
- There are few people transitioning from programs than was originally envisaged.
- The impact of reduced funding based on incorrect assumptions about transition rates and numbers has had a significant impact on service clients, staff and service providers.
- The lack of clarity about Continuity of Support and the shape and funding for the mental health supports in the community, other than NDIS is an added stress for clients who don't know if there will be any supports for them if their NDIS application isn't successful.

Recommendations:

1. State seek a clear indication of percentages of people who have or are likely to transition to NDIS from Commonwealth funded programs. This percentage should not include an assumption that all people who have disengaged or who could re-submit their application will be successful.
2. State seek assurances from the Commonwealth that Continuity of Support and NPS funding be re-calibrated to enable capacity for NGOs to support the numbers of people not gaining access to NDIS (including people unable or unwilling to apply).

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;

At the end of June 2018 there were 227 people with psychosocial disability who had active plans (NDIA SA Dashboard, P1)[6] and yet funding for DSS funded programs was to reduce by 50% at 1 July 2018. In July DSS offered to return funds based on point in time data at 1 July which has been helpful for organisations that didn't exit clients or make staff redundant. At time of writing some service providers

[5] Source: Senate Community Affairs Committee, Answers to Estimates Questions on Notice, Social Services Portfolio Question No: NDIS SQ17-000236

[6] https://www.ndis.gov.au/medias/documents/sa-dashboard-aug18/SA-Dashboard.pdf

have had reasonable funds returned while others have not. The result is that there are already people out there who have lost services, and skilled and qualified staff potentially lost to the sector.
The Integrated Carer Support Service is not yet out to tender, let alone implemented. With current timelines, MHR: CS will cease before the Integrated Carer Support Service (ICSS) is fully available to Carers. The remainder of MHR:CS funding is due to transition in November 2019.

In the MHR:CS program the appropriate exit point for the Carer is when the Carer is actually receiving support via the yet to be established ICSS. This means that the contracts to provide the services need to be let, the service needs to be established, the Carer needs to have applied and been deemed eligible and only exited from MHR:CS when actually receiving support through ICSS. This does create a layer of complexity because we are managing transition to two programs – NDIS for the consumer and ICSS for the Carer.

Feedback from NGO Providers and people with lived experience:

- In one service, 12 out of 83 people living with mental illness in MHR: CS currently have a plan. Five have been deemed ineligible. When Consumers leave MHR:CS, their Carer is no long eligible for support through the program.
- Some PHaMS participants are clear they do not want NDIS. Reasons include –
    - Feeling traumatised by the experience of having to gather evidence
    - Don't believe they need life-long support and therefore feel applying is a waste of their time.
- That 'a diagnosis is not required for NDIS is misleading'. Access requires that "all treatment options have been exhausted" meaning the disability will be life-long. Neither PHaMS nor MHR:CS require a diagnosis and so meeting this requirement is often problematic.
- CoS through PHaMS and MHR:CS is available until 30th June 2019. It is not clear what will happen to these people if CoS and NPS are not fully implemented by then, or there are more people needing CoS than funding allows for.
- The risk that people will go into crisis due to concerns about supports is real, for carers and consumers.
- The role of MHR:CS is to support carers in their informal caring role. Loss of this service without something equally as effective jeopardises both the Carer and care recipient.

Case Example 1
Regional PHAMS programme is based in the Riverland with the additional complexity of applicants not being connected into medical services makes collection of evidence around permanence very tricky.

Roughly 50% of that program's clients have been deemed ineligible, with only one choosing to appeal/re-submit.

Recommendations:

1. State Carer Support funding continue at least until the Integrated Carer Support Service is fully implemented.
2. State negotiates with the Commonwealth to gain commitment to funding MHR:CS until Carers are actually receiving supports through the ICSS.

3. The State negotiate funding for Continuity of Support and the National Psychosocial Measure that is commensurate with the number of people who will need support beyond NDIS.

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

In Victoria, the loss of psychosocial support funding resulted in 19% increase in ED presentations. The Victorian Government has now returned $70m to fund community mental health supports. MHCSA believes we should heed the lessons from other states.

Mental illness is responsible for 24% of the non-fatal disease burden in SA and yet only 7.1% of mental health funding was spent on NGO delivered services in the community in 2016. We've dropped below the national average for the first time in 10 years.

