



Productivity Commission Report into NDIS Costs

MHCC ACT Submission

24 March 2017



mental health
community coalition ACT

Peak Body in the ACT for the Community Mental Health Sector

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About Mental Health Community Coalition ACT Inc.

The Mental Health Community Coalition of the ACT (MHCC ACT), established in 2004 as a peak agency, provides vital advocacy, representational and capacity building roles for the community-managed mental health sector in the ACT. This sector covers the range of non-government organisations that offer recovery, early intervention, prevention, health promotion and community support services for people with a mental illness.

The MHCC ACT vision is to be the voice for quality mental health services shaped by lived experience. Our purpose is to foster the capacity of ACT community managed mental health services to support people to live a meaningful and dignified life.

Our strategic goals are:

- To support providers deliver quality, sustainable, recovery-oriented services
- To represent our members and provide advice that is valued and respected
- To showcase the role of community managed services in supporting peoples' recovery
- To ensure MHCC ACT is well governed, ethical and has good employment practices.

Executive summary

MHCC ACT appreciates opportunity to respond to the Productivity Commission discussion paper on NDIS Costs.

As the peak body for community managed mental health service providers in the ACT, this submission will focus entirely on to PSD. While we recognise there is a certain commonality of experiences with other areas of disability, there are also some very specific challenges fitting PSD into the NDIS model. Our submission is also shaped from the perspective of being the only whole of jurisdiction NDIS trial site.

The experience in the ACT is too easily dismissed due to the small size of the jurisdiction, the fact that it is essentially one city, and that its population is relatively well educated and affluent. These same characteristics of the ACT would suggest that implementing the NDIS in the ACT should be easier than in most other parts of Australia. If NDIS implementation is proving problematic in the ACT – too often leaving people worse off, opening up service gaps, proven services disappearing – then it might serve as a warning to the rest of Australia where the challenges of implementation will be greater.

Is the ACT the ‘canary in the NDIS coalmine’ for the rest of Australia?

MHCC ACT views the NDIS with great hope. It holds promises for a better more integrated life for people living with disability. It offers flow on benefits that will affect all Australians. But we must take care to ensure that we get it right. This requires time, investment, flexibility and persistence.

The NDIS is working well for some people, of course. But even these people have often had to overcome challenges to achieve this outcome.

However, in many ways the NDIS is not working well yet. While the rhetoric around the NDIS framework is about markets, it doesn’t take long to realise that it is not actually a market. It is a government managed and controlled system with great ambition, with fixed prices, information gaps, inexplicable outcomes and overly burdensome administrative practices. MHCC ACT sees the key issues as:

- Inadequate understanding of the complexities and specificities of PSD as compared to general disability, throughout the scheme and its governance and management structures.
- Refusal to take a partnership approach with the sector, and in doing so benefit from the breadth and depth of expertise of providers, carers and consumers.
- A pricing framework that is pushing towards commodification of services – an outcome not in the best interest of participants or achieving NDIS objectives.
- A pricing framework which is putting downward pressure on workforce quality, and organisations' capacity to attract, retain, train and develop a workforce that can deliver safe quality outcomes.
- A pace of implementation that is too fast for effective change management and is leading to the disappearance and shortage of services.
- Lack of integration with, and spill over effects onto, mainstream services. This is resulting in service gaps and disruption for people not eligible for NDIS IFPs.
- Loss of some highly effective programs such as D2DL, PHaMS, PIR. This is contributing to service gaps and also creating problems for continuity of care and helping to support people's systems to not regress.
- Significant unfunded cost and risk shifting to service providers in particular, but also to consumers and carers.
- Targets that mean that focus is on getting people into the system quickly rather than overall outcomes from doing so.
- Carers have not been at all well supported, undermining one of the pillars of the scheme

A series of recommendations have been made throughout this submission as to how to these address issues might be addressed.

Our overall recommendation however, is to view the NDIS as a long-term investment in Australia's future. Well-funded and structured it will deliver benefits to every Australian, especially those with disability. Dividends will flow although they may take a while to become evident.

On the other hand, if done badly it will incur significant human and economic costs. The state of market disruption already caused by the NDIS would also mean that fixing a failed system would be incredibly expensive to tax payers.

MHCC ACT also support the responses to this process from our peak body, Community Mental Health Australia. We also support submissions from our ACT member organisations.

MHCC ACT also refers the Productivity Commission to the submission we made to the Joint Standing Committee for the NDIS inquiry into provision of services for people with PSD under the NDIS.

We are very willing to contribute more to this process if asked.

Regards

Simon Viereck
EO
Mental Health Community Coalition ACT

31 March 2017

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Productivity Commission study into NDIS Costs

1. Scheme Costs

Recommendations

- The costs of implementation need to be included as a major cost driver
- The true scheme costs must take into account the significant unfunded cost shifting to service providers in particular, but also to consumers and carers
- Remove the expectation that people will exit a scheme where entry depends on having a significant enduring disability. Instead refocus on scheme outcomes: for example, change in hospital admissions; uptake of training; entry to workforce and volunteering.
- Adopt a partnership approach – involve real expertise in PSD rehabilitation and recovery when determining prices and benchmarks
- Increase investment in and redefine the role of the ILC in keeping with its original function of reducing the number of people needing the more expensive IFP
- The cost of not getting it right needs to be understood in order to properly understand the cost/benefit analyses of the NDIS

The way the NDIS is being implemented (as distinct from operational costs) is making the scheme more costly than necessary – both in short and long term. In other words, the management of the scheme by the NDIA and other government agencies is a very important cost driver. If management is effective and efficient, the long term costs will be lower – even if some of the initial costs are higher in the short term.

The most effective way of implementing the scheme would have been from the bottom up and over a period of time that enabled real transition to happen – change in business models, culture, and practices. By choosing instead to implement the scheme from the top down certain distortions have entered the scheme caused higher than needed costs:

- An incentive has been created for a higher proportion of people to test their eligibility for IFPs – the most expensive part of the NDIS and originally intended only for those who could not be supported by tier 2 services.
- Inadequate funding remains to build the base level of services for the majority of people (Tier 2/ILC)
- Extraordinary disruption to service delivery leading to loss of industry expertise and inadequate breadth and depth of services available.
 - The disruption to services caused has meant that many of the baseline services have been destroyed and/or withdrawn in response to the price signals of the NDIS market – leaving important service gaps
- Creating perception that this is the way to enter the NDIS, and that this is the only thing that the NDIS provides.

