

From hope and disruption to where? The important of a mental health sector that works for everyone.

Good Morning and thank you for being here today .

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I would like to begin by acknowledging that we are meeting on the lands of Australia's first nations, and pay my respects to their elders – past, present and into future.

I would also like to acknowledge and pay my respects to people here with lived experience of mental ill health; and to the Carer and Consumer movement who continue to work for better support and life outcomes for everyone.

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My presentation today is about the NDIS, mental health reform and service integration. It will draw heavily from the report we – the Mental Health Community Coalition of the ACT - published in June this year, titled: *“When the NDIS came to the ACT – A story of hope and disruption in the mental health sector”*

The ACT was one of eight NDIS trial sites around Australia, joining in July 2014. As the only whole of jurisdiction, whole of population NDIS site, the ACT experience offers an unique perspective into the experience of those touched by the NDIS and the ripple effects across the broader mental health sector.

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The ACT has a number of characteristics which make it an ideal testing-ground – a bit like a canary in a coal mine:

- small geographic size, essentially being one city with one government
- a population which is relatively well educated and affluent
- And probably also, a high level of familiarity with government processes .

These attributes – in theory at least – allowed the scheme to be implemented across an entire jurisdiction, with relative ease, and thereby expose issues which could be anticipated for the rest of Australia, where the challenges of implementation would be greater.

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Our report synthesizes the first 3 years of the ACT experience of the NDIS with regards to psychosocial disability. The first two of these was as a trial site, while the last year was the beginning of the nationwide rollout of the scheme.

While the report draws on published material where it exists, it is based heavily on the individual reported experiences of participants, carers, and service providers.

The gathering of this information happened over time during meetings, forums and the preparation of submissions on aspects of the NDIS.

MHCC ACT also undertook several surveys with self-selecting consumers, carers and service providers.

In March this year, the ACT Legislative Assembly undertook a review of the impact of the NDIS in the ACT. The report draws also from some of the submissions made as part of this process, including one made by MHCC ACT

The aim in compiling our report was to present a realistic picture of the ACT experience of the NDIS and psychosocial disability. As such it is very much a first-hand experience of the NDIS

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While we recognise that some of the issues around psychosocial disability and the NDIS are shared by other sorts of disability, it is now widely acknowledged that there are particular challenges with the NDIS when it comes to disability caused by mental illness.

The Mental Health Commission of NSW in 2015, described it like this:

Psychosocial disability differs from physical and sensory disability in important ways, which may affect people's ability to seek and access services through the NDIS, and their eligibility for them.

People with a psychosocial disability may be less likely than people with other types of disability to identify themselves as disabled and seek support. [They] often live with additional complex issues such as homelessness and poor physical health. They may have little or no contact with health and community services and therefore may not be readily identified as potential NDIS clients.

It goes on to say:

The core NDIS term "significant and permanent disability" is problematic in relation to psychosocial disability which, in line with the episodic nature of mental illness, may fluctuate over time. [It is also] at odds with the notion of recovery, which maintains that people can seek to live well on their own terms.

People must be judged to be disabled at the time of applying if they are to qualify for NDIS support, and this may further conflict with recovery principles.

Finally, there can be a conflict between the primacy of participants "choice and control" - which suggests their existing service providers should not be part of an individual's planning under the NDIS – and the value of having service providers with their knowledge of someone's needs as part of the planning conversation." (p.16)

This was written a year into the NDIS trial in the ACT and exemplifies many of the experiences and issues faced by people at that time in the ACT, and in many respects continues to do so.

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[SLIDE] - Productivity Commission quote

Everyone knew the introduction to the NDIS would be challenging - the NDIS is the only national scheme of its kind in the world.

But even the best prepared were in fact unprepared for the magnitude of disruption, the plethora of challenges, and the sheer blind faith they would need to work through this period.

Despite this there remains a widespread determination to make the NDIS work. A belief in the fundamental objectives of better life outcomes and choice and control for people with disabilities.

Towards the end of this presentation I will look at the present-day situation in the ACT – what is happening now? How are some of the unintended ripple effects and consequences of the NDIS being dealt with?

Thus the title of my presentation today: “From hope and disruption to where? The importance of a mental health sector that works for everyone”

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[SLIDE – PICTURE]

In preparing for this presentation, I have found my thoughts pulled in many different directions.