We know that psychosocial support programs keep people out of hospital and keep them well. For example supporting 33 people in the IPRSS program reduces their demand on hospital beds by the equivalent of 1 bed for an entire year. The evaluation of the Intensive Home-Based Support program indicated that cost offsets of reduced hospitalisation would more than pay for the cost of the service over time. There is good economic sense in retaining existing levels of support services in the community.

The proportion of people transitioning into NDIS from existing services is very different from original estimates and varies from program to program. MHCSA data for FY18 showed that at the end of June the proportion of people who applied and were deemed eligible for NDIS in the PHaMS program was about 26%[7], with 51%[8] of total PHaMS participants having tested eligibility at that time. Current data provided by the DCSI Transition Team[9] is showing that eligibility rates to date for NDIS varies considerably between State funded program types – from 6% in Mutual Support and Self-Help groups to 51% in a Housing and Support program. It is also worth noting that at this stage in the transition of State funded programs, many of the successful transitions are due to intensive effort on the part of SA Health, NDIA and NGO support agencies to transition people with the highest need across. If services are de-funded, the capacity to support people into NDIS will decline.

Of concern is the issue of people receiving housing and support together transitioning to NDIS where their NDIS packages typically cover support only – the contracted relationship between a housing provider and support provider is lost in the transition. SDA housing is unlikely to be available to many people receiving psychosocial disability supports, and for the most part is inappropriate for this cohort given that they are for the most part group homes. There are significant risks regarding the transition for people who currently receive coordinated housing and support packages.

[7] 26% is based on people who have had eligibility confirmed /eligibility tested. It doesn't mean they have an active plan.

[8] Based on the number or people who have tested eligibility/the average number of people who were in the program at the beginning of each month for the year

[9] "Summary of State Mental Health client transition – 15 October 2018". Provided to the NDIS Taskforce chaired by the Chief Psychiatrist.

Providers are reporting that as clients transition to NDIS, they still need "top up" services from their block funded program because the NDIS plan is not meeting their needs. This is unsustainable and sets up a falsely positive perception that the NDIS plan is meeting the needs of the participant.

In addition, there are some people who will probably be eligible for NDIS but due to mental health or cognitive issues, simply can't or won't undertake the application process. This is not because of a lack of support or effort on behalf of service providers or Community Mental health teams – it is simply the case that for some people, the journey to NDIS will be a long one. The mental health system must continue to support these people. See Attachment A for a case story to illustrate.

Feedback from NGO Providers and people with lived experience:

- Services are providing psychosocial support to NDIS clients who have transitioned from their programs because NDIS services are inadequate – this decreases support available to other clients.
- There will be a greater reliance on State funded services as Commonwealth funded services end.
- Many people who are not eligible for NDIS will have nowhere to go, given that the funding for CoS and NPS are inadequate to meet the emerging need.
- Section 55 data suggests that there are 1,800 people being supported by State funded mental health services. There are more than 1,800 people in SA who need supports.
- People have NDIS plans that don't meet their needs and need reviewing. Reviews currently are taking too long to complete, leaving participants without appropriate supports.
- The transition data is showing that fewer people are transitioning than expected.
- People who are ineligible may still have complex support needs.

Case Example

An *InDaily* article published 26th October[10] discussed a story of a man who completed suicide 3 days after discharge from hospital.

"Corcoran said he hoped that early, unsafe discharge had not been responsible for any deaths in Adelaide, but there was anecdotal evidence that the focus on "bed flow" was increasing the proportion of patients returning to hospital soon after being discharged."

(Maurice Corcoran, Principle Community Visitor)

The pressure on the acute care system can be partly alleviated by a strong complimentary community support system that is accessed as part of discharge (and hospital avoidance) and offer assertive outreach support. The Intensive Home-based Support Service does that and formal evaluation showed that 63% of participants said it kept them out of hospital (safely). It is critical that SA continues to provide block funded mental health supports that meet the needs of particular cohorts.

Recommendations

1. State seriously consider the economic and social value of funding services in the community at a higher proportion of budget to date.
2. State develop an accurate picture of who needs psychosocial supports and fund accordingly, thinking beyond known consumers - that there are a number of people who need support but are not currently accessing programs.