CASE STUDY 1

Socially isolated, coping alone, PIR closing

Through working with the (a public housing project), predominately in one location, it is estimated that 5 tenants would benefit from engagement with the PIR program. These tenants are not currently connected with NDIS or any other supports and they find the NDIS process off putting. These tenants are middle aged men who are socially isolated and struggling with issues of depression and anxiety. Some of them have a history of addiction as well. They have socially withdrawn as a way of coping with this issue alone.

Source: Service Provider W, 2017

The chaos of trailing and implementing a scheme before it is properly built, and under which the sands are constantly shifting, has proven very costly. This has been magnified by the lack of effective, real time, consistent communication with service users and providers. It appears that this is largely caused by:

- Lack of a partnership approach with the sector – many costly mistakes could have been avoided if the expertise in the sector was acknowledged and valued

- Adherence to an unrealistic rollout timeframe at the expense of ensuring things are properly bedded down before moving onto the next bit (discussed in more detail later). As well as the time taken by the NDIA to properly engage and enter people into the scheme; there is also the issue of time needed for service providers to support clients to engage with the scheme; and to adjust their business models
- Lack of adequate investment in certain aspects of the scheme – good examples include:
 - Inadequate investment and trialling of the portal;
 - Inadequate NDIA staff training resulting in inconsistent plans and information being given, leading to confusion and increasing the need for plan amendments before the 12 month
 - lack of capacity to respond quickly to queries, problems, etc. It is common for people to be on hold for 2 hours or to wait for months to get a response on an issue, if at all.

Utilisation rates are low for a variety of reasons which in one way or another can be traced back to decisions made about scheme implementation. From the experience of MHCC ACT stakeholders, the two key reasons seem to be:

- NDIA planners and decision makers not having the expertise they need to produce an IFP for a person with PSD that meets scheme objectives
- The fast pace of NDIS implementation meaning that services are not available in the quantity demanded or not fitting the criteria of the NDIS
- The NDIS pricing structure means providers cannot afford to supply them any more

Some of the more common reasons for low implementation rates are:

- badly structured plans – many examples of internally inconsistent or comparatively inconsistent plans; as well as plans that do not cater to the needs of the participant.
- not enough Support Coordination built into plans to account for the time taken to engage with services
- service disruption – not enough capacity to provide

- the system is cumbersome and difficult to navigate; particularly the portal which is also unreliable
- pricing structures not catering to the qualification and skills needs of workforce
- review processes locking up plans for months

Support services for people with mental illness have in the most part been built around principles of recovery. It has repeatedly been the experience of service providers that the NDIS framework – particularly in respect to prices – makes it extremely difficult to build recovery into a participant's package. Many refer to the NDIS model to be along the lines of a 'maintenance model'.

Another area that makes it difficult to implement plans is the large amount of unfunded administrative and background work needed on the part of service providers. For example - participants come with no background information provided – this means that every service provider involved in a plan must carry out their own risk assessment in terms of participant and staff safety. There are many other examples included in this submission.

The NDIS funding framework makes it almost impossible to send out more than one support worker in any given situation – this is not good risk management.

CASE STUDY 2

Service Provider – registration process is extremely time consuming

A well-respected busy psychologist, tries to register as an NDIS provider. He finds it is a time consuming and complex process but none the less persists, working through it in spare chunks of time he can find. However, he constantly comes up against hurdles. Finally, in desperation, he calls the NDIA. After waiting for more than half an hour on hold, he gets to speak to someone, and asks if there is a quicker more efficient way of registering – for example could he do it by phone? He is told that the quickest way is via the process he is already using. He asks the same question again, wondering if the person has not comprehended his question properly. He is given the same response. It is only his dedication to his clients that has kept him persisting.

Source: JP

The initial estimates for scheme participation were widely acknowledged as being inadequate. In the area of PSD specifically, it was widely known that there were many people not currently accessing services who would potentially become NDIS participants. The decision to implement the scheme from the top down has also encouraged people to test their eligibility – particularly in view of the impact the NDIS is having on general service availability.

The experience in the ACT to be suddenly told that the NDIA would process no more applications because we had reached our ‘target’ number of entrants, was shocking in every way (October 2016). As an insurance scheme, it was widely understood to be uncapped. It was particularly impactful on people with PSD, as in the ACT, these people were amongst the last to transition into the scheme trial; and due to the nature of their disability, news of this kind is enough to trigger someone into crisis. It was also in stark contrast to the NDIS article only a few weeks previously, with a photo of an ACT participant celebrating being the 5000th participant – nowhere was it stated that that meant there was only another 74 places available in the scheme for the ACT.

MHCC ACT has no way of knowing, in respect of overall expectations of scheme entry for people with PSD, where the balance lies between people who have entered the scheme having previously not accessed services and those who have been accessing services and refusing to engage. We do know that there are still people who fit the latter category.

It is hard to fathom how an expectation could exist for people to exit a scheme for which the entry requirements are to be able to demonstrate that they have a severe and enduring disability. Even if there were grounds for such an expectation, it borders on the absurd to expect this to have happened within such a short time frame.

CASE STUDY 3

What is the price of a life?

The impact from the implementation of NDIS has been significant. Prior to NDIS, our organisation was block funded for 35 participants and our client load that we successfully serviced was 70 participants. Our service provided temporary accommodation and a case manager for persons with a psychosocial disability to assist them with the reintegration and recovery process. **Under the current NDIS system, our program could not be fully**

funded as it wasn't considered that supported accommodation and the community program would be financially viable under individual supports.

Our organisation is currently funding the community program until June 30th 2017. A decision will have to be made if the program is to continue. At present, between the 2 sites, our support workers are assisting Non NDIS Clients access government services, linking service providers in with clients to assist their recovery progress and other health services. The visits per week total 140 between the sites. This is not inclusive of the meals that we serve twice a week. **These 140 visits per week indicate a significant gap in service provision under the NDIS**, which our organisation is currently fulfilling. These clients are either ineligible, have been refused a package or are too ill to make the application.