There have been times during the ACT NDIS journey when I have despaired at what we have witnessed happening on the ground with NDIS implementation – and in many respects continues to be reported around Australia.

- Communities genuinely divided between the NDIS ‘haves’ and ‘have nots’
- The Carer, where a first plan that finally meant a better life for his loved one, then experienced utter devastation when the next plan was radically cut
- Providers faced with increased suicidation and crisis amongst clients
- The experienced workers who have left the sector
- Providers exhausted and despairing at the way the process has been managed
- And programs withdrawn, leaving people with nowhere to go.

But then there are the times when the NDIS works well and I get insight into how life changing it can be:

- The carer who said that the NDIS meant that for the first time her family was able to meet and enjoy family life.
- The time a young worker recalled starting with a participant who refused to see her because she was too young. The worker persevered and with time a really productive relationship was developed and new ground broken.
- The group of participants who once they understood how their NDIS money was being used, elected to have their swimming trips at the local pool as it was cheaper than the one further away (and closer to another participant).
 - It occurred to me that this was what it was all about: increasing an individual’s agency, making rational decisions, and connecting to the local community. This is choice and control.

Consumer and carer advocates have told me they find the NDIS processes extraordinarily challenging – and they know the system, so how is the average person expected to navigate it?

I have spoken with participants absolutely humiliated and struggling to maintain their wellbeing when faced with the language and processes of the NDIS. And feeling the anxiety creeping into their lives again as they approach yearly review.

I remember a consumer telling me he was not going to wash his hair leading up to his plan review, or wear nice clothes, because if he looked 'normal', he was in danger of not being believed – and his plan cut.

And while many people felt that the notion of telephone interviews was inappropriate for people with psychosocial disability, one Carer I talked to was in favour of them – that way the person she cared for was judged on the evidence and not the fact that they looked and presented 'normally'.

I sat in a meeting with consultants who tried to convince a particular service provider to register for the NDIS. The Service Provider, who worked with marginalised at risk people, kept replying that they had looked closely at the scheme and done the sums, and it did not make economic sense to register. The consultants persisted with their argument regardless. One can only wonder why they would not hear what the Provider was saying.

So yes – gathering my thoughts for this presentation has been challenging – how to present a balanced picture of the ACT experience. The good, the bad and the ugly. From hope and disruption to where?

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SLIDE - 'REFORM'

So what did we find in our report of the first three years of the NDIS experience in the ACT? Is the NDIS really reform, and how is it impacting the mental health sector more broadly?

The 'change' aspect of reform is definitely happening. But the concepts of "improve, and make better" are less easy to answer.

It is no exaggeration to state that the advent of the NDIS in the ACT has put the sector and the people it provides services to, under enormous strain.

The NDIS is the biggest social reform in Australia since Medicare – and that took 10 years to really get fully functional.

When the ACT PHN – Capital Health Network - tried to collect data on services in the ACT specifically targeting people with a lived experience of mental illness at the end of the NDIS trial period, approximately half of the programs provided by non-government organisations were without organisational or temporal stability. The sector was extremely fragile and in a state of flux.

The scheduled transition of population groups from former support services to the NDIS has finished in the ACT - though of course people will continue to enter the scheme over time.

Although the intensity of the NDIS trial period has passed in the ACT, many NFP community mental health service providers would still regard themselves in a process of adjustment and transition to the NDIS. It takes time to rebuild strength and stability after the fundamental and rapid change such organisations have experienced.

While some useful things were achieved through collaboration between the local NDIA, the ACT government and the community sector during the ACT trial period, too often the concerns of NFP community service providers, consumers and carers fell on deaf ears.

Even worse, when valuable lessons were learnt during the trial period, they were mostly abandoned once the scheme progressed to full national rollout - only to resurface again as issues which are once again being addressed – often in a similar way to what we had done.

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Unfortunately, even though we are five years down the track, there are still many issues with the way the NDIS is working in practice which are a cause for concern. And even those for whom it works well in one year have no certainty that it will continue working well after annual plan reviews.

One of the most confronting aspects of this is that most of these issues are not new.

Recent announcements by the NDIS, and different levels of government, offer hope that things will improve for people with mental illness and psychosocial disability. But change is mostly slow and incremental and takes time to be felt.