[10] https://indaily.com.au/news/local/2018/10/26/a-lost-map-an-early-discharge-and-a-tragic-death-in-adelaides-south/

3. Increase State funded mental health services in the community to reduce ED attendance and admissions.
4. Reinstate programs that have known positive outcomes, for example Crisis Respite.
5. Block fund case management.
6. State advocate that CoS and NPS funding from the Commonwealth be reviewed in the light of accurate numbers of people transitioning from Commonwealth programs to NDIS.
7. To reduce reliance on "top up" support from the State, advocate the flexibility in NDIS plans for participants to move funds between Core Supports and Capacity Building in the same way that self-managing participants can.

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

It must be highlighted that the NDIS was designed to target only a relatively small percentage of people with severe mental illness who also had significant associated disability. This made sense at the time, when we also had a range of Commonwealth and State funded psychosocial services for other cohorts of people with severe mental illness. The subsequent decision to help fund the NDIS by significantly reducing capacity in psychosocial supports via the mental health system was disastrous. Without clear evidence that there will be services available post the NDIS roll-out, people who are found ineligible will face a mental health system with less options and less capacity. CoS in Commonwealth funded programs is only available until June 2019 (at which time CoS is planned only to be available via PHNs). The recent huge drop in DSS funding left many participants without supports or limited supports as providers reduced staff to absorb to meet new funding levels. The July response from DSS was, for many people, too little too late and people exited from programs are not eligible for CoS.

There is clear evidence that the CoS and NPS measures will not meet the needs of people in Commonwealth programs after June 2019 and those measures are yet to be designed. State funding is only guaranteed until June 2019 and while SA Health has been proactive in seeking to accurately measure future need, we are unlikely to have a clear idea in time for the June deadline.

Feedback from NGO Providers and people with lived experience:

- The predicted proportion of people eligible for NDIS is lower than first projected (evidenced in Commonwealth funded program transitions)
- Reports from PHaMS workers that being rejected by NDIS is a worry and stressful for participants. People fear what they will do without their worker.
- Impact for consumers and carers (as reported by people with lived experience and program staff)
    - Stress and potential trauma of going through the eligibility process and then facing rejection
    - Impact on emotional wellbeing – a sense of hopelessness and not knowing where to go next as services are progressively defunded and CoS is limited.
    - Loss of connection in the community
    - Impact on self-esteem, self-worth – no choice and control
    - People may lose faith and reject all services
- Limited options available in rural and remote areas for specific target groups, eg CALD.
- Small dollars for CoS and NPS – unable to reach all geographical locations in SA
- Strain on GPs, EDs and treatment services will increase with limited psychosocial supports.

Case Example 1
"We were given plenty of notice about the NDIS, but nobody knew how NDIS was going to work. We were told there would be funding to help with the services we needed and to help with appropriate services and it was available through application to the NDIS. But all it did was create upheaval and confusion.
NDIS may have had good intentions but failed remarkably.
The questions we had to answer showed little understanding of those with a mental health condition of schizophrenia, or other conditions. It was personally invasive – I did not like the process one bit.
I failed the process – I was living too well even though I was in the middle of the recovery process. It did not meet my needs. I slipped through and I am now left wondering how I am going to handle my disabilities in the future because this is a life-long condition."
Service user attending a Sound Minds group

Case Example 2
SAFKI PIR Client received a letter on Friday afternoon. Very distressed – was alone and had no supports and felt totally "rejected". Didn't cope over the weekend, felt they hadn't been listened to/ acknowledged again. "I am invisible, my disability is invisible, they think I am lying…I can't cope – what am I supposed to do now?"
Feedback from SAFKI PIR client to supporting service provider

Case Example 3
SAFKI PIR client received a letter stating ineligible due to lack of permanency (24.1 of the NDIS Act). This client was very angry and spiraled into having an episode of being mentally unwell for the next two weeks. She could not sleep, felt rejected. The client attended the (NDIS) forum so that she could have her say, as she believes many people are in the same position as her. There is no information forthcoming about what information she will receive – this is waiting 5 months after being told she was ineligible.
Feedback from SAFKI PIR client to supporting service provider

Recommendations:

1. Continue to fund State programs at the current level for at least another 12 months beyond 1 July2019, to give time to properly quantify need and design services for the future.
2. Appropriately block fund programs that support this cohort with clear, timely and accessible entry points.
3. Maintain transparent communication about the transition process – issues encountered and strategies to resolve.
4. State advocate that the NDIA conducts a twelve-month review of individuals found ineligible for NDIS supports, to gather impact data and consider validity of the initial decision.

