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Introduction

This is one of three papers prepared by Psychiatric Disability Services of Victoria (VICSERV) for the Victorian Department of Health and Human Services. The papers aim to build understanding about the lessons in mental health of the introduction of the National Disability Insurance Scheme (NDIS) at the Barwon launch site in Victoria, particularly ahead of the future roll-outs of the Scheme in 2016 and beyond.

This paper presents in-depth case studies of consumers and family/carers in Barwon.

The original purpose of the Case Studies paper, when it was proposed as part of the VICSERV Project in 2014, was to:

- Provide detail and analysis of the similarities and differences – in client assessment, service models, service provision and outcomes – between a Barwon NDIS trial site client and a Community Mental Health Support Service (CMHSS) client in another Victorian non-NDIS region.
- Detail and highlight the support currently available to families and carers through Mutual Support and Self Help Group funding in the Barwon launch site.
- Provide consumer perspectives on their experience of the National Disability Insurance Scheme (NDIS) through the whole process from establishing eligibility to receiving a plan.

The Paper was intended to provide a sharp 'compare and contrast' analysis of the types of support available under both service platforms, to enable an understanding of the differences and similarities in both supports and approaches to support delivery between the two services.

The State-funded mental health services in the Barwon launch site were due to transition away from Victorian Government block funding to National Disability Insurance Scheme funding in December 2014. The block funding however was continued by the State Government beyond December 2014 for a further six months. As a result, the community mental health services in Barwon retained their capacity to employ their skilled and experienced workforce and to provide a greater array of services, as their unit price funding was not reduced. The 'NDIS-only service provision' in mental health did not occur.

As a result, the in-depth case study of the Barwon consumer does not reflect a pure National Disability Insurance Scheme (NDIS) Plan. At the time of writing, service providers and consumers report that consumers in Barwon often receive supports that are both different and beyond the scope of their National Disability Insurance Scheme (NDIS) Plan because the service providers have the capacity and capability to do so. The service provider in the case study, for the reasons described above, was therefore able to provide a far greater range of services, flexibility and responses than what is contained in the consumer's National Disability Insurance Scheme (NDIS) Plan.

The planned 'compare and contrast' case study has subsequently not been able to describe significant differences in client assessment, service models, service provision and outcomes between the Barwon NDIS trial site client and a Community Mental Health Support Service (CMHSS) client in another Victorian region.

What has been possible to describe are the packages of support, approaches and models of care that are currently available in state-funded mental health services in Victoria and which we believe must also be included under the National Disability Insurance Scheme (NDIS).

This Paper has been able to detail and highlight the support currently available to families and carers through Mutual Support and Self Help funding in the Barwon launch site and, as originally intended, provide consumer perspectives on their experience of the National Disability Insurance Scheme (NDIS) process, from establishing eligibility, to receiving a plan.



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Thanks also to the Victorian Department of Health and Human Services for providing the funding for this project.

Methodology

Six case studies have been prepared from interviews with consumers and support workers. The case studies are included in Appendix One and provide detail on engagement, goal setting, assessment, support models, worker skills and outcomes achieved.

One of the case studies is about a consumer outside of the Barwon region. This case study is used in Section 1 to compare with a case study about a consumer with a National Disability Insurance Scheme plan and supports in the Barwon region. A case study on carer support has been used in Section 2 to highlight family support provided through Mutual Support and Self Help Funding in Victoria.

Nine interviews were conducted with consumers on their experience of the National Disability Insurance Scheme. These interviews and the case studies are the source of consumer comments in Section 3 on the National Disability Insurance Scheme process and the supports they are receiving.

Consumers were recruited for interviews by advocacy services and mental health community support services. Recruitment was on the basis of finding consumers who were interested in participating in the research and had experiences that highlighted the impact of the National Disability Insurance Scheme. Consumers' names have been changed to protect their identities. The names of services and workers have also been omitted for this reason.



1. Comparison of a Barwon mental health (block funding) support package with a Victorian Mental Health Community Support Service support package

Introduction

The aim of this case study was to compare the individual support provided to a consumer in the Barwon National Disability Insurance Scheme (NDIS) trial site with that provided to a consumer of a state government funded Mental Health Community Support Service in another region of Victoria.

As discussed above, due to the continuation of the State Government 'block funding' to National Disability Insurance Scheme funded mental health services in Barwon, this case study provides an analysis of the packages of support, approaches and models of care that are currently available in state funded mental health services in Victoria.

The two consumers interviewed have similar demographic characteristics. Their support workers were interviewed separately to provide a service provider perspective. The similarities and differences between the two services in goal setting, assessment, support models and outcomes achieved are discussed and highlighted.

Consumer representatives

Adam lives in the Barwon region and receives individual support from a state funded mental health service provider. He has a Plan from the National Disability Insurance Scheme (NDIS). He is in his early 20s, has a diagnosis of schizophrenia and lives at home with his family. He is also a client of a local public mental health service. Adam was unwell when he first came to the community mental health support service (from a National Disability Insurance Scheme (NDIS) referral) and had recently had an acute psychiatric admission.

Liam has been receiving individual support from a Victorian state funded Mental Health Community Support Service for approximately 12 months. He is also in his early 20s, with a diagnosis of schizophrenia and lives with his family. Liam also had been unwell when he first came to the service and reflected that at the time.

I was an absolute mess. I was having my episodes of schizophrenia all over the place. I was a horrible mess. I was hurting everyone around me: not physical – frustrating them, making them angry. Just because I didn't have the social skills not to. (Liam)

Assessment processes, care coordination and risk

Adam's story highlights the importance of assessment processes and coordination with carers and clinical services for consumers experiencing episodes of acute mental illness.

A month after Adam attended a meeting with a National Disability Insurance Agency (NDIA) planner, the community mental health support service received part of his Plan with the line items associated with the supports Adam chose from their service. A worker from the service contacted Adam, who initially declined the service. In the course of the conversation the worker identified that Adam was probably unwell at the time and obtained his consent to talk to his mother who, in turn, asked the worker to talk to Adam's treating clinician. The mental health clinician advised on Adam's mental health, treatment, psycho-social support needs and how individual support could fit in with Adam's treatment plan. The service was requested to participate in future case conferences. A request was then submitted to the National Disability Insurance Scheme (NDIS) for care coordination. Given Adam's fragile mental health, the support worker continued to consult on a weekly basis with Adam's mother and treating clinician for a month before funding was approved.



Adam's worker has taken a very coordinated and collaborative approach to his recovery, working closely with his family and clinical mental health service:

If Adam wasn't receiving support from any of us, he would be extremely unwell. Now he is able to come to (clinician) or myself when things are not going well. She may give me a call when things aren't 100%. She has worked with him for longer, had more insight. I was able to speak to her and she advised how to approach Adam and what is and is not appropriate, how far to push him, communicate re his medication. If an episode occurs, if concerned, I can ring her and see if she has seen him and if anything has occurred. If she has advised he has been a bit unwell we might just have an appointment in his home, might not go as far. Not putting him in situations where it may make it worse. (Adam's worker)

Liam was referred to the Mental Health Community Support Service (MHCSS) by a mental health nurse working with his private psychiatrist. The nurse provided background information on his mental health status and support needs. At intake Liam met with the service's manager who went through a registration process including an initial risk assessment and management plan. Whilst no immediate risks were identified in regard to his mental health, he was experiencing psychotic symptoms and was initially seen on a weekly basis. This has moved to fortnightly visits as his mental health has improved. Liam and his worker are in the process of organising a joint appointment with his psychologist as Liam has said that he sometimes forgets to raise issues he needs to address at these appointments.

Comparison: The Barwon service, in contrast to the Victorian state government funded service, did not receive background information from the National Disability Insurance Scheme (NDIS) about Adam's clinical history, current mental health status or recent psychiatric admission. The National Disability Insurance Scheme (NDIS) assessment and referral process could have seen Adam miss out on a service altogether or receive supports in a way that could exacerbate his mental illness.

Goal setting and support models

Liam and Adam's experiences of schizophrenia have fractured their sense of identity and self-worth. They speak about their goals, activities and relationship with their support worker in terms of wanting to change: to feel whole and worthwhile.