This reduction in funding has also had a significant impact on the communities that we service. **In the past 12 months there has been 5 deaths between the sites from preventable situations, 2 were clearly suicide.** The 2 suicides occurred within 4 days of each other, but at different locations.

- Client A suicided successfully at his 3rd attempt in a 2 week time frame. No other services were available apart from government systems
- Client B suicided after attempting to obtain help and was unable to get any assistance other than what we could provide as an organisation.
- Client C died from ongoing comorbidity issues stemming from his mental health. His approval for an NDIS package came through after his death.
- Client D died from an accidental overdose – however he had been unwell for a time and had made several attempts at overdosing previously, his application for NDIS was approved after his death
- Client E died from natural causes. Our service had placed an application for the NDIS and no notification was ever received from NDIA whether eligibility was met.

Source: Service Provider S, 2017

When it comes to PSD the simple fact is that the NDIS targets a group of people whom, without support, are severely disabled, and at times even at risk of ending their own lives. Properly supported, many of these people can become more engaged in their communities and some might enter the workforce. At the very least, adequate support will see the person staying in their community and out of hospital. Taking away that support – or exiting the scheme – will only mean that these people will become acutely unwell again, often within a relatively short period of time. Letting this happen would cost tax payers a great deal more than running the NDIS well.

We know some people are exiting the scheme because trying to work within the scheme is so complex and difficult it is having an adverse affect on their mental health and wellbeing. Otherwise people would only exit the scheme if they moved into the 65 plus age group or they died. A high scheme exit rate could even indicate a system that is leading to a high suicide rate – which of course would be perverse.

If a person with PSD was correctly assessed as being eligible for the NDIS it is unrealistic to expect them to leave the scheme – even allowing for the episodic nature of the PSD. They might have periods of changing intensity of support need – but the need remains regardless.

The question around increased package costs implies that there is fat or excess in packages. From our experience this is not generally the case – although we have seen a few exceptions to this. Rather the so-called ‘increased plan costs’ are a reflection of the lack of understanding of the specificities of supporting people with PSD when the scheme was designed.

In most cases increased package costs are more likely to be a more accurate reflection of the real costs of supporting people with PSD. Even then many plans are judged as lacking, and a growing proportion of people are reporting that they are actually worse off under the NDIS than before it.

Following on from this, the mismatch between benchmark package costs and actual package costs when it comes to PSD is, in our experience, again most likely a reflection of a lack of adequate understanding of what it involves to support a person through psychosocial rehabilitation and recovery. It would be useful to ask:

- How was the benchmark package determined?
- For what illness?
- Informed by what sort of lived experience?
- In consultation with what sort of service provider expertise and experience?

CASE STUDY 4**Afraid of being declared bankrupt under the NDIS**

Participant is a 30 year old male with Autism and Bi Polar disorders.

Under his first IFP, life improved and he received a better range of supports than before the NDIS.

In his second IFP, he is funded for a day service program and for one to one support to attend the programme, but is not funded for any of the activities in this programme. His travel allowance only funds 50% of his travel costs to attend this programme. His mother is left to pick up the bill for these funding gaps. She is also an NDIS participant, on a disability pension and no other form of family support.

One of his goals is to be able to live at home full time, so he is gradually decreasing the nights he spends in supported accommodation. As such, his plan has funding for three nights of accommodation - but for him to keep his accommodation place he is charged for a full week's accommodation. The shortfall in funding is charged to his mother.

Additionally, her son's plan has been locked down by the NDIA due to a change in part of his plan. This has resulted in her son's major carer not being paid for 6 weeks. This is pushing his mother to a point of crisis as she tries to find ways to pay bills she has never had to pay before. She is worried about being declared bankrupt because she is unable to afford these additional costs.

Source: Participant R&J, 2016/17

As will be noted throughout this submission, what we are seeing in response to the introduction of the NDIS, is a series of rational responses to the so-called market that has been established according the NDIS Framework. Organisations and individuals are responding to the price signals and other distortions in this market in a very rational way.

2. Scheme Boundaries

Recommendations

- Transparency is needed around eligibility criteria and application to potential NDIS participants with PSD
- Emphasis must be placed squarely on functional impairment
- Eligibility interviews and other important parts of NDIA processes must involve face-to-face contact with NDIA staff
- If no other option than a phone call is possible, then strict protocols must be in place that include safety and support for the person with PSD to secure an appropriate plan.
- People with PSD must have a support person with them or nearby when having their eligibility interview
- Flexible ways must be found to engage with people with the most highly complex PSD, using a partnership approach with the participant and their support team
- Funding must be provided to Service Providers in recognition of the hours of work involved in preparing someone with PSD for the engagement with the NDIS – regardless of whether eligibility is granted or not.
- All levels of government must work effectively together to ensure there are no gaps in service

Eligibility criteria for the NDIS creates many barriers to entry for people with PSD. It can also produce unpredictable results. It has been talked about a lot – and often dismissed as fantasy – but the reality is, the deficits focus of having to prove enduring severe disability is a barrier. People with PSD do not traditionally associate with having a disability; and many do not even relate to having an illness at all. Instead, care and support for people with PSD has been around what they can do, about getting better, and about recovery.

There is a persisting lack of clarity around how the eligibility criteria are applied to people with PSD; and subsequent lack of clarity around how decisions are made when using the

information submitted against the criteria. We hear often of inconsistent outcomes – both in terms of people being found eligible or ineligible.

Also what we see happening – against scheme guidelines – is a strong focus on diagnosis rather than functional capacity. Under the NDIS, the presence of PSD requires medical evidence, which essentially equates to a diagnosis.

Many potential NDIS participants with PSD have a long history of interaction with government services. Over the course of this journey they have been let down many times; made to feel like ‘the other’; and spent many hours of time pursuing things that produce little benefit. They have felt judged and demeaned in the process. They are, understandably, suspicious of government as a result. They are not necessarily keen then, to engage with yet another long and involved government initiative that invades their privacy; and another degrading experience of having someone they have no relationship with making such important judgements about them. These are the hurdles faced by service providers in getting many people with PSD to engage in the NDIS.

Intersection with mainstream services

Absolutely, there is a need for both the NDIS and a mental health system. One is not a substitute for the other. However, since the introduction of the NDIS, the intersection between these systems has become very unclear and difficult; as well as inconsistent between States and Territories.