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

Sufficiency of services means two things – that NDIS plans actually meet the needs of Participants, and that what can go into a plan and the linkages to mainstream and other services are effective.

Service providers have reported that often plans have a high dollar value but that most is coded to Core Supports, when participants need Capacity Building. This reflects a lack of understanding of the needs of

people living with psychosocial disability. Some Support Coordination is "in kind" meaning the participant is obliged to use a particular provider such as Disability SA. Service providers are reporting several months wait for Support Coordination from in-kind providers, meaning plans are not properly implemented and participants are left without support.

Psychosocial rehabilitation support has typically been provided by Certificate 4 qualified staff paid at SCHADS award level 4. NDIS requires only a Certificate 3 disability qualification (or none) and the pricing has been developed using SCHADS award level 2 as the guide. This is affecting the quality of service that can be provided and is unsustainable. The risk is that participants become more disabled as workers "do for" rather than "do with" participants in a way that builds agency.

Feedback from health professionals interviewed by Mental Health Australia offered the following feedback about psychosocial disability –

- "The NDIA engagement does not accommodate their disability
- The NDIA lacks a recovery-oriented and strengths-based approach, instead focusing on core supports, which generates long-term dependence (and costs) on the NDIS
- When mismanaged, NDIS processes can undermine wellbeing rather than promote recovery"[11]

There is no psychosocial-specific assessment tool used in the planning process and to date there are no reference packages for psychosocial disability. NDIS participants, Carers and service providers all report that Planners ask questions that appear to be more relevant to physical disability. This is likely a major contributor to plans that fail to meet the needs of participants.

The feedback we have received highlighted that the skills of Assessors, LACs and Planners are inadequate in complex cases. This has been reported numerous times and the NDIA have recently announced the intention to up-skill NDIA and LAC partner staff - this will be particularly critical for new people entering the Scheme. In the meantime, NDIA and LACs could engage the expertise of service providers who overwhelmingly have the interests of their clients at heart.

Feedback from NGO Providers and people with lived experience:

- The majority of supports other than Support Coordination, are Core Supports rather than Capacity Building. Core Supports are intended to support a person to complete activities of daily living or accessing the community, while Capacity Building supports are aimed and supporting a person to build skills in doing these things for themselves.
- The quality of plans is as variable as the skills of the Planner or LAC. Plans appear to be developed by people who are not skilled in mental health and may not have the skills to draw out the true needs of a participant.
- Providers are unable to retain skilled and qualified mental health and peer support workers at the rate indicated in the NDIS Price Guide. This is a critical issue when supporting people with complex needs.
- There are already thin services in rural and remote areas. Service providers report that it is often not viable to continue service with very small staff in rural and remote areas. Issues

[11] MHA: "National Disability Insurance Scheme: Psychosocial Disability Pathway", May 2018, p23

include physical infrastructure, program leadership, effectively supporting staff, and travel costs (especially traveling to remote sites).

- Inadequate funds for travel means that quality of service in rural and in particular remote regions may be affected.
- Case management is not included in plans. NDIS funds Support Coordination in many psychosocial disability plans but this role connects the participant to services but has no role in case management.
- There is inadequate funding to educate people on the benefits of supports. There is a risk that if a participant refuses supports there is little room to explore reasons, motivation or the right fit for the person.
- There is a risk of exploitation by unscrupulous providers, especially given the NDIA does not require a base qualification for support workers.