I wanted to be able to save money. I wanted to be able to feel like I was worth having on this earth. I wanted to feel complete. (Liam)

Leisure activities, social, talking about anything I need to talk to. I like it a lot, I think it is necessary. Doesn't hurt to have someone in your life, someone you can interact with, look forward to. See how I am going. Think there would be a lot of (voices) without (worker's name). Need to have people interaction. I think I have changed, getting to know what it is like to be human, getting to know what he thinks about things. (Adam)

Adam: Adam's goals were established through a meeting with an National Disability Insurance Agency (NDIA) planner. Adam found the National Disability Insurance Scheme (NDIS) planning process 'a bit intense for me.' The goals in his plan are to participate in activities he enjoys, such as a (name omitted) group, get to places on his own without relying on his mother for transport, and to get a job.

Adam's initial funded supports for the community mental health support service were for 13 hours per week of group based activities and 12 weeks of individual social skills development, at which time a report on progress would be required. Funding for one hour per week of service coordination was requested by the mental health support service and approved by the National Disability Insurance Agency (NDIA).



Adam's service uses the Mental Health Recovery Star¹ as a tool for supporting consumers to manage their mental health and support their recovery from mental illness. It is completed collaboratively by the service user and worker and measures and supports progress towards goals. Adam is not yet ready or able to engage with these tools and might take some time given his fragile mental health. Working with him has been a slow process of building rapport and trust over a period of months.

Adam has not been attending any groups since issues about his behaviour in a group were raised before the commencement of his National Disability Insurance Scheme (NDIS) funded supports. He is very clear that he doesn't want to attend at the moment as he is nervous that he will slip up and talk about the wrong things.

Adam struggles with communication skills, needs a lot of work, doesn't understand barriers and wouldn't be able to read people's facial expression. [He] can be in your face. (Support Worker)

Adam is benefitting from, and is very positive about, the individual support he is receiving on social skills development. The group support funding in his Plan is not what he needs or wants at the moment. (As a result the group support hours are not being used).

A lot of assumptions are made in relation to the participant, he doesn't have the insight to understand what it means for him: [he] might say 'I want to join groups' but (the planners) don't look at what he needs to achieve this. [He] probably should have started off with one-to-one support with the worker. That is the gap. It makes our job hard, we're put into a situation where we have to say 'we can't approve that because it's not on the Plan' when the process of getting on a Plan is very overwhelming. They almost have to beg for the National Disability Insurance Scheme [NDIS] to give them that line item. (Adam's Support Worker)

Liam: Liam's Mental Health Community Support Service (MHCSS) uses the Collaborative Recovery Model (CRM) as the practice framework.² Liam's support worker talked about how the service uses the three main tools – the 'Camera', 'Compass', and 'Map':

The Camera is about identifying values, Compass is specific goals and setting them, looking at motivation levels and confidence: how you might over-achieve in that area or you might not quite reach the goal and what that looks like. Then there's the Map tool that really breaks down the goal into steps – it supports potential barriers, solutions to those barriers. We kind of work through these sheets either in conversation form, without the sheet if that is what someone prefers, or if that is the best way to engage someone or we can sit there and do it with them. (Liam's Support Worker)

The approach to goal setting and developing a plan with Liam within the state funded Mental Health Community Support Service (MHCSS) has been gradual with the support worker taking a coaching or motivational interviewing approach to working with Liam to 'look at what he values in order to think about what is most important to him and what he wants to work towards.' From identifying values, they move on to him setting goals and then identifying the steps to reach his goals. Liam was very positive and said: 'We just talk about them and do those little form things and write things down, make graphs, just stuff, it's so helpful it really is.'

¹ The Mental Health Recovery Star is a tool developed in the United Kingdom that is designed for adults managing their mental health and recovering from a mental illness. It is completed collaboratively by the service user and worker and measures and supports progress towards goals.

² The Collaborative Recovery Model is a recovery-oriented practice framework developed by the University of Wollongong with a focus on increasing wellbeing and promoting psychological recovery.



Comparison: For **Adam**, the National Disability Insurance Scheme (NDIS) process has been a barrier to the mental health community support service changing supports in response to his changing needs and stated preferences.

For **Liam**, in the state funded Mental Health Community Support Service (MHCSS), system goal setting and developing plans to meet his goals, has been very flexible and very much about supporting him to identify what is important to him and what steps he is going to take to reach his goals.

Skills of workers

Both of the support staff working with Adam and Liam display skill, flexibility and insight in their work. Both employ coaching skills and work within a recovery oriented practice framework that balances a duty of care with self-determination.

Liam: Liam's support worker explained a recovery oriented approach and how principles of self-determination and efficacy/self-management inform her practice:

When I began work with him he was struggling more to do activities of daily living like clean up after himself, cook, get out of the house. And at that time I could have signed him up to a whole bunch of groups, made phone calls and pushed him into things. Instead I made him aware of the opportunities that are out there, told him of the groups at (organisation name). I let him decide what he wanted to do, make his own decisions, perhaps make some of his own phone calls to make that happen. It is hard to know how much support to give and how much you step back. I think that is always going to be a bit of a tension. On that note if someone is in crisis we will respond to that. (Liam's Support Worker)

Adam: As Adam has been unwell his support worker speaks with Adam's mother weekly and has met with Adam and his family several times in the past few months. This has provided his worker with important information for coaching and supporting Adam around his social skills and behaviours. (This work is not formally funded through a National Disability Insurance Scheme (NDIS) cluster).

....Adam's mum will bring up concerns, an opportunity to have a conversation with myself there in relation to some of his behaviour re engaging with other people or disappearing for hours. I can then take that and think about how I can support Adam re this.... They know Adam a lot better than I do. Adam may get defensive and might say, 'I don't want to talk about this' but it gives him an opportunity to listen. It is important for the participant to be part of conversations, it's about them not what I or his Mum wants. It's about supporting him as much as we can and supporting him to understand. (Adam's support worker)

Outcomes

Both Adam and Liam have experienced improved mental health since commencing with the community mental health support services. They are both very positive about the support they have received and the progress they have made towards their goals.

Adam has regained enough confidence to start going out on his own and recently went to the movies by himself. He is very keen to get a job and is hopeful of getting work one day a week through his disability job service provider. The community mental health support service has been very persistent in providing Adam with a very sensitive and coordinated service to best support him in his recovery.



Liam said about working on his goals:

Feeling complete was helped by making those decisions easier. I still feel like I am missing some things, but I can't have everything. Saving money: they helped put plans in place that I didn't stick to at the time because my impulse control was horrible. Thankfully that is a lot better now though.

Conclusions

The case studies show many similarities in the services provided by mental health service providers in Barwon and the Victorian state government funded Mental Health Community Support Service (MHCSS). (As described in the Introduction, the block funding that was continued by the State Government in Barwon has meant that the community mental health services in Barwon have retained their capacity to continue to employ their skilled and experienced workforce and to provide a greater array of services than is currently available under the National Disability Insurance Scheme (NDIS) clusters and pricing.)

The **similarities** include:

- Goal setting is determined by the consumer and can change over time.
- Workers are skilled in working in a recovery practice framework including gaining trust through insight and empathy; establishing a therapeutic working relationship; using coaching techniques; supporting self-determination; and having a good understanding of mental illness and its impact, duty of care and clinical risks.
- Both workers are able to assess changing needs and provide flexible support in response to the fluctuating requirements of the consumer.
- Both organisations work within an established recovery oriented practice framework.

The **differences** include:

- The Barwon National Disability Insurance Scheme (NDIS) Plan was for 13 hours per week of group based activities and 12 weeks of individual social skills development.

The **unknown factors** include:

- It is not clear whether this level of worker skill would be available at the current National Disability Insurance Agency (NDIA) unit average price of \$35.
- Some examples of the support that would not be ordinarily funded/ provided in the National Disability Insurance Agency (NDIA) Plan but were apparent in the case study include:
 - phased engagement with an individual worker over a number of months
 - case conferences/meetings with the family and clinicians
 - flexibility to respond to Adams needs outside the itemised service items.

Assessment and goal setting:

- The National Disability Insurance Scheme assessment is mostly a 'one off' opportunity to identify the consumer's goals for their Plan (usually 12 months).
- Adam had 13 hours of group support identified when in fact he was unable to attend the group identified in the plan.
- Without significant worker intervention there is little opportunity within the National Disability Insurance Scheme (NDIS) to change the goals and services where the consumers' needs or goals change.
- Where a worker identifies the need for a significantly different intervention (such as with Adam), it is up to the worker and the organisation to make a choice to act outside of the Plan. This risks a service not being paid at the rate of the intervention if it is not in the Plan, which could limit flexibility and responsiveness.