- States and Territories made different decisions about what was in and out of scope for the NDIS;
- Further, these decisions were made very early in the process when detail of scheme design was limited – it’s fair to say that in many cases decisions would now be different given how the scheme has evolved

As a consequence, there are growing numbers of people in danger of, or starting to, fall through gaps in service provision. We are seeing some highly effective evidence based programs being dismantled as the funding is moved into the NDIS – in particular the PHaMs and PIR programs. These programs have changed the lives of people who have participated in them and the undoing of them can only be described as “*throwing the baby out with the bathwater*”. Why does a new scheme necessitate the undoing of such a significant investment in the mental health and wellbeing of vulnerable Australians that has been shown to work?

Surely we are clever enough to design a scheme or system that contains the best of what we have already with the innovation and potential of the new? Judgement on the retention of a program should not be made on the basis of who funds it, but rather the value it produces.

CASE STUDY 5

Closure of PIR leaving people with nowhere to go in the ACT

- Gaps in community support for people with severe and enduring mental illness who would previously have been eligible for PIR, are clearly already happening as they no longer have a specialised mental health service to go to. This includes people who are eligible for the NDIS but who don't have support to access it, and those who are not eligible for or do not wish to engage with the NDIS
- Uncertainty about the existence of the PIR program after July is affecting the wellbeing of PIR participants currently within the program: where will they go for support? It is also leading to the loss of experienced staff who cannot afford to live with such employment insecurity.
- The NDIS has a focus on the individual and therefore there has been a shift away from a systems focus. In the ACT there is now a complete lack of services that are able to offer psychosocial disability supports to people with mental illness outside of the NDIS.
- The role of a PIR Support Facilitator is not synonymous with an NDIS Support Coordinator.
- The disappearance of PIR creates a gap in continuity of support for people transitioning from other, shorter programs – for example the 12 week TRec program that supports people are discharge from acute psychiatric care or at risk of going to hospital.

Source: Service Provider W (2017), in consultation with other PIR providers

There has been a significant cost (and risk) shifting onto service providers, acute hospital mental health services and emergency services:

- Significant increase in administrative costs due to the complexity of managing the scheme; in turn this has moved experienced staff away from face to face contact –

where they make the most difference in someones life – to spending more time behind a desk

- Change management costs, including substantial business restructuring
- Costs of engaging and preparing people to enter the scheme
- Inadequate way NDIS caters for emergency situations
- Inconsistency in IFPs requiring huge amounts of time trying to get them rectified
- An apparent inability of the NDIA to answer queries time efficiently and consistently
- Increased recruitment costs due to the inability to pay wages needed to attract suitably qualified staff; or to keep them due to ongoing uncertainty around funding.

CASE STUDY 6

How long can we operate at a loss?

Our Individual Support programs are operating at a loss. The main barrier is that the price NDIS pay service providers to undertake this service is less than what it costs the provider in employee wages to provide the service (we lose \$4.50 per hour per service currently). Major providers in the ACT have pulled out of the market and so have many of the smaller providers which has left (organisation names) as the major providers in this space. We will have to look at transitioning out of this cluster if the price does not improve

One of the other issue is that participants who have funds for Support Coordination are utilising these funds for coordinators to engage with the NDIS, phone calls waiting for up to 20mins to get answered, multiple emails that don't get responded to in a timely fashion.

We have to bill 6.3 hours in a 7 hour day in order to just break even. This leaves little time for training, admin etc.

Source: Provider B

The original intention of the 2nd tier of the NDIS – now known as ILC – was to provide the baseline of supports and support connections for the majority of people with mental illness and PSD. This was with the objective of reducing the number of people needing the more intense

and expensive IFPs. The decision to implement the NDIS from the top down has significantly curtailed the ability of the second tier of the NDIS to achieve this:

- When redefined as the ILC, the focus changed to one of connections to services. In a growing number of cases these services have disappeared, or are in danger of doing so due to the impact of the NDIS IFP framework.
- The amount of funding available for this second tier is extremely inadequate given the needs of the remaining approximately 90% of people with PSD and severe mental illness needing support

The expectations in the sector that the ILC can fill the gaps opened up under the NDIS are low. There is also widespread scepticism about the usefulness of appointing a LAC to an area where they have no local knowledge, as has happened in the ACT. Time will tell.

3. Planning Processes

Recommendations

- Unless specifically requested by the participant for something different, planning should:
 - be conducted in face-to-face meetings between the NDIA planner and the participant
 - every effort should be made by the NDIA to ensure that the participant has a support person of their choosing with in meetings with NDIA staff.
- A plan finalisation meeting should be allowed for to explain the plan and the rationale behind it. This would also allow for simple mistakes to be identified early and corrected, without going through a review process. It would also improve transparency of processes, tools and decisions.
- Where a Support Coordinator is named in a plan, this person should be notified before a phone call is made to a participant with PSD.
- Planners should have adequate training (including in interpersonal communication skills) and a sufficiently deep understanding of PSD to be able to produce an adequate

plan for the person's needs the first time. They should be involved in continuous quality improvement of processes.

- Planners could be measured on the basis of adequacy of the first plan produced for a participant; registration of and response to complaints; random observation of planning meetings; and satisfaction recorded with the plan at annual review.
- However, Planners must not be put in a position to wear the burden of NDIA organisation failures to support them adequately in doing their job well.
- Review processes should be simplified and shortened. Whole plans should not be frozen without good reason to do so. Data should not be wiped with the expectation that the participant or service provider then re enter it.