Case Example 1
Individual Psychosocial Rehabilitation Support Service (IPRSS) client has received a plan with no support coordination and he does not have a clue where to start. His plan does include "Aquaponics horticultural support". The plan suggested that support can be funded to teach a support worker alongside the client to learn how this works and then support him in the future. Upon looking at the client's IPRSS support plan, he has a hydroponic set up in his unit to grow veggies. The client doesn't know where to begin to find such a support worker. The support provider found it very strange that NDIS funded this type of activity when it is closely linked to the growing of cannabis, and that there was no funding for support coordination when the client clearly needs it.
(provided by service provider)

Case Example 2
HASP client discharged from Eastern Community Mental Health once they received their NDIS package, on the assumption that NDIS would provide case management. For example, they thought they had no role if the person refused services when unwell. This has become an un-funded support by the NGO providing support coordination services.
(provided by service provider)

Case Example 3
Metro Options (State funded program) client transitioned to NDIS with a $150,000 NDIS plan that was largely unusable. The plan included many hours of Core Supports and very little Capacity Building. His mother reported that he would be overwhelmed with so many hours of contact, when what he needed was half the hours per week, of skilled support to help him make decisions about his daily activity, together with effective case management when he needed it.
(provided by service provider)

Case Example 4
"I have an NDIS plan. The majority of this funding is locked into Core Support with the concept that people do things for me and due to physical limitations this is needed but capacity building barely gets a look in and it is through capacity building that I am likely to develop and grow, to move from suffering life to experiencing life. By building capacity the concept of recovery can become a reality giving strength to step forth to see myself as a master of my own life not a victim of it."
JB – NDIS Participant and poet

Recommendations:

1. Advocate that NDIA re-evaluate the need for case management that should be provided by a service provider that the participant has rapport with and trusts. This could be a modification of Complex Support Coordination, and require experience in case management along-side Certificate IV in Mental Health or Certificate IV Mental Health Peer Work, rather than assuming a professional qualification (eg. OT, Social Worker) is required.
2. Advocate that NDIA co-design a reference package (or several) for psychosocial disability with consumers and carers. The package should be flexible enough to meet the individualised needs of participants and include provision for Capacity Building supports, case management if needed and episodic needs that can be instigated in a timely fashion.
3. Advocate for a review the Price Guide to cater for skilled mental health and peer support workers at SCHADS level 4, with adequate training and practice supervision. Taking case example 3 above as a guide – packages may well cost less to deliver or are likely to decrease over time as participant become more skilled in managing their own recovery.
4. Up-skill LACs and/or employ mental health specialist LACs in each region.
    - ***Note:*** this has recently been announced as part of the Psychosocial Disability Stream included in the Complex Needs Pathway[12].

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

There are no "defined" mental health programs and therefore all participants must test their eligibility to access the NDIS. All Commonwealth programs stipulate that participants are unable to access CoS unless they have applied and been found ineligible for NDIS supports. The State is considering the same approach. The data collected by the MHCSA during FY18 indicates a 40% throughput in programs. People have exited for a number of reasons but for the most part, the program has met their needs and they are ready to move on. That could be interpreted to mean that a high percentage of program participants are likely to be wasting their time applying for NDIS, as they would not be regarded as having a life-long disability.

Existing programs have become "referral engines" for NDIS. Rather than providing necessary supports, mental health and peer support workers are focused on supporting their clients through the NDIS application process. Much of the time is spent in translating language and dealing with people's fears and concerns, dealing with the risk and at times reality of re-traumatising people as they strive to prove they are disabled enough to meet NDIS criteria. This is compounded by lack of clarity about the extent of CoS and the shape and funding for the State mental health system into the future. See Attachment B for a comprehensive personal story from a Consumer in her journey to apply for NDIS. Consumer CH articulate the tenacity required to keep going in the application process, hoping NDIS will make a difference in her life.

The MHA report suggests a "Phase 0" where supports to connect to the NDIS are funded;

> "In the broadest terms, the Phase 0 requires:
>
> - Assertive outreach
> - Personalized NDIS engagement support
> - Resources for the community

[12] https://ministers.dss.gov.au/media-releases/3691

> The skills, experience and knowledge required to deliver the majority of these services already rest within the community mental health sector and in some instances with the NDIA or its partners"[13]

The question is whether the best choice is to attempt to upskill LACs or fund mental health service providers to undertake this process. MHCSA believes that the NDIA should leverage of existing skills in the sector and fund appropriately.