Risk Management / Assertive Support

There was no indication in the National Disability Insurance Scheme (NDIS) Plan received by the organisation of Adam's mental health status, recent psychiatric admission, or any risks that might be apparent. The worker was able to identify in the first telephone conversation that Adam was possibly unwell. A less skilled and experienced worker may have taken Adam's statement that he did not need support at face value and not followed up any further. In this case study, the worker was skilled and experienced enough to identify that he was not well and subsequently followed up to gather more information to ensure he could assist Adam appropriately.

The key differences highlighted by these case studies are a greater capacity within the state funded Mental Health Community Support Service (MHCSS) to:

- identify clinical mental health history and risks in the referral and intake processes
- take a developmental or gradual approach to assessment, goal setting and progress towards recovery
- quickly change what supports are provided and how much support they provide in response to consumer needs, particularly in response to deterioration (or improvement) in mental health.

These differences reflect the episodic nature and risks associated with serious mental illnesses. They also reflect the fact that community mental health support services have a rehabilitation or recovery focus. Processes and practices have developed holistic models incorporating recovery and self-determination, balanced with a duty of care in relation to the risks posed when someone is acutely mentally ill.



2. Carer case study

Introduction

This case study outlines the range of supports provided to a carer through a carer support service in the Barwon Region. Mutual Support and Self Help funding is provided to a range of services across Victoria that provide information and peer support to people with a mental illness and/or their carers. The carer support service provides a wide range of support including information and advice, support around relationships, advocacy and education. The future of this funding is uncertain and may not be available in the Barwon Region, if current block funding of community mental health support services ends.

Kathryn is the carer for her sister, Angela. The family live in the Barwon region and are from a culturally and linguistically diverse (CALD) background. Kathryn found out about the National Disability Insurance Scheme (NDIS) from a supported residential service where her sister had been a resident. She was told about the carer support service through a contact at the local area mental health service where Angela had formerly been a client. Kathryn assisted her sister to apply for National Disability Insurance Scheme (NDIS) funding as she had Angela living with her, was tired and was *'finding it really hard to do everything.'*

Model of support to carers

Kathryn contacted the carer support service and, according to the carer support worker, *'came in because she was struggling a little bit, things weren't going too well.'* Kathryn had a range of financial, health and emotional crises and initially the carer support worker organised assistance with bills from a carer brokerage fund.

The carer support worker feels that the family has done a lot to support Angela, but that this had put their relationships under a lot of strain and that:

I think that my involvement has been able to assist Kathryn and her mum and dad to keep a more loving relationship going to the best of their ability. I think they learnt a few things where they can keep the relationship.

The worker organised for Kathryn and her parents to attend a carer program run by (organisation name). Kathryn said:

So I think them attending the course kind of helped me then to give them a better understanding of why I am doing certain things and at the same time I had to change my ways as well.

The carer support worker explained how the service works:

We do a care plan and work out where the priorities lie. Chat first, unburdening, how things are going, not (as) a counsellor.

They will then identify areas where the service can assist, such as offering a healthy lifestyle program or family education program delivered by family members/friends of someone with a mental illness. The service *'gives structure, sees them for 8 months or so'*. Then:

If anything comes up they would be communicated to. If they needed something I would hope they would contact me. ... With Angela and Kathryn, we will touch base through communications: mail outs, emails, text messages. She comes in here with Angela a lot.

The carer support worker is doing more advocacy work in attending meetings with carers and consumers since the commencement of the National Disability Insurance Scheme (NDIS) trial, whereas in the past:

We used to empower carers and consumers to do their own thing. We had luxury of time, to let it unroll a bit, to give them the chance to manage it themselves, to give them that power. Nowadays I'd rather jump in there and help because we might not have a whole lot of time to



get this one right. I sense there is a bit of urgency about things. The Government might say 'well, before that, why weren't you feeling that urgency before?' But you were trying to give people some opportunity for them to learn and them to manage because that is the recovery model. That is what we were trying to do. But nowadays you sort of think, "no, we better get on this one, I think we'd better help this person because she might end up with nothing.'

Conclusions

The carer support worker assisted Kathryn and her family with advocacy to access financial assistance, emotional support and peer education programs. The support in turn has benefited Angela by assisting the family to get through some crises, have a better understanding of mental illness and to help maintain their family relationships.

Mental illness can be very confronting and distressing for carers. Relationships can be placed under tremendous strain and put at risk. Carer support provided through Mutual Support and Self Help funding support benefits both carers and consumers by assisting to sustain relationships between carers and their loved ones.



3. Themes: consumer experience

Introduction

This section of the paper explores consumers' experiences of the National Disability Insurance Scheme (NDIS). Consumers were interviewed about their perspectives on the National Disability Insurance Scheme (NDIS) eligibility and planning process, and whether they are satisfied with their Plan and the supports they are receiving. Most consumers interviewed have transitioned from state government funded community mental health support services and wanted to talk about the role that those services play in assisting them to maintain and manage their mental health.

Some of the themes that emerged were:

- **More communication was needed from the beginning**

In the beginning not enough information was provided to know whether I should apply for help from the National Disability Insurance Scheme (NDIS). It wasn't until people like (organisation manager) said 'I would go with you.' A lot of people were confused, they didn't know where they stood.

The communication process needs to be improved. They need to let their clients know how things are going, how the pilot program is progressing. If they are changing certain things, they should make sure their clients are aware.

- **Support was needed to get through the eligibility and planning process.**

One consumer has recently returned to the Barwon region and has been living in his car. A Mutual Support and Self Help funded service assisted him to apply for National Disability Insurance Scheme (NDIS) funding:

I was too slow, I kept hearing about it on TV, but I didn't understand what it meant. Also I do have a disability but a lot of times I'm afraid to admit it, very afraid to admit it. (Name of worker) has everything written up – all he needs is a signature from my GP.

Another consumer needed support as he has difficulty with reading and paperwork:

Well I just think there is too much paperwork involved to set it up. They (support services) were very helpful. I'm not very good when it comes to paper work, I'm more of a physical person, so I found that side of it hard. I'm very slow at reading. We did it together (with support services).

A third consumer finds the National Disability Insurance Agency (NDIA) meetings very stressful and is unable to attend without support:

With them I get very highly stressed when I have to talk to them. I don't ever go by myself in there, because I don't feel comfortable there. I find it hard to talk to people generally. I have agoraphobia. I have difficulty going to new places. With my mental health I have high anxiety and severe depression, post-traumatic stress disorder. It makes talking to them very hard.

- **Plans and supports were good once put into place**

I am very pleased with them. I have been doing art with (name of person). Since being interviewed by NDIA (National Disability Insurance Agency) and given a grant ... as I wanted to go to art school.

The good thing was that I got what I needed at the end.



I got the plan and didn't know what it is, I couldn't make any sense out of it. The new plan is perfect.

Very happy 'walk in walk out', thank you very much. I went back the second time with my worker, (though) the first time they said no (that I couldn't take my support worker). I have got my learner's (driving) permit, grief counselling, my goal to do my courses, online courses, want to do a mindfulness program, peer support.

- **The assessment process has been traumatic for some consumers transitioning from existing services.**

The NDIS (National Disability Insurance Scheme) process was totally frustrating, to get the forms filled out and get it all written up and the way it was meant to be – not once, not twice, but three times. If I hadn't had the support, I would have given up. It is confronting.

I had been sent to a psychiatrist to get an updated report on my condition. They hadn't, because I asked for that report to be confidential, my planner hadn't read it. It had just been filed away wherever. So she had no idea of my needs or my history. ... It made me re-live everything that I had gone through and was starting to cope with. I was seeing a new psychiatrist and had to go over my complete history.

- **Consumers are aware they are involved in a trial and there are teething problems.**

One consumer felt that the National Disability Insurance Agency (NDIA) staff she saw at first did not understand mental illness:

If people get up and walk out I understand why. NDIS (National Disability Insurance Scheme) needs to have a big shake up and know what people really want. They don't know about bipolar, probably read it in a book. People who are working with us need to know about mental health. They don't know anything about mental health.

But she added: They have 'ironed out some of the wrinkles. I'm sure there are a few more to do.' Another said: 'It is a new thing for them as well. They are learning as well.'

- **Getting things wrong can be damaging for someone who is very vulnerable.**

For one consumer, it was very distressing to have supports put in place which she was very happy with and then withdrawn at the direction of the National Disability Insurance Agency (NDIA):

I am appealing to the NDIS (National Disability Insurance Scheme) people to please give people what they really need and not what you don't need. I am appealing to them as one of those people who have their service to please review what their help will be. To specify right from the start if it's not there. Not like giving hope but after the end there is no hope really.