In appearing before the ACT Legislative Assembly in May 2018, just before launching our report, we stated that - *“at the moment we have the sense that the level of disillusionment and disengagement with the shaping and implementation of the NDIS is high, and we feel strongly that this needs to change.”* (p.41).

A Service Provider quoted in our report said:

Initially the NDIS was sold very well and everyone had high expectations. However, the reality was the implementation was really bad, with too many changes, conflicting and inconsistent information, no coordination originally, no planned handover. Families had no idea how to use or access supports, lots of delays in stages of transitioning, push backs and delays. (Service Provider 1)

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The ACT Human Rights Commission (ACT HRC) summarised the state of the NDIS in the ACT midway through 2018 by stating:

“At this time, the ACT HRC considers the intent of the scheme, as set out in the legislation, is yet to be fully realised in the ACT. The ACT HRC has identified a number of key factors that impact on the full achievement of these outcomes, as follows:

- The current NDIS processes are complex, bureaucratic and not user-friendly;
- There is a lack of accessible complaints management and resolution, particularly in relation to NDIA decisions;
- There is a lack of assistance to access and navigate the system, which places an increased burden on informal supports and other service systems, and results in some vulnerable people not accessing the scheme;

- The approach to plan approval appears to be to apply standardised or benchmark levels of support rather than consideration of the individual's reasonable and necessary supports as required by the legislation;
- Delays in processes, inaccessibility of NDIA staff and limited accountability of the NDIA impact on participants' outcomes;
- The developing disability services market in the ACT is not yet able to fully meet participant's needs and deliver quality supports across the sector.

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We raised 11 concerns, or recommendations, in the conclusion to this report. I will go into varying levels of detail for each of these, relying heavily on first person accounts to support them.

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1. The rollout of the NDIS needs to be driven by outcomes rather than outputs

The narrow focus on target entry numbers to the scheme continues to undermine its integrity.

The University of NSW, Canberra Public Service Research Group, made this analysis in their submission to the ACT Legislative Assembly Inquiry:

The scheme's rollout is outpacing the readiness of people with disabilities, disability service providers, local area coordinators and the NDIA to achieve its stated aims, and its sustainability hinges on its interface with mainstream public and community services, which is a minefield of competing priorities and jurisdictional ambiguities across federal, state, territory and local government

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Suitability or quality of plans would be a better indicator of the success of the scheme.

Woden Community Service wrote in their submission to this Inquiry:

.... [We've been] involved in many wonderful outcomes for people with NDIS plans and can see the potential of what a "good plan" can achieve for someone living with a psychosocial disability. Having a reasonable spread of funded activities, including a focus on capacity-building activities, allows the participant and the provider to keep a recovery focus to the support provided.

But in many cases plans are not of good consistent quality. This quote from a Service Provider sums it up well:

The [NDIS] plans coming through are inconstant and inadequate; the principal of no disadvantage has not been fulfilled by many plans in many cases. (Service Provider 6)

When the NDIS is done well, the outcomes can be significant. At the launch of our report, St Vincent de Paul talked about the key beneficial outcomes possible when the NDIS works well:

- When Plan-Managed, it gives opportunities to participants for further access to psychologists.
- It provides opportunities not previously available to the same extent – such as assistance with in-home domestic activities.
- It has allowed services to grow and assist more vulnerable people.
- engagement has been increased for more vulnerable participants who previously had limited engagement.
- Participants with a dual diagnosis have increased access to assistive technology.
- Participants that are accessing in-home supports are no longer at risk of homelessness and are passing their inspections.
- Participants that are vulnerable and have limited control over their circumstances, have a sense of control over their supports.
- Supported independent living has given participants that are not able to independently live an opportunity to lead new lives.

The extent that outcomes such as these are achieved would be a more meaningful measure of success and progress than simply participant numbers alone.

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2. There needs to be a comprehensive mental health system in place for all.

Only about 10 per cent of people with serious and enduring mental illness are expected to participate in the NDIS when it is fully rolled out.

But as we know, in many cases the services from which funding was rolled into the NDIS catered for a larger proportion of people needing support. Large service gaps have opened up and people are falling into them – to where and what is only now beginning to be addressed.