Feedback from NGO Providers and people with lived experience:

- There is a cohort who struggle to understand the process due to their current mental state or cognitive impairment. They form a large part of the "hard to reach" group.
- Consumers, Carers and service providers report that people are afraid of the outcome of the process. They are afraid of judgement, the plan and data (their diagnosis) being on record for ever and all to see (insurance, work places etc).
- People do not want to be labeled and seen as disabled.
- Disability language in NDIS is seen as deficit based rather than strengths based.
- General confusion and inconsistent information. There are too many layers to the system and that is confusing people.
- People know that if they apply and are successful, they will lose their current support worker and sometimes provider, with whom they have built rapport and trust. This more of a problem in the mental health system than disability where the NDIS workforce is less likely to be different.
- Many people are content with the services they are receiving but are unaware or may be struggling to comprehend the consequences of not having an NDIS plan, or not at least applying.
- The needs and nuance of working with Carers must be considered. For example, a provider talked about a mother who did not want to engage with the NDIS as she didn't want strangers in her house.
- While the NDIA talks about choice and control and the applicant is supposed to be "in charge" of the application process, people report that it is so difficult that they can't do it and so they risk disengaging. In addition, the process takes a long time and there is a lack of communication from the NDIA about time frames. Some people have reported that applications get lost, or supporting information gets lost and must be re-sent. Phone communication is only through one central number so enquiries about the progress of an application is difficult. For people with cognitive issues this can feel insurmountable, stressful or traumatizing.

Case Example 1

Male approx. 40yo trying to manage with schizophrenia connected to a Community Mental Health team who had been receiving support services from an NGO provider for many years. Those supports stopped when he got his NDIS plan and Centacare were asked to come in with Support Coordination. The participant didn't really understand what it was Centacare did and kept thinking that the Support Coordinator was going to be his "support worker". Centacare spent some time on 2 occasions explaining their service to him and told him we would be able to link him to suitable supports which would use his plan funds. He signed an agreement with Centacare and the Support Coordinator started looking for supports.

Soon afterwards someone from a LAC was doing an audit of plans and seeing who had not used them and decided to call him and have a conversation about why he wasn't using the funds in the plan. He

[13] MHA "National Disability Insurance Scheme: Psychosocial Disability Pathway", May 2018, p16.

was very confused and called Centacare to cancel the agreement with them but would only leave a message and they are now unable to contact him as the phone number he left Centacare is not responding.
There is a risk of too many people being involved and confusing participants. This person is now at risk if his Support Coordination is cancelled because he won't go and find another Support Coordinator (due to not understanding it) therefore he won't receive any supports from anywhere. The LAC should have seen he was a mental health client and perhaps contacted Community Mental Health or checked with the person who did the plan in their office (who knew we were involved). This is also evidence of a breakdown in communication within their own office and a lack of experience working with mental health clients.
(provided by service provider)

Case Example 2
Feedback from members of the Sound Minds Group in Adelaide

- One member had no idea about what was involved and was not aware that there was any need to apply.
- Another always spoke of his experience with the mental health system in a positive sense as diagnosis opened doorways for him but though he has started the transition process he has found himself unable to complete the process as the whole concept initiates panic within. He is aware that it may be necessary to submit an application to receive service, but the inner panic is stronger than his drive to follow through with the procedure. He said, "I know of others who receive most of their services through a volunteer organisation and have had their application denied."
- There were not any really positive reports around the transition and there was a strong hint of despondency. The application process is deficit based not assets based. The focus is not on what you can do but what you cannot do, and members did not see this as a positive.

Case Example 3
Client supported by an NGO service provider, with support worker providing assistance with application.
"Client applied for NDIS but was told the address on his application did not match the address at Centrelink (public trustee) therefore they wanted his confirmation of exact address.
The support worker called NDIA because the client wasn't well enough to speak to them. The NDIA worker who took the call said they wanted to speak to him directly and they would place a hold on the application until he was able to call them. It has been 3 months and the client is still not able to call.
The support worker called NDIA back and was told she only had permission to make one phone call and she had used that (sounds like prison). Although she explained the address was correct on his application and that was where he physically lived and the one linked to Centrelink was with Public Trustee, they said they would not take this information from her and his application would be cancelled and he could reapply in 3 months' time with all new paperwork that was current from Doctors etc."
(provided by service provider)

Recommendations:

1. Advocate for flexible pathway to test eligibility, with shared strategies to connect with people who have no natural or planned supports and cannot or will not apply. Alternative gateways to applying for NDIS could be through service providers working in partnership with LACs or NDIA if that works best for the client. Fund this support appropriately.
2. Advocate for clearer communication to people with cognitive issues who don't understand NDIA language – "meet people where they are at" rather than expecting people to learn NDIA language. Work with people with lived experience to develop the language required.
3. Advocate for NDIA to block fund NGOs to support people through the application and planning process where appropriate. This is very important for new people and for clients transitioning, should be in addition to current support funding so clients get their support needs met as well as support for the NDIS application process.