Her carer feels that:

I don't think they really know what they are doing, I am sorry to say. Because one is saying one thing and then when I say 'look, this is how I understand it' and then the other person who is working for the NDIS (says) 'yes, yes that's right.' If you don't word it properly then it is not part of the plan.



- **Consumers rely on community mental health support services to help them manage their mental illness.**

Most consumers interviewed for this project were middle aged people with long histories of mental illness. They have worked hard on finding ways to manage their illness and identify the support of community mental health support services as being crucial to their mental health and wellbeing. Two consumers who have been involved with Mutual Support and Self Help Groups offered their reflections:

I might not have been here if I didn't have (organisation). If you are left alone with your thoughts for too long when you're not feeling well, it's not a good idea.

When I do go down, I get really unwell and stay really unwell for months. Before that happens it would be good to work on it to try and prevent, to be aware I am going down, and work towards making it not as bad. Trying to organise activities and things so my mind is off my depression and I don't end up getting down there. I go up high and sooner or later I come crashing down. I need and I've developed a strategy to stop me crashing down... Bike riding and activities

- **Consumers transitioning to the National Disability Insurance Scheme (NDIS) were fearful that they would lose the support they have and become unwell.**

I thought my program was going to get taken away. I was very stressed if I thought I was going to lose it. I would be very isolated. Even now with what I got I'm isolated. My health would be worse. I wouldn't have anything to go to. It would be very bad. I would become even more isolated. Probably my mental health would go down, my mental health would be worse, probably my anxieties as well. I wouldn't have a reason to go somewhere even that would bring me down.

Having the support of a worker helps stop me from going into the depths of despair. It all comes down to the talking and the working through how you are feeling at the time. Before that my life was not worth very much. It's pretty hard to put it into words.

It was a real problem for me to have to go through five interviews. If they had looked at my file first it would have saved me a lot of angst. I felt powerless insofar if I didn't conform to the system I was going to lose out. I was going to lose the supports that I already had. I couldn't afford to do that: emotionally couldn't afford it.

This consumer had experienced a tragic death in her immediate family and was 'worried about if they took my mental health worker away from me. I don't know what I would do. If I didn't have her I would have gone nuts.'

- **Some consumers believe National Disability Insurance Scheme (NDIS) funding is too 'black and white': They want more flexibility in group and individual support to assist in managing their mental health.**

This consumer receives individual support through his National Disability Insurance Scheme (NDIS) plan and he feels that:

When I am not well, I need more assistance than when I'm well. That fuzzy area of not well and well – do I decide that or does my worker? It's difficult to decide for me as the person who needs the help.



These two consumers are involved in a Mutual Support and Self Help group and want more flexibility about attending the service,

They want you to come five hours per week every week. They don't want you to come in a bit here and bit there. That's hard because with mental illness you may not need to come in. Then you might get sick again and need to come in every day. Because mental illness is not like a broken leg or something. You might need it for a certain amount of time and then be well and not need it for 6 months and then all of a sudden need it again.

(It needs to be) bit more relaxed. Used to be a place where you could just come in. With mental health you have ups and downs. Sometimes can be real bad and sometimes real good. You could just come in there if you need someone to talk to, have a chat – there is a lot of care in there.

- **Concern that the National Disability Insurance Scheme (NDIS) is not consistent with their recovery**

(With the) NDIS, you have to say your worst case scenario. With (support organisation name) we work on getting better. You have to tell them the worst to get what you need and it doesn't always fit in. It doesn't always fit if you are working on recovery to go back and have to say what you are like at your worst. That's not good. But if you told them how you are now and were honest about heading towards recovery you would not get the supports that you need to keep you there.

- **Positive experiences with National Disability Insurance Agency staff**

He is lovely, very pleasant, and easy to get on with, nothing is a problem to ask him. That streamlined it. It flowed beautifully because I really had an affinity with not just (organisation manager) but the lovely lady who came from NDIA to interview me at my home. I missed a couple of appointments so she said 'we can come out to see you if you like.' I was getting bogged down with my husband being in palliative care. Served them morning tea, was there for an hour and a half at least. They could see my art work at home.

The NDIA staff were really good, no trouble, really nice.

- **Negative experiences with National Disability Insurance Agency staff**

I went to the NDIS and had the interviews with them. That was ok. They treated me like 'poor (consumer name), she is a disabled person. Poor thing, like she is mentally unwell...' The way that they treated me was like I am sick and they are the sane people and can tell you what to do.

Shocking. When I did my NDIS (plan) a lady came to the house and asked me questions that I had already answered when I went for my disability pension: can you walk by yourself? Can you cook by yourself? Bit of a pain. Talked about your life in general and then turn it into a plan. I wasn't happy and told them. I walked out on him. I was most upset when I was in there. They told me I have to start to learn to do things independently.

The process itself is difficult. The communication is really lacking. Seems to be too many people in her (NDIA worker) care. The times I have contacted her when I have needed help she seems to be rushed, not able to listen to my concerns comfortably.



- ***Mutual Support and Self Help Programs provide a sense of community and support that assists members to maintain their mental health***

There's a lot of care between members. I'd be so upset if something happened to (service name). It's such an important place in Geelong. We do great things. I ride the bike every Thursday. I find riding the bike a big advantage, feel good up there. All I hope is that nothing happens to (service name) with this setting up (of the NDIS).

This consumer felt that the funding for the service worked better before the NDIS:

I preferred it when they had the \$200,000 or something. They seemed to have more money to do outings, meals and groups. Now they seem to be counting their pennies.

This consumer has had a long history of trauma, mental illness and social isolation. She has found stability and support with a Mutual Support and Self Help program:

I've been involved for 8 years, it's been my rock. I look forward to a Wednesday coming and doing whatever needs to be done. I've done lots of talks on my mental health, surveys, whatever things have come up. My life is more motivated with social things that go on here, going out for a dinner, going out for movies, being involved in a cooking group, camps we have gone on. The staff have been wonderful.

Conclusions

Most consumers interviewed were satisfied with their National Disability Insurance Scheme (NDIS) Plan and the support they are receiving. It is not clear whether this range of support and skilled workforce will be available after the Victorian Government's block funding ceases in June 2015.

The process of establishing eligibility and obtaining a Plan was often experienced as difficult or even traumatic for consumers interviewed while transitioning from existing services. Apart from the stigma, difficulty and trauma inherent in living with a serious mental illness, some consumers have also had other life traumas that exacerbated the uncertainty and stress of the NDIS processes for them.

The support of community mental health support workers was identified by consumers interviewed as being critical to getting through the National Disability Insurance Scheme (NDIS) eligibility and planning process and getting the support they need.

Consumers said in their interviews that they use services to support them to manage their mental health: being engaged in activities, connecting with others and receiving individual recovery oriented support. They want to be able to use services flexibly, depending on how well they are: to be able to rely on services to have the skills to support them to manage their mental health and to respond by increasing supports if they start to become unwell.



Appendix One: Case Studies

Consumer Case Study: Anne

If it hadn't been for the support that (my worker) was giving me I would have given up and said it is just not worth the aggravation

Anne is in her early 60s and lives on her own in the Barwon region. She has had mental health issues since her early teens. Anne has received community mental health support services for about five years prior to the commencement of the National Disability Insurance Scheme (NDIS) trial in the Barwon Region. She was receiving weekly individual support, attended a weekly social group, and received assistance to attend a Voices Vic³ group in Melbourne each month. She also received a cleaning service from her local council's Home and Community Care funded service.

Anne's experience of the National Disability Insurance Scheme (NDIS) eligibility and planning process was, in her words, 'terrible':

First off, before I got my first interview (I notified them) to say that I would not be available for 6 weeks. When I got home from being away I received a letter that basically said that I had missed my appointments. It was like I wasn't interested enough to bother contacting them but I had. I started off on the wrong foot right from the start.

The letter said that Anne had missed her plan handover appointments and was sent a completed plan with approval for an hour and a half of individual support per week. With her support worker she made another appointment but felt like a nuisance asking for changes to her plan:

I felt like I was begging for money and felt I was a lower class of person. They were very condescending: 'here is a special folder for you'. I was made (to) feel guilty for needing support.

Anne explained that:

I had been sent to a psychiatrist to get an updated report on my condition. Because I asked for that report to be confidential, my planner hadn't read it. It had just been filed away wherever. So she had no idea of my needs or my history.