CatholicCare in the ACT noted in their submission to the ACT LA Inquiry:

Many of the block-funded programs which did not transition into the NDIS are based on the premise that those not eligible for the NDIS don't need regular ongoing support. This however is not the case for many individuals and families dealing with complex and challenging situations.

The author of the "Mind the Gap" report, Associate Professor Jennifer Smith-Merry, , summed this issue up in the following way:

What is significantly worrying is that at full roll out the scheme is only designed to meet the needs of 64,000 people with severe mental illness, yet existing services are being closed and funding moved into the NDIS. This means that many people are going to miss out on the services they need."

People interviewed for our report made some of the following comments:

"People who are eligible are better off than before, people who aren't eligible are worst off." (Service Provider 4)

"For those ineligible, we have no idea what the plan is to fill the gaps, and they are really starting to appear." (Service Provider 6)

“Perhaps they could have thought of a stronger contingency plan for people who aren’t eligible, what that means for them. Some people I see as quite deserving have been not found eligible.” (Consumer 2)

“I think the ACT Government were very naive in phasing out funding in the ages and stages. There is such a large potential to leave people behind, high and dry, and now service providers struggle to support people who haven’t got in [to the NDIS].”

(Service Provider 6)

P. 32 When the NDIS came to the ACT (2018)

The NDIS was never meant to be the mental health system. Yet it was implemented in a way which led many people to feel like it was indeed the new system - great chunks of funding withdrawn from existing services leaving many people with little choice but to try and get into the NDIS if they needed support.

The original plan was that the NDIS would contribute to building a baseline of solid supports for all people in need, reserving packages only for those with the greatest and most complex needs. But by being implemented from the top down – so to speak – it created a perverse incentive for everyone to try and get a funding package.

At the launch of our report St Vincent de Paul Canberra Goulburn shared the experience of a high density housing community they support, which is isolated from services. The introduction of the NDIS and the subsequent reduced level of supports St Vincent de Paul could offer, led to conflict and division within this community between those who were NDIS eligible and those who were not.

- The Board of St. Vincent de Paul agreed to continue to fund the Community Rooms in this community, absorbing the costs but with a reduction in support.
- On their second attempt, SVDP was successful with an Information Linkages and Capacity Building Project grant through the NDIA to commence July 2018 for 2 years to try and address this divide.

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3. The boundary between the NDIS and the mental health system must be clarified.

There will always be areas of overlap and soft boundaries between health, disability and social services. With the introduction of the NDIS, and definition of some mental illness as PSD, the confusion and blurring has become an impediment to person centred services.

A person-centred approach is needed to ensure people do not miss out on vital services nor are bounced between systems when they encounter issues.

We have probably all heard of the famous insulin case. Whether it's the chicken or the egg is for the bureaucracy to resolve – the sorting out needs to happen behind the scenes.

Participants' wellbeing should not be caught between arbitrary bureaucratic boundaries.

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4. The NDIS must address the specificities of psychosocial disability, including the episodic nature of mental illness and the importance of relationships based on trust

It is widely agreed that psychosocial disability is not an easy fit with the NDIS, and that this has led to all sorts of issues. Our report and many others have highlighted these difficulties.

One of the most distressing quotes in our report was made in a submission to the ACT LA Inquiry in to the NDIS:

“Our client has had such a difficult time with the NDIS that their suicide ideation and self-harming behaviour have both significantly increased (ADACAS 2018)

Professor Merry-Smith notes in reference to the ‘Mind the Gap’ report:

“While the NDIS is an exciting reform for people with disability, its current structure does not fit easily with the lived experience of people with psychosocial disability ... What this shows is that people with psychosocial disability have significant problems accessing and being accepted into the scheme, and that plans are not meeting their needs. ...

And, the Vice-President of Community Mental Health Australia (CMHA), Kerry Hawkins, said:

“The [Mind the Gap] report reinforces the gaps the sector has been identifying including that people with psychosocial disability are not engaging, not applying or withdrawing from applying, that the criteria are creating barriers, and support to access the NDIS is lacking.”