7. Any other relevant matters.

The NDIS Planning Wait time and Process

The time gap between eligibility and the planning process can be months, at which a whole new suite of information is required to establish the support needs of the participant. Service providers have reported clients being required to travel to the LAC office rather than the LAC coming to them; LAC employees from interstate who are unaware of psychosocial disability providers / community supports in SA and LAC employees and Planners who ask disability questions in planning meetings. Specific types of support should be discussed at planning meetings –

- Support Coordination (is there are a requirement for case management?)
- Capacity Building supports (rather than Core Supports)
- Carer support and respite
- Provision for urgent and unplanned needs, due to episodes of illness[14]

The new psychosocial disability stream will go some way to address these issues but should be evaluated at regular intervals to test whether strategies are working.

Case Example

"I have a physical disability in addition to my psychosocial disability. The Planner asked questions about my physical disability and side-stepped any conversation about mental health. As a consequence, I have a plan that meets my physical needs but not my mental health needs."

NDIS Participant

Housing

Housing remains a problem where participants in existing programs may have received housing along-side support (eg HASP). Upon entering NDIS they are likely to have support only, given SDA is available for a small cohort of NDIS participants and is usually group homes.

[14] Extrapolated from MHA "National Disability Insurance Scheme: Psychosocial Disability Pathway", May 2018, p4.

Workforce

The workforce implications are enormous. NDIS funds support at SCHADS award level 2, while the mental health workforce is currently paid at SCHADS award level 4. SA risks losing a significant number of experienced, qualified and motivated mental health support workers and peer workers through this transition.

Recommendations:

1. The State considers the implications of housing specifically relevant to mental health and devise a plan to address including a housing and support program (HASP or similar).
2. State supports the addition of a new Capacity Building rate paid at SCHADS level 4, to take in Mental Health Support Workers and Peer Support Workers.
3. Advocate that the new Psychosocial Disability Stream be reviewed at regular intervals, engaging with participants, carers and service providers. Results should be transparent and made public.

Attachment A

This is an example of a client who we (NGO service provider) are unable to support through the process of testing eligibility for NDIS

J has been supported by the State funded IPRSS program. Her referral came to us about 10 years ago. J lives in a house with her sister who struggles with drug addiction, and her elderly mother who has been hanging on by a thread for years. I know that if we (IPRSS provider) were not involved this person would most definitely have spent many days in hospital and been a great concern to the mental health community team. With IPRSS support she has maintained a level of wellness and connection which has supported her to stay home. Without IPRSS and her mother she absolutely would be one of the State's most concerning cases requiring full time care.

J consistently displays the following:

- Disorganised thinking, behaviour and speech
- Delusions including delusions of persecution, acts on delusions
- Difficulty maintaining attention and concentration
- Consistent presentation of derailment and tangentially
- Difficulty following and understanding conversations and directions
- Difficulty learning and maintaining new information
- Difficulty dealing with abstract concepts
- Preoccupation with particular subjects and persons (real and delusional content)
- Paranoid thoughts
- Confusion and disorientation
- Vagueness
- Vulnerability

Attempts to explain NDIS has resulted in fixation with the word 'insurance' and resulted in frequent attempts to access money from the Public Trustee, Consumer frequently becoming distressed and attempting to access money and attempt to pay IPRSS workers for support

Attempts to explain NDIS process resulted in distorted perception that mother was withholding money from her – resulting in strained familial relationship dynamics

Given the above presentation of J and previous attempts by workers to explain NDIS (resulting in consumer displaying confusion and significant distress), the service provider believes the consumer does not have the capacity to understand and therefore make an informed decision regarding accessing the NDIS at this time.

Attachment B_ Consumer Story: Undertaking the Application Process for NDIS

Personal examples – By CH, 11-10-2018

I have applied to the NDIA to receive the NDIS. I was successful in the application and am grateful to be a recipient of the NDIS, I am still waiting for a planning meeting. I would like to let you know about my experience of the application process.