In Section 4 of the Productivity Commission Discussion Paper, 'Planning Processes' a system is described which would be effective if it were practiced (with the notable exception of the use of phone calls). During the ACT NDIS Trial we were moving closer to this type of system and reports were that it was improving the planning process outcomes. However, since national rollout began, things have moved further away from such a system once more. The key issues are:

- Planners are not adequately skilled to understand the complexities involved in living with PSD or how to structure a plan that supports recovery and the episodic nature of PSD;
- The planning process does not involve multiple conversations between NDIA planners and the participant;
- There is a lack of transparency around how decisions are made and the tools used in the process;
- There is a lack of consistency around how decisions are made and the tools used in doing so, as evidenced by the ongoing reports of inconsistent plans;
- Lack of clarity around what are health and what are disability services, means that participants often miss out on crucial services to support their recovery

- Some plans cannot be properly implemented because while one aspect of the support might be funded, another crucial aspect may not be:
 - Particularly in the area of Support Coordination
 - Also, commonly experienced when people need transport funded; or, for example, attend a day centre but are not funded for the activities at the Centre. (See case study 'Afraid of being declared bankrupt under the NDIS')

Using phone calls as the basis for the planning process is very inappropriate and will not produce the best outcomes for people with PSD (and other types of disability). Indeed, it is against the Government's own advice to the Australians in terms of protecting themselves against fraud and scams (see box: Alarm bells should be ringing). Participants have no relationship with the person on the other end of the phone and therefore are at a disadvantage in terms of a planning conversation where they are considered as equals and experts in their own lives and the support they need. ACT experience has been that people with PSD end up with far more appropriate plans when they are supported through the planning process, including the interview with NDIA staff.

Alarm bells should be ringing

'Be cautious if you are contacted by someone claiming to be from the government. If you are concerned, get that person's contact details and phone back using one of our advertised phone numbers.' (Australian Government, Department of Human Services – www.humanservices.gov.au/customer/scams, 20 May 2016)

'NEVER provide or confirm your personal details, or give money to someone unless you made the call using details you found yourself and you trust the other party.' (www.scamwatch.gov.au, 6 May 2011)

'Phone scammers pose as Federal Government employees' (WA ScamNet, <http://www.scamnet.wa.gov.au/>, no date given)

The NDIA (and other government agencies) are increasingly using phone calls to conduct important processes and gather information from some of the most vulnerable people in our society. Concurrently, there are increasing warnings – including from Government – about the rapid increase in incidence of telephone and internet based scams.

- What proof is being given to NDIS participants of the identity of the person on the other end of the phone? How can this be verified?
- Why are calls being made to participants not adhering to a scheduled booking and why are provisions not being made to ensure the participant has a support person with them?
- What sort of monitoring is in place to ensure the NDIA employee conducts the phone call with due care and professionalism?
- What sort of safeguards are put in place in case the phone call triggers an intensification of symptoms or even a crisis (remembering that PTSD, anxiety, paranoia, suicidation are very common in this population group)?

The recent example of people adhering to government advice in terms of protecting oneself against scams and fraud led to many people getting nasty surprises when they suddenly lost entitlements in the Centrelink robo-debt saga.

Using the phone to undertake planning might save time in the short run, but it very quickly leads to other problems which directly and indirectly raise the costs associated with the NDIS. The most obvious symptom of this is the need for plan reviews before the annual review process. Plans that are not entirely used can be a symptom of this also – internal inconsistency can make plans very difficult to implement. Inappropriate plans raise ethical issues resulting in need for a review.

Indeed, when one examines section 4 of the Productivity Commission Discussion Paper, it's very difficult to comprehend how all the steps could be taken effectively through a single phone call.

The plan review process is also woefully inadequate and very costly. MHCC ACT has not heard yet of anyone having a review process that involved an authentic review of the efficacy of the existing plan – what worked, what didn't and where and how changes could be made.

What has been reported is:

- Very brief, surface level conversation
- Phone calls being received before scheduled review and with no warning

- NDIA staff making the phone call do not explain what the call is for or check in with the participant if the timing is appropriate, if there is a support person present, and if the person is well enough to actually best represent themselves at this time
- An extremely strong trend of cutting supports and package value, including in such crucial areas as Support Coordination.

CASE STUDY 7

A flawed planning process producing bizarre results

Second plan – participants needs reduced but more funding allocated

Participant #1 is a 52 year old woman who lives alone who had previously been homeless and sleeping in her car with a history of self-harm. Participant #1 had her first plan which budgeted for *Assistance with daily life at home in the community, education and at work (\$500.00)*; *Assistance with daily life at home in the community, education and at work (19,000+)*; *Improved life choices (\$13,000+)*. During the life of this plan her life improved markedly

Her second plan, however, was perplexing. It increased in value and the funding was allocated in a non-sensical and irregular manner. She received two support budgets: \$39,000+ for *Core Supports* and \$26,000 for *support coordination*. In part this reflects a review process that gave no time to the participant to communicate the positive life changes she experienced during her first plan.

The Support Coordinator considered it unethical to accept this plan as it was. They have other participants with greater need and a much smaller amount of Support Coordination allocated.

Kitchen adaptation funds allocated for participant with brand new serviceable kitchen

Participant #2 is a 38 year old woman who lives alone with mental health issues and stage 4 cancer. Her plan budgets for *assistance with decision making, daily planning and budgeting x 20* which she does not need as she is highly organised and has no issues with managing her finances. It also budgets for *diet consultation and diet plan development x 10* which the participant states she also has nil issues with. The third support budget is for *home modification – kitchen adaption.....so reasonable and necessary decision can be made regarding potential modifications to existing kitchen* Participant #2 lives in a brand new home with a modern serviceable kitchen with all necessary amenities.

Inappropriate plan – demonstrates fundamental lack of understanding of PSD

This example is of a plan that was reviewed prior to review date with no warning; over the phone with a participant who has problems communicating and had no support with her; and which resulted in reduced supports.

Participant #3 is a 43 year old woman who lives alone with a chronic mental health condition which she does not understand or manage without extensive supports and assistance. This woman was contacted by the NDIA two months' prior to her stated review date. She is very quiet and finds communication very challenging. She needs to attend a regular clozapine clinic; she does not drive and is unable to use public transport; she lives a long way from her clinic and does not have close access to health and shopping amenities; she is unable to maintain her home without regular domestic support and she frequently does not provide access to support services.

In spite of comprehensive evidence from her professional treatment team, her review plan included only \$3,000 for the year for support coordination and also included a budget for *finding and keeping a job!*

This woman is unable to manage basic tasks of independence and has a significant untreated substance use issue; and her family are elderly and unable to provide consistent mainstream support. This participant is also at high risk of suicide as she regularly stockpiles medications and alcohol.

Inappropriate process – demonstrates fundamental lack of understanding of PSD

Participant #4 is 64 year old man who lives alone with a chronic mental health condition which he has little insight into or understanding of; he also has significant health issues – tardive dyskinesia – which means he has frequent burns to his hands when making hot drinks for himself. He has a very involved long-term carer who does not live with him and a very involved long-term clinical manager. This man also lives with significant thought disorder and frequent delusional thinking. This man was contacted by the NDIA for a plan review over the phone to which he consented. A new plan was made without any notification to mainstream supports and the participant does not know if he has received his plan in the mail or not.