Anne had not seen a psychiatrist for a long time:

It made me re-live everything that I had gone through and was starting to cope with. I was seeing a new psychiatrist and had to go over my complete history.

The experience was very distressing,

They didn't read it. I went to all that stress and aggravation for them not to really need it in the first place. I got a letter from my doctor and my psychologist and they didn't seem to take a note of any of those.

³ Voices Vic at Prahran Mission is a state-wide specialist program led by people with a lived experience that aims to improve the lives of people who hear voices. The Melbourne group is a structured group led by trained facilitators.



Anne felt that it was unreasonable for an unknown person to decide on her needs and what was best for her on the basis of a one hour interview. She had been nervous and felt that it was a very formal and unfriendly setting.

I left the plan handover feeling worthless, powerless and the victim of a system which does not take into account the individual needs of a person.

Getting a plan approved that met her needs was a difficult process:

I had about five interviews. Because to start off with I wasn't given anything very much, I wasn't given my house cleaning, I wasn't given Melbourne visits. All they would give me was my hours with my (organisation name) support worker, which just wasn't enough for me. So after about five re-tries I ended up getting the plan that I wanted, or needed, more to the point.

If they had done their job right the first time that stress and strain would have been limited. If they had read that report, then they would have known some of my history. That struggle and that stress and the strain of getting what I got after 5 interviews wouldn't have been necessary.

Anne says that attending the monthly Voices Vic group in Melbourne with the support of her worker has been very important to her mental health:

I go to Melbourne with Voices Vic. which has helped me a lot to understand the voices I hear and how to deal and how to cope with those.

When asked what was good about the National Disability Insurance Scheme (NDIS), she said:

The good thing was that I got what I needed at the end.

Anne is concerned that the National Disability Insurance Scheme (NDIS) process doesn't work well for people with a mental illness:

I honestly don't believe that the process between mental health and NDIS worked together. They have no comprehension of what it is like to be part of the mental health supports. With mental health you don't physically need wheelchairs or things like that. You need counselling and that is where your support workers come in. Having the support of a worker helps stop me from going into the depths of despair. It all comes down to the talking and the working through how you are feeling at the time. It was only the last ten years that I have been involved with psychologists and psychs and support workers. Before that my life was not worth very much. It's pretty hard to put it into words.

Anne thought the National Disability Insurance Scheme (NDIS) process could be improved:

I suppose if the process wasn't as formal as it is that would help greatly. If they accepted the fact that the help that you are getting prior to NDIS was valued. I felt that what my worker and (organisation name) had done for me, they were indicating that maybe that was not the best for me. They suggested other things, other than what I was already doing. Maybe the same things but just with different people. With mental health you have to have a rapport with people before you can open up, and that can take time.

Anne contrasted the process of assessment and engagement by the National Disability Insurance Agency (NDIA) with what she experienced with the Psychiatric Disability and Rehabilitation Support Services (PDRSS) prior to the commencement of the National Disability Insurance Scheme (NDIS) trial.

I was introduced to (organisation name) through my psychologist. The whole process was gentle, it was done in my home where I felt comfortable, it wasn't formal.

(organisation name) do it softly, you're not sort of thrown in on your first meeting to spill your guts type of thing and be given your services and out the door. No caring.



Anne believes that the Psychiatric Disability and Rehabilitation Support Services (PDRSS) have contributed to her well-being:

I now have some belief that I am valuable and that I can actually do things that I didn't think I could do before.

I have support to go (to a group); because of the support I am able to go, able to say yes to attend function this week. I was able to say yes to doing this today which I would not be able to do in the past.

The thing is when these interviews started nothing had changed from what I had asked for right at the beginning but I had to go through five interviews to get what I needed but my needs hadn't changed. A whole lot stress and aggravation that I really didn't need to go through. If it hadn't been for the support that (worker name) was giving me I would have given up and said it is just not worth the aggravation.

Anne worries about what will happen under the National Disability Insurance Scheme (NDIS) if she has a crisis with her mental health:

I often wonder (about) if I hit crisis. Whereas before if (support worker name) was here for an hour or an hour and a half and I was in crisis that hour and a half would extend out to what was needed. With NDIS she is funded for an hour and a half. If I was in crisis what happens to the time that was required? (organisation name) said if that happens they will find the time to spend with me and help me through that if that happens. But NDIS is so black and white it doesn't allow for situations like that.

Anne also feels that the National Disability Insurance Scheme (NDIS) is not consistent with a recovery or strengths based approach to mental health:

(With the) NDIS, you have to say your worst case scenario. With (support organisation name) we work on getting better. You have to tell them the worst to get what you need and it doesn't always fit in. It doesn't always fit if you are working on recovery to go back and have to say what you are like at your worst. That's not good. But if you told them how you are now and were honest about heading towards recovery you would not get the supports that you need to keep you there.

Anne believes that the National Disability Insurance Scheme (NDIS) process has had a negative effect on her mental health:

Going through this NDIS process I went backwards. I had to go right back to the beginning with the psychiatrist. After working with (organisation name) I had been empowered to a certain degree, I lost that strength. I became vulnerable again.

It was a real problem for me to have to go through five interviews. If they had looked at my file first it would have saved me a lot of angst. I felt powerless insofar if I didn't conform to the system I was going to lose out. I was going to lose the supports that I already had. I couldn't afford to do that: emotionally couldn't afford.



Consumer Case Study: Jane

It's like a family group. We do things and help people out. It feels safe. It feels like a home.

Jane is a middle aged woman with a long history of mental illness who lives on her own in the Barwon region. Prior to the commencement of the National Disability Insurance Scheme (NDIS) trial in Barwon, Jane had been volunteering in and receiving support through a Mutual Support and Self Help Program⁴. Jane now has a National Disability Insurance Scheme (NDIS) plan and supports.

Jane's goals in her Plan are to:

- continue to engage and socially participate in the community
- engage in a course of interest
- independently manage finances/budget

Jane's objectives in her Plan are to:

- continue to engage in groups and maintain social inclusion
- attend a course in horticulture
- develop the skills to independently budget her finances for a holiday.

Jane has received funding via the National Disability Insurance Agency (NDIA) for the following supports for her National Disability Insurance Scheme (NDIS) plan:

- one hour per week of coordination of supports
- lump sum funding for transport which she is self-managing
- funding to attend a camp
- two hours per week of assistance to access community, social and recreational activities (individual weekdays)
- weekly attendance at a cooking group.

Jane is continuing to volunteer at the community mental health support service. This participation is no longer supported by government funding. The Service is also providing some transport support that is unfunded.

Jane comes from a stressful family background:

(It was) rough in the family, a lot of violence, with my Dad coming out of the war, the Vietnam War. He used to put an axe on the table at night, quite scary. I've lost a couple of sisters to suicide. I am an orphan, taken off my mum and step-father when I was 12, put into care.

Jane first moved to the area and made contact with the Psychiatric Disability and Rehabilitation Support Services (PDRSS) after fleeing family violence:

I was so lonely and so sad. I was so isolated, I picked up the phone and rung and they organised to come and meet me and had a few home visits. I made little steps outside the house. Every day was a challenge to get out of bed and get going, some days were better than others. I'm not a perfect person or profess to be but have a lot more knowledge that I would not have gained without (service name). It takes a lot of guts to start again. I came out of a horrible relationship, lost my property because of him, he harassed me, stalked me.

⁴The Mutual Support and Self Help Program is a community mental health support service providing information and peer support to people with a mental illness and/or their carers. This can involve the sharing of experiences and coping strategies, the provision of information and referral services, and the promotion of community awareness.



Jane's Support Worker noted that Jane was:

....participating and helping out with anything that needed to be done here. That is how I first met Jane 5 years ago. Through that time we would support Jane as needed. So if Jane came to us requesting support, for example, to go to the doctors or attend appointments we would provide that support.

Jane also participated a lot in our planned service delivery so she would always be part of any planning we had. For example, we'd get a group of people in and ask what would you like our service to look like? What sort of stuff would you like us to do? Leading one of our peer programs, Jane did that also, volunteering and being part of our groups when we go away. So she attended some carer retreats, supported carers and assisted.

Jane's life has been an enduring struggle as a result of her long history of trauma, mental illness and social isolation. The Mutual Support and Self Help Program (MSSH) provided her with the stability and support that she desperately needed:

I've been involved for eight years, it's been my rock. I look forward to a Wednesday coming and doing whatever needs to be done. I've done lots of talks on my mental health, surveys, whatever things have come up. My life is more motivated with social things that go on here, going out for a dinner, going out for movies, being involved in a cooking group, camps we have gone on. The staff they have been wonderful.