[SLIDE]

In our report people made the following comments:

Here's what we learnt about the planner and process: the planner was not trained properly, they had no mental health background and little understanding of psychosocial disability, they asked compulsory questions related to physical disability, they didn't read the records, and didn't review the last plan to see what had worked. (Carer 1)

The NDIA has very little understanding of psychosocial disability and the damage that they can do to people with psychosocial disability by giving them funding, hope and a better quality of life one year and then taking it away the next year. This reinforces what has continually happened to them in the past. (Service Provider 6)

The participant's original package was \$37,000, but after annual review the package was reduced to just \$2,500. All of his external supports have dropped out completely and he is back where he was before NDIS – if not worse. All his cleaning supports, his laundry and social supports have dropped out completely. An internal review was completed and sent to NDIS two months ago with an urgent status. We check it weekly for progress. To date there has been no progress with this review. The client, who has a psychosocial diagnosis, is now isolated within his home. (Service Provider 4)

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5. The NDIS workforce must be qualified, experienced and skilled in working with people with psychosocial disability - organisations need to be able pay wages commensurate to the attraction and retention of such staff

I would like to start by saying that this recommendation is made with great respect for the current workforce.

In response to the NDIS framework, organisations registered as NDIS service providers restructured, and many positions were redefined. Existing staff were often faced with the choice of working in a lower paid role, a more administrative type of role or leaving.

The other issue around the workforce is particularly in regards to specialist workers to support people with psycho-social disabilities. The transition into the NDIS saw the movement of a large portion of skilled and experienced mental health workers away from NDIS funded services. With providers having to significantly reduce wages to come in line with the NDIA pricing, many workers left the sector or changed roles which left people with psycho-social disabilities without familiar and skilled workers to support them. The long-term impact of the NDIA pricing is the deskilling of a critical specialist workforce. Support workers are operating even more independently in the field, with less training, support and experience. (CC – LA Inquiry)

This begs the question of the repercussions on the client group – they are still the same group of people with the same needs – but how are they being met now?

The timing of the introduction of the NDIS is also interesting given its proximity to the Fair Work Australia ruling on wages in the community sector.

Additionally in the ACT, a partnership between the ACT government and the community sector had succeeded in getting at least 75% of the community mental health work force qualified at a Cert IV level – and often higher. Before the NDIS there was competition for jobs advertised, and applicants were often highly qualified for the positions.

The following quotes sum up the experiences on the ground very well:

There's now a two-tier system in the sector, NDIS casual workers on one side and management and block-funded services on the other side...Certificate II for NDIS, Certificate IV for anything else. Other areas may require a bachelor degree or higher.

(Service Provider 5)

Our key workers, while the expectation is they have a minimum of a Certificate IV, generally had tertiary level qualifications. But we can't afford [to hire at that level] anymore.

(Service Provider 6)

In other block-funded programs there is still the expectation for tertiary qualifications, but this is no longer viable in NDIS programs. We still have standards of work quality but can't afford to hire people with higher education. (Service Provider 6)

The NDIS pricing schedule also does not allow for the same level of supervision of staff to ensure adequate support for them, and for exploring ways to better engage and support clients. WCS p.36

The burnout of staff is a very human cost. There's a lot of anxiety in the workforce about future of jobs and pay rates. (Service Provider 5)

[SLIDE]

6. The NDIS framework must build the capacity of service providers to provide strong recovery-focused supports for participants with psychosocial disability

Service providers report that the NDIS framework makes it very difficult to build recovery into participants supports. The need for adequate capacity building funding in plans has proven a contentious issue. The change to increased choice and control is genuinely positive. But such change must be done in tandem with the substantive evidence base and experience in delivering recovery-oriented services.

As described by a service provider:

In testing eligibility for NDIS people must describe their deficits and the debilitating effects that the condition has on their lives. This in itself is a demeaning introduction to the Scheme which doesn't encourage a description of what people have done to overcome their conditions. Moreover, people feel that if they present too positively, they won't receive the supports that they need. So they must dwell on and go into great detail about the limitations that mental illness imposes on them, rather than focusing on what they can do with support. This access model is totally at odds with best-practice recovery approaches. WCS, p.34

But providers are trying to maintain recovery focus:

We maintain recovery, and if we thought we couldn't do that we would get out of the NDIS. (Service Provider 4)

As stated by one organisation in the MHCC ACT survey for the ACT LA Inquiry:

The NDIS framework makes it difficult to deliver recovery services but we have forged a model that can work. It requires combining service delivery with support coordination (with two clearly different teams) but important communication between the teams to be able to support the participant with recovery activities. We have seen some fantastic results using this model but are acutely aware that it is not the preferred model of the NDIA.