Yes, you are eligible! No, you are not!

Participant #5 is a 27 year old man who lives with his mother and has mental health, a chronic health condition and cognitive impairment. His mother reported that she received two letters – both dated the same day with one stating that her son is ineligible to the scheme and the other letter stating that her son is eligible to the scheme. The mother phoned her son's service provider totally confused.

Source: Provider R, 2017

There is also cost shifting onto participants and providers during the planning and review processes. The time involved in working with a participant to prepare and engage with planning processes is not built into any aspect of the NDIS pricing framework; the same applies to the review processes.

The review processes themselves are problematic. Whether it be an interim review or annual review, the NDIA imposes a mandatory freezing of the entire package and removal of it from the portal. This means bookings can no longer be accessed and payments for services cannot be made. At the end of the review process, the Provider/Participant is expected to re-enter all the valid information that was removed.

This is applied with no exceptions – even if it's a case of needing a simple mistake corrected. In most cases, service providers keep providing the service, but by doing so they take on the financial risk of eventually being paid for their work. Reviews are also taking a very long time to complete. People are commonly informed that it will be at least 8 weeks. There is a perception in the community that this is a mechanism to deter people from asking for any type of review in the first place.

The implications for scheme sustainability from the points made above are not good:

- High costs of getting plans wrong and review processes that exacerbate these costs
- Participants are losing faith in the NDIS
- Providers are having costs shifted onto them which are not funded

CASE STUDY 8

Costly glitches in the system

“One of my participants went for an early plan review on 6 February 2017. According to her old plan, the review was to be in April 2017.

“The new plan began on 21 February 2017 and all the service bookings that were active in the old plan were made inactive on the portal by the NDIA. Due to what I believe to be a glitch on the portal, I am unable to make a standard service booking to activate the new plan. Although the plan says there is \$1369.12 in CB Choice and Control, when I make the service booking I get an error message that says there are no funds available. I have written 3 emails to the NDIS about this with no response. I emailed a formal complaint to them yesterday.

“This is particularly problematic for reviewed plans because we have regular services already in place. Our participants continue to receive services but we are unable to pay any invoices, because we cannot claim the funds from the portal. Also in the case of my participant she is wanting to go to hydrotherapy but we can't start this until we know that the service can be paid for through the portal.

“We waste an inordinate amount of time trying to sort these issues out with the NDIS. At this stage we have four participants that are affected by this 'glitch'. A staff member spent 45 minutes (probably mostly on hold) to the NDIS trying to sort this out to no avail.”

Source: Provider W, 2017

4. Market readiness

Recommendations

- Slow down the pace of NDIS implementation – replace costly mistakes with getting it right in the first place; revise targets to align with achieving quality outcomes
- You get what you pay for – quality of outputs (services) is a direct result of the quality of inputs (what you pay for qualifications/skills/experience of workforce)

- Build a system that demands and pays for a minimum Cert IV qualification as an entry level requirement for at least 75% of the workforce (look to the example of the ACT experience in achieving this)
- Ensure staff understand properly the complexities of the different sorts of disability and what it takes to support people to a level in keeping with NDIS objectives.
- Cutting corners and cost shifting is false economy – services will become unavailable and people with PSD will end up in the more expensive end of the health system
- Simplify service registration processes – especially in cases where a recognised qualification and member of appropriate professional body can be demonstrated

The speed of implementation of the NDIS is having a detrimental impact on the scheme. We have seen the focus placed on achieving target numbers (ie outputs) rather than solid consistent decision making (ie. outcomes). This is a false economy (if indeed any economy was involved to begin with) as it increases the costs associated with subsequent review processes; people falling through the gaps; heightened distress levels in people with PSD leading to hospital admissions in some cases; quality services being withdrawn or falling over; and experienced professionals leaving the sector. Of course these things are associated with any change process – but the extent to which this is happening in the area of PSD is alarming.

The PSD service sector already operates in a market. There is already competition between services of many kinds to attract and retain clients, win government contracts, gain philanthropic funding, and the like. Small local services are now increasingly competing with larger nationwide services. The model introduced by the NDIS though is NOT a market – for a start it is based on a premise of fixed prices, and to make matters worse, these prices are not reflective of the true costs of running innovative, efficient businesses delivering quality outputs. It is also replete with information gaps, conflicting information, inconsistent outputs from the NDIA.

The NDIS framework is also leading to a 2-tiered system: those who have the personal or financial capacity to self-manage are able to use their funds to effectively subsidise fast access to quality services of their choosing. Those who are agency managed must choose from the services available at NDIA prices.

CASE STUDY 9**Provider de-registers from NDIS**

The NDIS sets the basic rate for support work at \$43.58 per hour.

"Ultimately that NDIS rate is a bargain basement rate for what is expected to be a platinum quality service," said Rob Woolley, general manager of Just Better Care in the ACT.

Just Better Care charges non-NDIS clients \$52.80 per hour.

Mr Woolley's company has decided to de-register from the NDIS. That means it will not be bound by the scheme's rates — but it also will not be able to do any work for the majority of NDIS participants whose plans are managed by big agencies.

The company said it had no choice because it lost \$200,000 last year providing services on NDIS rates. "We think we're a prime example. If we can't make it work, nobody can," Just Better Care Canberra owner Mr Fergus said.

Mr Fergus said other providers are also thinking of de-registering. If that happens, the number of workers available to provide services at NDIS rates could collapse. "This is a great scheme. We've seen some fantastic outcomes with the people that we work with," he said. "But this pricing issue ... is putting that at risk."

Extract from Canberra Times article by Norman Hermant, 6 January 2017

MHCC ACT has significant concern around workforce issues and NDIS participants with PSD.

The NDIS pricing framework is lowering the quality of the workforce that Providers can afford to employ – in terms of qualifications, skills and experience; and terms of employment (highly casualised). This is a false economy as without adequate support many of these people will increase their access to the more costly clinical and emergency health services. Not only are community managed mental health services cheaper to provide they consistently produce better outcomes. People's wellbeing is improved by being supported in their community rather than a hospital.