It is like a family group. We do things and help people out. It feels safe. It feels like a home.

Jane's support worker noted the participation in the Mutual Support and Self Help Program provided a means for monitoring Jane's mental health:

When she becomes unwell she would withdraw so we would follow up to see if there was anything we can do to support her.

For Jane the main thing would be that social inclusion. If she wasn't coming here where would she go? How would that impact on her with not having any supports at all?

Jane also received support for pursuing her educational goals:

Did Cert. IV Mental Health and passed. Would never have passed without the support of the team.

Jane experienced a lot of difficulty with the National Disability Insurance Scheme (NDIS) process and felt like giving up:

It was totally frustrating to get the forms filled out and get it all written up and the way it was meant to be: not once, not twice, but three times. If I didn't have the support I would have given up. It is confronting.

I have a problem, when I'm reading things I can read them the wrong way; the clinical stuff did your head in. The intensity of it, the paperwork, the questions and answers was yuk.

For one of the appointments, one of the staff came with me and got that sorted. If they hadn't been there I would have given up, (decided) 'no this is too hard'. Support enables you to go through the process and get to where you want to be.

Jane felt that the National Disability Insurance Scheme (NDIS) process was difficult due to her mental illness:

Stuff like that does my head in. Either I can be slow doing something or I can be really fast. And with the bi-polar you can be sitting in a planning meeting and you can be listening but, sometimes you know, sometimes there are voices, your head is going round a hundred miles an hour. It's like holding on to the table, (thinking) like 'when am I getting out of here?' You just want to go but you can't.



At the same time Jane spoke very highly of the National Disability Insurance Agency (NDIA) planner,

He is lovely, very pleasant, easy to get on with; nothing is a problem to ask him. That streamlined it. Hey it's OK.

Jane's support worker said of the National Disability Insurance Scheme (NDIS) process,

It was more about 'Let's talk about what you can't do.' It wasn't recovery focused, how we would usually have conversations. It was more: 'OK, tell me (what you're like or need) on your worst, worst day' because then we would report on that.' So on top of that I did a BASIS-32⁵ and the CANSAS assessment⁶ to hand in, and we spoke about, then, her worst days. The functioning side of it, again that was down to us. She didn't necessarily have that clinical perspective. It was more or less what we had been doing with her and how we have supported her.

The support worker felt there were particular challenges with getting Jane's eligibility approved as she wasn't receiving clinical mental health services at the time:

They are quite specific, but it wasn't enough because self-assessment maybe didn't have enough weight as a clinical psychologist filling in a form. She was really the only one that I handed in those assessments because it wasn't needed for other clients.

Supporting Jane through the National Disability Insurance Scheme (NDIS) process was difficult but very important for Jane's mental health as she feels that:

I might not have been here if didn't have (organisation). If you are left alone with your thoughts for too long when you're not feeling well, it's not a good idea.

Her support worker also felt that the potential negative impacts of not getting funding were very serious for Jane:

If Jane was doing this alone I think she would have, number one, not done it, or, number two, if we had to actually stop delivering a support to her and her stop seeing us ... look, who knows what could happen. There would have been a huge decline in her mental health state and probably a long stint in hospital, which she has had before. Because from seeing us, you know, maybe three times a week to nothing ... would be very, very difficult for anyone. She wasn't linked into any other mental health services.

(She) has found this to be a safe place, a place where she is valued. A place where her opinions are warranted. She offers a lot here as well as the support that we give her. So I guess with her it has been a real two way street in lots of ways. She has benefited but we have benefited probably more from having her around and being part of our organisation.

The support worker explained about Jane's goals in her National Disability Insurance Scheme (NDIS) plan:

It was really around that social participation, the groups. It was also around a horticultural course which she did here. It was also around an independent one because we are planning a

⁵ BASIS-32 is designed as a measure of the major symptoms and functioning difficulties experienced by people as a result of a mental illness.

⁶ CANSAS is an assessment of need tool that is part of the Camberwell Assessment of Needs: questionnaires used to assess a wide range of problems potentially experienced by people who have with people with severe or long term mental health problems.



trip (for her) to Bali. So all these goals were based on what we had up and running (before the NDIS).

So her supports in her plan: It was 'individual' to 'come on our camp'. Then they put in some numeracy skills development. That was around budgeting to go to Bali, then some group stuff and two hours a week for appointments. No, that's it. And around coordination of supports to make sure it is all working and choosing which service provider to deliver whatever support she wants and points of crisis so she has somebody to come back and talk to if need be.

Jane noted that transport had become an issue for her with National Disability Insurance Scheme (NDIS) funding:

One of the girls after cooking was driving me home but that has changed so somebody else had to drive me home last week. I don't know how I am getting home tomorrow night. I don't like going home over there in the dark. That is the only thing I am not sure on.

Jane's support worker explained that, while Jane receives a lump sum for transport in her (National Disability Insurance Scheme (NDIS) plan, transport is an issue in practice:

Jane is paid a lump sum and she has to self-manage that money. We used to do a lot of transport for Jane and now we can't. In her plan she has got that travel (allowance) that is her paying for taxis to get everywhere. They have done that in lieu of the mobility allowance.⁷

If we were going straight off this plan we couldn't be driving her to those (appointments). We would have to meet Jane at the medical appointment. She would have to catch a taxi there.

Well, if I was part of a group that I got a lift to every week and it would cost me \$12 to get home from every week, would I go? If we were running off this plan without any in-kind (assistance), we would have to say: 'You need to catch a taxi home, you would need to catch a bus. We actually shouldn't have you in the car because we can't claim for anything.'

No, we haven't done that. We picked her up last when she had some (medical) tests done. She has no family, no friends who would be able to pick her up and take her home. You could not leave by herself in a taxi after this procedure.

The time that I put in I would (lodge) under 'coordination of support' but not claim the kilometres.

To all of a sudden turn around and say 'I can't drive you anywhere' after she comes in, she volunteers, she does a hell of a lot for our organisation, impacts on my values and why I work here as a worker.

With her National Disability Insurance Scheme (NDIS) funding, Jane explained she is:

Starting a program to do with maths, reading and language. Going to look forward to have a go at that, give everything a try.

When asked if the funded National Disability Insurance Scheme (NDIS) plan and supports meet her goals or needs she felt:

I do to a degree. I suppose what I really want to happen is I want to move so I will have to go back and readdress it with them and have another look.

⁷ Previously paid through Centrelink fortnightly



Jane said that the National Disability Insurance Agency (NDIA) planner had said if she needed to change her plan it was not a problem. However, she also added that:

If pre-NDIS, (organisation name) would have helped probably with some other organisation. Would have scurried around to get a truck, got volunteers to help me pack.

The support worker also raised the issue of lack of flexibility with the plan around goals saying that:

She wants to move house. There is nowhere here (in her plan) in the next 12 months for her to get any support to do that. I do know Jane has had an (occupational therapy) OT assessment last week to look at her house and whether it suits and fits her living there. You know the bath and stuff. Some of it is mental health and some of it her other conditions. There is nowhere here that says we can support her to look for alternative accommodation. If we had to, if Jane wanted it, she would have to go back to the NDIA and say why her circumstances have changed to get that added. Say the 'exceptional circumstances' that have happened for her to change her goals. She can't just go in and add that to an individual plan that we make for her and for us to deliver it, because it is not funded. There is no room for us to do an individual plan as the plan has been developed and goals set by one or two appointments with an NDIA planner.

Jane's support worker felt that one of the positives of the National Disability Insurance Scheme (NDIS) was that:

People start getting what they are paid for. If you want me to do this and I'm not doing it you can sack me. More accountability for services.

However, she also identified a risk with stopping a service that was connected with her:

If Jane became unwell and sacked us, who is going to follow up how Jane is? She could go the next 10 months without receiving anything from her plan. Who follows that up?

The Support Worker expressed a desire to support Jane to realise the potential of the National Disability Insurance Scheme (NDIS):

It would be working with Jane to have the capacity next time to self-manage and self-fund. You would want that with all your participants: to understand it a bit more. Not just go: 'You have to go from this funding, now you have to fill out these forms and you are going to get funded like this.' To have a better idea of the scheme, to have a better idea of the processes. To have a better idea of the language, to get a lot more in your plan. Because that is what it is. You can look at two different plans and they can be totally different and you wonder why one has got psychology and the other hasn't.