[SLIDE]

7. Specific support for carers (in their own right) must be provided to ensure they are not left in a worse position due to the NDIS

One of the catch-cries of the early days of promotion of the NDIS was that noone would be left worse off. I think there are many carers who feel that they are in fact worse off under the NDIS:

They have excluded the carer, who is looked at as part of the problem not the solution. I don't think they understand the role carers play or what they do. They have this stupid idea that the NDIS is going to set the carers free which is just not going to happen because they will still provide 87% of the care. They have cut services to carers which impacts on us and impacts on the consumer. (Carer 1)

I have no idea what it was like before – under the NDIS it sounds like there may be some room to support me, but at the moment I have no supports coming from service providers or the NDIS. (Carer 2)

There have been no resources for respite allocated. In the 16 years of my son's illness, the only respite I have had have been a few 2-day trips away with Carers ACT. (Carer 4)

[SLIDE]

8. There needs to be a diversity of viable providers in the NDIS marketplace

The ACT will not be well served into the future by financially vulnerable organisations, which are being driven to employ a low-skilled workforce with a high churn rate, delivering a narrow range of highly commodified services. Nor by organisations which do not have the capacity to outreach into the community, support people whose needs are the most demanding, or respond flexibly and quickly to people's changing needs on a day-to-day basis. Implementation of the recommendations in the 2017 Productivity Commission report on National Disability Insurance Scheme Costs¹, would improve things to some extent.

Purely from a business point of view, financial sustainability is very difficult to establish with the funding body of NDIS, however without services such as we provide, participants with a psychosocial disability would go completely unheard and unrecognised.

Four of the five organisations surveyed for our submission to the ACT LA inquiry into the NDIS said they were not viable purely based on revenue generated from NDIS service delivery. All three organisation which answered the question asking if they had considered de-registering from the NDIS answered that they had.

“This has been a real struggle and we are not winning!”

“It has created much more complexity and uncertainty in delivering services for us as an organisation, making it very difficult to plan a business model that we can work towards achieving. The administrative burden is enormous and almost impossible to sustain. We have had to close our doors to people requesting services for shorter periods of time and needing flexibility.

¹ Productivity Commission 2017, *National Disability Insurance Scheme (NDIS) Costs*, Study Report, Canberra.

The constant changing goal posts of rules by the NDIA causes confusion and mistakes that then take many unfunded hours to rectify.

We have lost experienced recovery workers who are no longer catered for in an NDIS model. This is a huge loss for our participants and for us as an organisation. We have had to employ staff on lower wages and with differing conditions to those in block funded programs. Thousands of unfunded hours to sort administrative discrepancies and fight unreasonable planning and review decisions.”

“The business assumptions under the NDIS are not based on real businesses within a quality framework.”

[SLIDE]

9. The NDIA needs to take a genuine and more transparent partnership approach with consumers, carers and service providers in the interest of optimising outcomes and minimising costs associated with the NDIS

There has been a lack of a partnership approach in building and refining the NDIS. Consumers, carers and providers have not been recognised for their expertise, experience and knowledge in the provision of services to people with psychosocial disability - especially when it comes to recovery. Instead, they have largely been viewed with suspicion, and as being driven by narrow self-interest. As a result an 'us and them' attitude seems to prevail within the NDIA.

I would encourage [the NDIA] to see us as friends not enemies. They seem to view us as an enemy because we are the one they pay, but they can't do it without us. (Service Provider 6)

If the NDIA went and communicated with your support network first before starting from scratch that could be really useful. (Consumer 4)

Even though the ACT was a test site, it was often difficult to get the reality of the sort of unintended consequences already highlighted today to be taken seriously.

We were often told that providers just have to get used to competition and working in a market economy (which in reality they had been successfully working in for many years.)

But none of us could see a market economy – instead we saw market failure and organisations and individuals reacting rationally to that failure:

- Prices fixed below what was required;
- incomplete, inconsistent and sometimes even inaccurate information from which to organisations were expected to restructure their business models;
- constantly changing parameters; information being lost;
- inefficient processes leading to hours of unproductive highly costly time.