Where once a Cert IV level qualification was established as a minimum qualification to do this work; there is now talk in many quarters about lowering this to Cert II level qualification - the level that organisations can on average afford to pay for under the NDIS. This creates ethical

dilemmas for service providers: How can an organisation continue to provide quality, whole person, values driven recovery oriented services? Does it commodify its services to remain viable under the NDIS but do so with the realisation that this is not in the best interest of the service user? Such dilemmas have already resulted in one ACT organisation announce that it will be deregistering from the NDIS (see case study), and others withdraw well respected services with proven outcomes.

If the new minimum standard was to become a Cert II level, it would represent a significant de-investment in the ACT community mental health workforce. There has been a successful government and industry policy to improve quality and standards such that 75% of the workforce have at least a Cert IV qualification in the ACT. An unforeseen flow on from policy was that before the NDIS Trial in the ACT, organisations were increasingly reporting university level qualified experienced people applying for positions. Now they are reporting losing their most experienced staff in pursuit of more job security and equivalent or better pay.

The other likely consequence of lowering qualification levels of those working with people with PSD, is that at best the sector becomes a training ground for new graduates who leave after gaining enough experience – producing a high churn rate and therefore increased recruitment, training and induction costs; as well as time spent building relationships between new workers and existing service users. This would be exacerbated by organisations' inability to provide any sort of prospect for a career structure. This is in an industry already known for having relatively low pay rates, and small pay differentials between early and advanced career positions. Under current NDIS framework it is hard to see how casuals/part-time workers could be transitioning to full time workers where the experience since NDIS introduction is in the opposite direction.

So yes, there is knowledge that pay, career structure and conditions are not competitive with many other areas of the job market people can take these same skill sets to. The best way to overcome this is as simple as it is difficult to make happen: to understand and recognise the value of this work, and pay for it accordingly. This is obviously not something the government wants to hear but it is the simple reality. People need a reasonable income, job security, an ability to support their families. People living with PSD – some of the most vulnerable people in our society – deserve to receive services from well-qualified staff.

The lack of quality and safety framework from the beginning of the scheme putting workers and participants at risk. For example, where it was once standard practice to send workers out

in pairs in many circumstances, the NDIS framework does not support this, posing risks to both workers and service users. How do we know that appropriate services are being delivered without this Framework?

Another related area of risk for Service Providers is the lack of information provided by the NDIA to service providers about participants. Where once this information was accumulated as part of the process of getting to know the client, establishing a relationship, determining how best to support the client; now the client comes with funding for a service but no background information. How does one keep clients and staff safe in such a situation? Indeed, how can such a situation produce an appropriate client focussed service?

Many people with PSD don't have access to IT devices; are afraid of them; or unable to use them. This must be factored into thinking around service provision and management under the NDIS. Service Providers are already often placed in the unenviable position of having to help participants use the My Gov website in order to use their NDIS plans, including by entering passwords – technically this is breaking the guidelines of use, possible the law.

There may be some areas of work where skilled migrant workers are can help build workforce capacity. Working with people with PSD requires sound interpersonal communications skills. There are also cultural issues associated with different attitudes towards mental illness; and cultural differences in having people work with you if from a different cultural background: in the ATSI community, for example, we have been told that many people would prefer no service to having a service delivered by a non-ATSI worker. These factors provide both opportunities and impediments that need careful consideration.

Service providers have been reporting from the beginning of the ACT NDIS Trial the difficulty in engaging people with PSD with the NDIS. This problem is not going away – if anything it is starting to get worse as more people have negative experiences, and word spreads. People are choosing not to test their eligibility or are dropping out due to the complexity and frequent frustration involved with navigating the NDIS. It is making their mental health issues worse.

CASE STUDY 10**Falling through the gaps to unwellness**

Under block funding we were contracted to operate Open Art – an early intervention program for people suffering from mild to moderate mental health issues. Open art was just that - an art program engaging people in art therapy.

We had one participant James, (name changed) 64, whose wife had had a serious accident requiring him to become a full time carer. During this time he had a breakdown suffering from anxiety and depression. He was referred to Open Art and attended twice a week for 4 hours each time. He attended for 6 years and was well on the way to recovery and managing his health. However, with the introduction of the NDIS and the withdrawal of block funding James was no longer able to participate - he was not unwell enough to receive a package under the scheme, and he was also on a low income so did not have capacity to pay for the classes.

The result for James is his disconnection from community, his time to be creative and restore his wellbeing

Source: Provider B, 2017

The introduction of the NDIS is a massive social reform. It has required huge cultural and business model changes of service providers. To a large extent this change has not been made in partnership with service providers – indeed they have regularly been made to feel part of the problem instead of part of the solution. The very positive change to increase consumer choice and control should not necessitate pushing to one side the substantial experience, knowledge and understanding of how to deliver recovery-oriented services to people with PSD.

The move from block funding to clients purchasing services directly from service providers has happened way too quickly. This has been exacerbated by the NDIS financial/price framework which reflects a fundamental lack of understanding of the costs involved in delivering quality recovery oriented supports to people with PSD. Services have been commoditised by the NDIS in what is actually a market that needs to be values driven with a whole person/whole of life approach; with flexibility to adjust to the episodic nature of PSD as well as each individual's particular circumstances.

As a result, service providers in the ACT are generally working at or beyond capacity. Financial stress is high – MHCC ACT has been told that many providers are carrying levels of debt in the vicinity of \$200k. They are relying on cross subsidising from other services or the remnants from block funding. This is clearly not sustainable. In the meantime, participants with NDIS plans are reporting that they can't find providers with capacity to provide the services they wish to purchase.

The other issue in regards to this is the substantial amount of unpaid work required of service providers to support potential NDIS participants engage with the NDIS. It is not unusual for service providers to invest 30 plus hours in this process, sometimes spread out over months. This work is not paid for by the NDIS in any way.