In some ways I am lucky. I have a degree in Psychological Science at UniSA and have had some help to apply for the NDIS. Whilst having significant psychiatric diagnoses and significant disability related to these, unable to work or manage daily living activities, these two things helped me to navigate the process. I was able to coordinate getting a Psychiatrist and Psychologist report, discharge letters from psychiatric hospital admissions, evidence from contact with Mental Health Triage Phone Line and a Social Work assessment. I was given good advice on how to apply and the required information and documentation for the application, by NEAMI - MeWell; an NGO that advised me on how to prepare the application, I was able to portray this to the people who took part in assessments and reports for the application.

My Psychiatrist had completed other applications for patients to access the NDIS but was given no indication of the required information, for example – how detailed the application had to be, the required evidence of psychosocial disability or the areas of information the NDIA were looking for. My Psychiatrist and Psychologist were very grateful to me for having provided this information to them and said they wouldn't have been able to do the application without it.

Having this information and being able to gather together the requirements of the application there were still significant issues I faced throughout this process, which would also make the process more difficult for anyone who did not have the support and skills I was able to produce.

The time it took to gather this information from various professionals and sources was great. It took a lot of coordination and patience to do this and nearly ended up in not being able to complete the application in the time required, already having had an extension.

The professionals writing reports for the application had to do this in their own, unpaid, time, as well as spend appointment time with me to work on the application. This detracted from my therapy and affected my mental health where I would have otherwise been working on ongoing issues during this time.

The stress and anxiety during this process was great. Issues such as having my life and my mental health examined and exposed for the purpose of receiving support from the NDIS is a process which can be triggering and dehumanizing. Exposing all the difficult issues of my life can be threatening and create a feeling of personal unsafety, having things said about my mental health for the purpose of the application can undermine progress made and cause instability.

Support is needed during this time, as well as time taken up from therapy there were issues that came up which needed more support throughout the application. If people, like myself, in sensitive

psychological environments have to gather this on their own it is enough to make a person back off from applying.

If extra support to apply is needed, where does this support come from? Not many people that I know would be able to do this NDIS application without professional support as I did. I did this application out of necessity. I do not have any other mental health support from mental health services or NGO's and this support from the NDIS is necessary if I am to cope with everyday living and to continue in psychological therapy and move forward in my life. I wouldn't be able to continue forward without it. So it was a matter of personal survival that I apply for the NDIS, if this was not the case I probably would not have continued with the application.

If I did not have the encouragement of NEAMI MeWell, the NGO supporting me in my application, I would not have even thought I could apply for the NDIS. NEAMI had known me from other services years ago and thought I had a good chance of getting accepted. It was by chance I met them at a stall in a shopping center promoting the NDIS. I went to enquire about other people in mental health applying for the NDIS but they encouraged me and supported me to apply.

The waiting times for the whole process is a problem. My life was put on hold waiting for a decision. Once a decision was made I had a lengthy wait for a planning meeting confirmation. During this time I still had no support in my life, apart from a psychologist, who I am paying for partly out of my own resources, and a psychiatrist. I had no other support in my life and was just holding on to my life for a decision by the NDIA. I am very grateful for the support that I will receive from the NDIS, I would not be able to have this support in any other way, but the process is a difficult one and could be made easier. It has detracted from the positives of the NDIS and caused hardship.

People with cognitive disability, as myself, struggle with understanding this process and the meaning of the delays and confusion as to what is going on. The waiting times mean that there is a loss of consistency and understanding what the process is. Without a proper understanding and explanation and support of the process it is difficult to actually continue with the whole process and people are lost to the service because of this.

I am one of the fortunate ones, to be successful in my application and to have been able to have the opportunity to actually apply, but many others in my situation are not as successful as I have been.

There are many difficult thought processes to go through when applying for the NDIS. Like –

If I have a good day I think the NDIS will say I shouldn't be receiving it and not eligible. I have had to have a lot of reassurance about this and have now accepted this won't happen.

Because I have skills to apply and be functional in certain areas of my life that NDIS will think my disability is not significant enough, where it is the case I have had to work very hard at achieving these, at significant personal cost.

I think that there is an attitude in society that if I am receiving the NDIS I am not capable of functioning and there will be discrimination against me because of this, in the area of employment, or any other group or organisation I am involved with.