I thought often to myself – would corporate Australia be expected to operate in such conditions? Would they tolerate being forced to work in such an environment?

[SLIDE]

10. A simpler, less bureaucratic approach is taken to the administration of the Scheme as it affects carers, consumers and service providers

I feel that this recommendation needs little explanation. There have been countless reports of the difficulty understanding and navigating the system, as well as criticisms of the overly bureaucratic processes and the lack of transparency and delays in how problems are dealt with.

In our report, people interviewed said:

The process, the forms and the information coming out of the NDIA was really hard to understand, confusing and often contradictory. (Carer 2)

The amount of bureaucracy! Families have enough trouble surviving and they can't wait for six months because of bureaucracy. (Consumer 5)

Interpretation of [NDIS] plans especially for people with psychosocial disability is complex. (Service Provider 1)

In July this year the Administrative Appeals Tribunal took the unusual step of criticising the NDIA and urging ministerial intervention.

As reported by Disability Services Consulting, these remarks were made when ruling on the case of a Participant who was appealing the reduction of supports in her second Plan. Before the Tribunal could conclude on the matter, the NDIA issued a third Plan, again with reduced supports. This effectively nullified the work of the Tribunal thus far, causing further delays for the Participant.

The AAT argued that this was far from an isolated case, describing the NDIA's decision-making process as slow and difficult to interpret.

“It seems to the Tribunal entirely inappropriate that a Participant, working with finite resources and coping with the added burden of a disability, should need to be left in doubt as to the status of decisions made affecting his or her entitlement”

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11. All work associated with the NDIS is billable and appropriately funded.

This last recommendation is closely related to some of the previous ones. A robust, flexible quality system needs adequate funding.

[Its] very difficult to make the program sustainable due to having to employ staff at a lower level, the ever changing price code, [that] we are still supporting participants who are not eligible, ... [and it] is a loss to our organisation to continually help people to apply.

NDIS administration is 30% of our costs, not the 9% provided for by the NDIS (Service Provider 2)

Service provider responses to our survey for the ACT LA submission:

We would not do this lightly but unless we can turn our financial situation around we will be considering pulling out of the NDIS.

With the introduction of NDIS and all the requirements, staff induction and training is required to be more intensive however funding does not exist to provide it.

Community Mental Health Australia made the following point in their submission to the LA Inquiry in the ACT:

For example any delays in putting in place plans or reviewing plans which leads to consumers and then providers not receiving payment, leaves providers in a position of having to make a decision to provide services and not be paid. CMHA Sub to Joint Standing Committee 2017

And Woden Community Service wrote that:

The service and financial risk has been left squarely at the feet of the service provider, particularly given the inconsistency of plans. The service risk is presented through lack of communication from the planner and through the client. WCS

believes the introduction of the Scheme has shifted the financial burden to service delivery agencies. WCS Sub to JSC 2017

In a case study shared by St Vincent de Paul at the launch of our report they spoke of a client with Schizophrenia and an Acquired Brain Injury for whom they were required to provide over \$30,000 worth of supports while waiting a reaction from the NDIS to a “Change in Circumstances’ lodgement. Eventually SVDP had to take the case to the AAT.

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[SLIDE]

Turning now to the final part of my presentation – where are we now? What has NDIS implementation in the ACT meant for broader mental health policy reform and service integration?

Its obvious from my presentation that the NDIS has caused massive change in ACT NFP community mental health services, and more broadly. Very simply put - it has led to service dis-integration – we have lost workers, services, time and energy for collaboration and innovation, and big service gaps have opened up between the NDIS haves and have nots - many would also add between those with self managed and agency managed NDIS plans.

Many of our organisations now carry levels of debt not previously experienced, or if they have the capacity, rely on cross subsidising from other parts of their business model to remain a viable NDIS service provider. This should not be happening and its not sustainable.

[SLIDE]

At the same time this year there are finally signs that the ACT government and the NDIA are recognising and responding to some of these issues.

New initiatives are being announced in the ACT and nationally which are contributing to improving the NDIS outcomes for people with psychosocial disability, filling support gaps and improving service integration.