As workers, when we support people through a review, hopefully we will be able to learn a bit more to empower them to be able to get a bit more and own their plan more and their goals more.

Jane's perspective on the National Disability Insurance Agency (NDIA) is that:

I think the NDIA is still in its growing stage. I think my package will get rearranged and we need to see if it can be rearranged in the package. It is great for people who need it; to learn and grow from it is really important. To really utilise the supports. At the end of it being happy with what you have. I really hope that it stays. I can't say (it's) worse or better, just different, takes a bit of getting your head around.

(It's) ironed out some of the wrinkles. I'm sure there are a few more to do.



Consumer case study: Angela

Angela has a serious mental illness, is in her 30s and lives with her sister Kathryn in the Barwon region. She is from a close and supportive family who are from a non-English speaking background. Before moving in with her sister, Angela was living in a supported residential service. Kathryn heard about the NDIS from the supported residential service proprietor and assisted her sister to apply.

Before the National Disability Insurance Scheme (NDIS), Angela had not been receiving support. From the meeting with the Disability Insurance Scheme (NDIS) planner it seemed that Angela would get the support she needed to pursue her goals. Angela hoped that the Disability Insurance Scheme (NDIS) could help her recover from her mental illness and has a number of goals she wants to achieve, including learning how to make and fix computers.

Kathryn had some suggestions for the National Disability Insurance Scheme (NDIS) planner about how the plan could work to accommodate Angela's mental illness:

I suggested doing a course, kind of one-on-one – because of her paranoia she cannot stand crowds. She needed to have this health and fitness. She wants to go the gym. She wanted to be able to be a little bit independent. She wanted to be able to drive. So is there any organisation who could actually do that? She says there is and we just have to make a plan.

Kathryn also hoped that being more occupied would take some of the responsibility for Angela off her shoulders. Angela and her sister were very happy with the plan and the support that was being provided. Kathryn explained:

Just not long ago they started to actually have someone here because she was able to enter into this free course online. Someone from (organisation name) was helping her to achieve that goal.

Kathryn outlined some of the support that emerged from Angela's Occupational Therapy assessment:

(Angela) would need someone to help her to explain what she is doing to motivate her to do her homework. (Name of support worker) was the one doing that. Another lady helps her how to use the bus. Helps her out how to do something around her room, cleaning because I asked that specifically. Because she cannot stand people around her, she is very negative about people, thinks that people talk about her, put her down. This person is helping to make her understand what the real situation is.

Kathryn also welcomed the National Disability Insurance Scheme (NDIS) support:

It was helping me. I don't have to do everything. She tends to rely too much on me. Having them there, part of it is easing the load. Keeping her busy so she is not thinking negatively all the time.

However, when the (organisation name) provided an update to the National Disability Insurance Agency (NDIA) they were advised that their organisation's interpretation of the plan was incorrect and they were obliged to withdraw two of the supports that had been provided. Angela was very upset about losing these supports:

The help that I need for learning to make a computer and fixing it. They said they cannot fund it. Before they said, before I get in, 'Yeah there are some organisations that we know can fund it'. But now all of a sudden there is no funding.

Angela feels like the issues with her plan are personal:



Seems like they are trying to put me down. I don't know why I don't do anything wrong with them. They changed everything. Seems like they do not want to fund me at all. Also that, everything that I need, they will say that it is not part of it. What do I get that I need?

Kathryn talked about the confusion with Angela's Plan,

In the plan there is money put aside to help her achieve the goal that she wants. This (worker name) was doing that, helping her out with her assignments, explaining it properly, what the course was all about. We just had a review with the NDIS and (Organisation Service Coordinator name). They said that's not part of it, it has to stop. Even saying about the transport, the bus, you know, 'They shouldn't be doing that'. I said 'That's not right, this is the plan and this is what she needs'. Kind of they're divided. I don't think they really know what they are doing, I am sorry to say. Because one is saying one thing and then when I say 'Look, this is how I understand it' and then the other person who is working for NDIS says 'yes, yes, that's right.' It's kind of (around the) wording. If you don't word it properly then it is not part of the plan.

Kathryn felt that the lack of flexibility about how the supports could be provided didn't meet Angela's needs:

I told them about having this fitness that she would need to probably go to a gym and now they are saying she has to be in a group. It can be funded if she is in a group. But the thing is what I have told them all along that she cannot handle the group because of her paranoia. So she is kind of just going along with it because it has been funded but is it really going to help her if she doesn't feel comfortable?

Angela was upset about the lack of clarity about what she was entitled to:

I am appealing to the NDIS people to please give what you really need and not what you don't need. I am appealing to them as one of those people who have their service to please review what their help will be. To specify right from the start if it's not there. Not like giving hope but after the end there is no hope really.

Kathryn said of the Disability Insurance Scheme (NDIS):

It is a new thing for them as well. They are learning as well.



Carer Case Study: Kathryn

Kathryn is a client of a carer support service in the Barwon region. Her sister Angela has a serious mental illness, is in her 30s and lives with Kathryn. They are from a close and supportive family who are from a non-English speaking background. Before moving in with her sister, Angela was living in a supported residential service. Kathryn heard about the National Disability Insurance Scheme (NDIS) from the supported residential service proprietor and assisted her sister to apply.

Before the National Disability Insurance Scheme (NDIS), Angela had not been receiving support. Kathryn had Angela living with her, was tired and *'finding it really hard to do everything'*. Kathryn had a range of financial, health and emotional crises and initially the carer support worker organised assistance with bills from a carer brokerage fund. The carer support worker explained that, *'Kathryn came in because she was struggling a little bit, things weren't going too well.'*

The carer support worker feels that the family has done a lot to support Angela and that:

I think that my involvement has been able to assist Kathryn and her mum and dad to keep a more loving relationship going to the best of their ability. I think they learnt a few things where they can keep the relationship.

Kathryn and her parents attended a carer education program run by (organisation name) and Kathryn said that:

So I think them attending the course kind of helped me then to give them a better understanding of why I am doing certain things and at the same time I had to change my ways as well.

The carer support worker outlined the carer support service's general approach:

We do a care plan and work out where the priorities lie. Chat first, unburdening, how things are going, not a counsellor. They will then identify areas where the service can assist such as offering a healthy lifestyle program or family education program delivered by family members/ friends of someone with a mental illness. The service gives structure, (we) see them for eight months or so. Then, if anything comes up they would be communicated to. If they needed something I would hope they would contact me. With Angela and Kathryn, we will touch base through communications: mail outs, emails, text messages. She comes in here with Angela a lot.

The carer support worker advised that the issues that occurred with Angela's plan (see Angela's case study, above) may have been related to the National Disability Insurance Agency (NDIA) not really understanding community mental health services:

Unfortunately with the NDIS there are a lot of cogs in the wheel and there's areas along the way where it can go wrong. It is always based on perception of the plan, what they are getting from the service or what they wanted the service to give them.

The carer support worker noted that there was scope however to adjust:

A person with a mental health package can ask for a review of their package at any time. That is quite achievable. The goals might change. No: maybe the goals stay the same but how the goals are reached might alter.

The carer support worker observed that consumers are starting to change plans to reflect their preferences:

A few have changed from direct support, one-on-one support to wanting to be part of a group setting. There is a lot of flexibility. The package size may not change but what happens within the package can be tweaked. You don't hear people saying 'I've got a \$15,000 package and



now I want to have a \$25,000 package'. You don't hear much about that. The monetary side isn't a real big issue for a lot of people.

The carer support worker feels, however, that prior to the National Disability Insurance Scheme (NDIS), Angela would have received a more responsive service from their organisation:

Eventually we would have got it to a more manageable situation which is what the NDIS wants it to be. With everything slotted in and there are times and whatever. But initially she would have received a bit more response to her needs, in the old method.

The carer support worker also expressed concern that the way that National Disability Insurance Scheme (NDIS) plans and supports work means that there is a risk that people are more likely to be hospitalised as she believes there is less flexibility and capacity to monitor the mental health of consumers.

You know it does meet that need when a person's not travelling so good that they need help there and then, right at that point in time. So we were able to do that in the past and now it has to be slotted in now, timetabled. And if someone is travelling really, really, really badly it goes back to the clinical sector. It goes immediately back to clinical care. We probably would have seen them a bit more when they weren't travelling so good. We probably would have kept seeing them for a bit longer, we would have been able to phone them, see them, monitor the situation a bit longer. You know what I mean. Just say, 'Is this a relapse?' 'What's going on here?' We would have had more time to get to know them. Now we can't do that. If we think they are unravelling it sort has to be passed on pretty fast. Because we can't take the risk of someone getting unwell and then we see them next Tuesday, we can't do that. And maybe we would have averted that need for them to go to a hospital or something.