5. Governance and administration of the NDIS

Recommendations

- Government take a partnership approach with service providers, carers and consumers in all aspects and levels of the administration and governance of the NDIS henceforth.
- Establish an effective and independent complaints mechanism for times when consumers, carers and providers cannot resolve issues satisfactorily with the NDIS. This mechanism needs to have power to make things happen.
- Ensure that the NDIA has the capacity and flexibility to administer the NDIA effectively while at the same time not just becoming another large bureaucracy.
- Cost shifting to service providers especially, but also to a lesser extent to consumers and carers (especially with self management), is an issue with the way the NDIS is being implemented and administered
- It should be measured regularly and reported;
- strategies put in place to minimise the extent of cost shifting
- mechanisms established to provide fair recompense to providers when cost shifting is unavoidable, in the interests of service sustainability.

- A better system be established to monitor the performance of the NDIS; this should include some outcome measures and more realistic measure of satisfaction of NDIS participants and providers. It should also involve some level of independent oversight.
- Clarity is needed between the roles and responsibilities of different levels of government; and between DSS and the Department of Health. Buck passing needs to stop. We need both a health system and the NDIS and a seamless set of services so that no one falls through the gaps.

It is difficult to provide much detail in this area. The experience interacting with the NDIA definitely leaves one feeling like ‘the other’. There is a general lack of transparency and willingness to engage with non-NDIA staff in a genuine partnership relationship.

The NDIA reporting mechanisms do not give much insight into anything other than numbers. The way they measure participant satisfaction can only be flawed as the level of dissatisfaction being reported is too widespread. The other stakeholder in this system – the service providers – are not represented in this reporting. These reports appear to have been designed to paint only a rosy picture.

The statement on page 28 of the Productivity Commission discussion paper - *“The risks associated with devoting too many or too few resources to the administration of the NDIS may not be symmetric. While a generous operating budget could be wasteful, insufficient funds could curtail the NDIA’s ability to deliver the scheme efficiently (and result in higher package costs).”* – is the key challenge in this area.

MHCC ACT would also argue that the degree to which the right balance is struck in this regard influences the amount of cost shifting that occurs. At the moment the level of cost shifting from the NDIA to the service providers/consumers/carers is massive, and almost totally unfunded. This is particularly in the areas of administration, registration, engaging people with the scheme and mid plan reviews. As such, the real costs of the NDIS are understated – possibly to a significant degree.

The other aspect of getting this balance right is the extent to which end users – consumers and carers – actually do experience greater choice and control and a more user centric system; that they find themselves no worse off; that they are meeting more of their life goals.

They also need to feel that the impact of PSD on their lives is properly understood; and that decisions are being made by people who are adequately trained and treat them as equals.

The NDIA's market stewardship has been totally inadequate. It is one thing to implement and support a change process. But if the process is designed in isolation from those providing and using the existing system; if the pace of change is unreasonably fast; if the uncertainty too high and widespread; the missing information too great; the ground constantly shifting beneath providers and users feet; the integration with other parts of the system missing; the resources not available to implement it; and the alarms raised by experienced professionals ignored – then that change process will fail. This describes the experience in the ACT during the change process, the consequences of which have been discussed throughout the report.

Another part of the failure of stewardship is the sharing of lessons learnt in the trial sites. This is invaluable information which would help prevent the repeat of costly mistakes and provide transparency around why decisions have been made in the way they are as the scheme continues to be shaped and built. Similarly, there has been no sharing of submissions made in response to policy consultations.

As the peak body for community managed service providers in the ACT, MHCC ACT has witnessed on many occasions very legitimate concerns dismissed as motivated by self interest, a reluctance to face change, and a lack of innovation and professionalism. The message is very much 'get used to operating in a market place – that is your new reality'. Obviously people delivering this message have not studied economics or they would have realised that fixed prices deliver market failure, not robust markets delivering quality outputs.

This new 'market' has been developed and implemented from the top down. There has not been a partnership approach, it has not acknowledged the valuable expertise available to inform the system, and very importantly, it has involved the destruction of evidence based programs that have been professionally evaluated and shown to be highly effective. Personal Helpers and Mentors; Partners in Recovery and Day to Day Living being very good examples of such programs in the ACT. Partners in Recovery has been described by many people as the single most effective system they have experienced.

6. Paying for the NDIS

Recommendations

A bipartisan commitment be made at all levels of government to:

- a transparent and sustainable way of ensuring the NDIS is funded such the scheme produces tangible benefits to all Australians over time; recognising that:
 - the NDIS is one part of the broader health and wellbeing system, and the importance of it being well integrated with these other services
 - properly addressing the social determinants of health are also a vital part of ensuring the success of the NDIS
- the NDIS is viewed as an investment in our future;
- the objective over time is for the NDIS to become a world best practice model for supporting people with disability.

The simple message here is that the costs of disability do not disappear. But there are more and less efficient ways of managing these costs.

CASE STUDY 11

Complexity of the scheme causing undue distress and cost shifting

Organisation A has been experiencing an increase in highly distressed and unwell consumers, many of whom have demonstrated suicidal ideation. When explored further, many of the consumers reported that attempting to deal with the extreme complexity of the NDIS application process was the cause of their downward turn. Some felt that one had to be exceedingly intelligent to deal with the application. It was agreed by this committee that this was indeed so.

Moreover, Organisation A felt that this 'spike' was also due to the fact that the NDIS funding cuts did not allow NGOs to provide psycho-social support, ie. case management workers. Consequently, the psycho-social support that was available to consumers before the introduction of the NDIS was no longer available to them, leaving consumers who are unwell.

Finally, even when consumers were approved for generous NDIS packages covering a wide range of services, the cuts in funding to community support services mean many of the services approved of in the package were just not there anymore

Source: Peak Body C, 2017

Feedback from engagement forum with tertiary emergency MH services

The National Mental Health Commission demonstrated very clearly the costs associated with mental illness and the benefits of getting our approach right, for all Australians, in their 1 December 2014 report, “Contributing lives, thriving communities – Review of Mental Health programmes and services”.

The most costly system is one in which people die; have a high churn rate through the more costly hospital and other tertiary mental health systems; and unpaid carers cannot participate in the workforce and end up unwell themselves. The NDIS is an investment in a better and more cost effective way of supporting disability and keeping people out of hospital. It will take time before the benefits flow, especially in a more systemic way. We should not let short termism undermine this potential.

In many ways what is confronting about the cost of providing the NDIS is that perhaps for the first time we are being presented with a better picture of the true financial commitment involved in supporting disability properly, and in a way that enables more people to actively engage in their lives, communities and the economy.

END.