We often felt that given the small size of the ACT, that it would take NSW and Victoria to start rolling fully into the NDIS before it would be recognised that what we were saying was not confined to the ACT but had broader implications. Whatever the reason for recent improvements though, we welcome them – specialist teams, better training, additional measures to support people with the most complex needs, recognition of the specificities of PSD.

We also get the sense that in designing supports and services there is more conversation and consideration of how to do this based on outcomes, and consumer choice and control.

Mental health is starting to be viewed more holistically, including by giving more consideration to the social and economic determinants of mental health. There is more effort made to build on and integrate existing services.

The national level initiatives by the NDIA are probably better known – improving the pathway for people with psychosocial disability and measures for people with complex support needs.

But there are also more local initiatives happening.

The ACT government recently announced its 'Integrated Service Response program – designed to be able to react immediately to people in crises for a short period of time so they don't deteriorate to the extent that they need hospitalisation while waiting for longer term plans to be put in place. This program involves a close partnership with the local NDIA office, and access to senior decision makes.

The ACT PHN, Capital Health Network, in collaboration with ACT Health, are working together with consumer, carer and provider peaks to design the ACT's National Psychosocial Support Measure built around outcomes. It is hoped that a similar approach will be taken with the design of the Continuity of Support Measure early next year.

ACT Health is introducing the Lifespan Suicide Prevention model into the ACT – an evidence based program that draws upon and builds on existing services, and in doing so contributes to service integration.

And in June this year, the ACT announced its first Office for Mental Health. This Office will focus heavily on the social and economic determinants of health and improving service integration and peoples experience of services and support for mental health in the ACT.

So after the chaos and disruption that our sector has experienced over the past 5 years, we are now seeing signs of hope for improvement, and a mental health system that works for everyone.

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Turning again to the title of my presentation today – “From hope and disruption to where? The need for a mental health system that works for all”. Perhaps we are starting to see signs of improvement – of a system that does indeed cater for all.

At the same time, its hard to understand why the journey to now has had to be so painful and disruptive, and why we have had to lose so much along the way. As an advanced nation we should be able to design, implement and support reform more effectively than what we have lived through over the past 5 years. Transition should be understood and planned for – by its very definition it takes time and it is worth getting right so that the foundations of something new are solid and robust.

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I would like to finish my presentation with one last case study from the ACT – and I will leave you to draw your own conclusions as to the pros and cons of the situation.

[SLIDE]

At our report launch, Richmond Fellowship shared their experience of the introduction of the NDIS to the ACT:

“RF made the utmost use of the [ACT Government] NDIS taskforce opportunities, successfully gaining grants to prepare our organisation for NDIS. We felt good about this at the time and were generally optimistic. However, we did have an ongoing concern about the disparity of \$45 per hour under NDIS for outreach support and individual support vs the required \$60-70 per hr for our skilled and well-trained staff.

The roadmap to NDIS had no bearing on the reality of life as an NGO in NDIS funding space. This came to bear very quickly with our Live Your Life program – block funds were reduced based on the ages and stages roll out of NDIS.

Reluctantly, we gave notice to our ACT contract managers of our intention to cease our existing LYL and HASI / HARI funding arrangements as at 31 Dec 2015. There was

no feasible way to maintain support to the existing 50 ish participants under the proposed reducing funding offer, particularly as our experience of the rollout of NDIS was not as expected.

There was an enormous amount of work required to prepare participants NDIS application forms, support them in the concept of transition (disability vs Recovery language), manage the frequent changing process within NDIS and to await a funded plan.

It very quickly became evident upon receiving the participants NDIS plan that neither funding nor line items reflected the needs of our people. Because mental illness challenges cannot be easily transferred into a traditional disability context, our participants were receiving at times very little NDIS support, much of which was difficult to negotiate with the absence of skilled and experienced staff across the sector.

We had determined that our only other viable option under the new NDIS funding model was to develop a supported residential accommodation program. This decision was reached following costing analysis, needs and gaps analysis and determining that we had existing property assets, our staffing assets, motor vehicles and experience with such a program we had offered in some form since 1988.

.... It is fair to say we were surprised at the demand for supported accommodation. Once word was out, we were receiving on average 2-3 referrals a week. There were of course delays we had come to expect from the NDIS process but from our 'go live' date in October 2015 to the present all beds have been full and we are working on additional homes to be opened soon."

Thank you.