The carer support worker believes that with the National Disability Insurance Scheme (NDIS) it is critical that stronger relationships are developed with clinical mental health services. She feels that services like hers have to work really hard during the trial period. The carer support worker is doing more advocacy work in attending meetings with carers and consumers than in the past:

We used to empower carers and consumers to do their own thing. We had luxury of time, to let it unroll a bit, to give them the chance to manage it themselves, to give them that power. Nowadays I'd rather jump in there and help because we might not have a whole lot of time to get this one right. I sense there is a bit of urgency about things. The Government might say 'well, before that, why weren't you feeling that urgency before?' But you were trying to give people some opportunity for them to learn and them to manage because that is the recovery model. That is what we were trying to do. But nowadays you sort of think 'no, we better get on this one, I think we'd better help this person because she might end up with nothing'.

This is part of what the scheme is and what we need to provide in order to make the scheme effective for people. I mean people go into planning meetings and they are not quite sure what they are asking for.

The carer support worker provided this assessment of the National Disability Insurance Scheme (NDIS):

What I like about it in a way is getting the plan developed quite early. However, there can be issues with this, in that in the past there was more time to develop a relationship, to firm up the plan, to change the goals if they needed changing. If circumstances changed, if they got unwell it didn't mean that their monetary thing had to be stopped and restarted.



Consumer case study: Adam

Adam is a young man in his early 20s living with his family in the Barwon region. He has a serious mental illness and has had extensive involvement with clinical mental health services over a number of years. He is currently unemployed and in receipt of a Disability Support Pension.

Adam has been very dependent on his family for support and for going out into the community. He had been attending a group program before the National Disability Insurance Scheme (NDIS) commenced. However, there were issues with his behaviour in the group and he was referred for individual support via the National Disability Insurance Agency (NDIA). His current support worker advised:

Adam struggles with communication skills, needs a lot of work, doesn't understand barriers and wouldn't be able to read people's facial expression. (He) can be in your face.

Adam went through the National Disability Insurance Scheme (NDIS) planning meeting. He found the process 'a bit intense for me.' The goals in his National Disability Insurance Scheme (NDIS) Plan are to participate in activities he enjoys such as the (name omitted) group, get to places on his own without relying on his mother for transport, and to get a job.

A month after the planning meeting, the community mental health support service received part of Adam's Plan with the line items associated with the supports which Adam chose their service. The Service was not aware that another service provider was also involved.

The National Disability Insurance Agency (NDIA) funded the community mental health support service to provide group based community, social and recreational activities approved for 13 hours per week and individual social skills development. The latter was approved for up to six hours per week for 12 weeks. A report on progress towards goals and future recommendations would be required before additional funding will be considered.

A community mental health support service worker contacted Adam to introduce the service and discuss his plan. Adam said that he did not need support, was doing well and was on a journey. He spoke about spiritual figures that he was in contact with and the worker became concerned that he was unwell. Adam gave consent for the worker to contact his mother, who advised that Adam had recently been discharged home after an acute psychiatric inpatient admission. She said that he needed support and would like the Service to contact the clinical mental health service to discuss how his new supports and plan would integrate into his current care.

The clinical mental health service provided advice on Adam's current mental health issues, clinical services and future psycho-social support needs. The clinician advised that Adam needed a male worker and one-on-one supports to learn social skills and behaviour management techniques. The community mental health support worker was also advised of behavioural risks. The clinical worker wanted to slowly introduce the individual support to fit in with Adam's treatment plan. The community mental health support service was also asked to participate in future case conferences.

At this stage the contact with Adam's clinical mental health service and Adam's mother was not funded via the National Disability Insurance Scheme (NDIS). The community mental health support service worker contacted the National Disability Insurance Agency (NDIA) to request care coordination funding for liaison with clinical mental health services and family members. Behaviour support funding was also requested. The National Disability Insurance Agency (NDIA) staff were not aware of Adam's recent inpatient admission, the extent of his support needs or clinical mental health history. The National Disability Insurance Agency (NDIA) stated they would consider the care coordination request but there was insufficient evidence to warrant behaviour support funding.



The community mental health support service continued to consult with the clinical mental health service and Adam's mother on a weekly basis regarding his support needs –a significant amount of work that was critical to Adam's mental health that was unfunded by the National Disability Insurance Scheme (NDIS).

One month later, the National Disability Insurance Agency (NDIA) approved one hour per week for care coordination. Working with Adam has been a slow process of building rapport and trust over a period of months:

One-on-one works well, building rapport for a couple of months, he does engage well when he is with someone and feels safe. On his own he is at risk, has given bank details to strangers, walking up to strangers, gets carried away. (Outcome) Star⁸- he wasn't wanting to look at it at all because of issues, the next step is to do another one. It will take a while - even having a conversation about an interview is a complicated conversation. If I ask him how he is feeling he becomes quite defensive.

Adam has not been attending a group since issues with his behaviour were raised before the commencement of the National Disability Insurance Scheme (NDIS) Trial. He doesn't want to attend a group at the moment and is nervous about slipping up and talking about the wrong things. His support worker thinks that talking about attending a group makes Adam feel vulnerable:

My main issue with the initial intake process for NDIS is there is no rapport built in relation to the participant and what is going on. A lot of assumptions are made in relation to the participant. he doesn't have the insight to understand what it means for him: (he) might say 'I want to join groups' but (the planners) don't look at what he needs to achieve this. (He) probably should have started off with one-to-one support with the worker. That is the gap. It makes our job hard, we're put into a situation where we have to say 'we can't approve that because it's not on plan' when the process of getting on a plan is very overwhelming. They almost have to beg for NDIS to give them that line item.

Adam is very positive about the one-to-one support he is receiving:

Leisure activities, social, talking about anything I need to talk to. I like it a lot, I think it is necessary. It doesn't hurt to have someone in your life, someone you can interact with, look forward to, see how I am going. I think there would be a lot of (voices) without (worker's name). I need to have people interaction. I think I have changed, getting to know what it is like to be human, getting to know what he thinks about things.

Adam has started going out on his own again and recently went to the movies by himself. He is very keen to get a job and is hopeful of getting work one day a week through his disability job service provider. He is quite happy with the weekly contact with his worker although would like a longer period of time each week.

His support worker believes that Adam needs longer-term intensive one-to-one support to learn social skills. He can get quite angry if spoken to the wrong way or if he feels threatened or frustrated:

If he wasn't receiving support from any of us, he would be extremely unwell. Now is able to come to (clinician) or myself when things are not going well. She may give me a call when things aren't 100 per cent. She has worked with him for longer, had more insight. I was able to speak to her and she advised how to approach Adam and what is and is not appropriate, how far to push him, to communicate re his medication. If an episode occurs, if I'm concerned I can ring her and see if she has seen him and if anything has occurred. If she has advised he has been

⁸ The Mental Health Recovery Star is a tool that is designed for adults managing their mental health and recovering from mental illness. It is completed collaboratively by the service user and worker and measures and supports progress towards goals.



a bit unwell we might just have an appointment in his home, might not go as far, so we are not putting him in situations where it may make it worse.

The support worker speaks with Adam's mother weekly and has met with Adam and his family several times in the past few months:

That's beneficial because every-time we have discussions Adam has been present, just for him to get an understanding of what is going on for his parents, they will bring up concerns, have discussions with Adam re his behaviours during the week. They have been through a lot re accessing services, it's been a journey for his mum. What can I do as a worker to support Adam and his family? What can we do as a team to support Adam? Adam's mum will bring up concerns, an opportunity to have a conversation with myself there in relation to some of his behaviour re engaging with other people or disappearing for hours. I can then take that and think about how I can support Adam re this, an opportunity to discuss with his parents issues I have with Adam re engaging him. They know Adam a lot better than I do. Adam may get defensive might say 'I don't want to talk about this' but it gives him an opportunity to listen. It's important for the participant to be part of conversations, it's about them not what I or his Mum wants. It's about supporting him as much as we can and supporting him to understand.

The support worker provided the following comments on the impact of the National Disability Insurance Scheme (NDIS):

In some way it (NDIS) makes services more accountable, I think, in what they are spending their funding on. As a support worker I really make sure that these things on their plan are being done.

(However), the ability to ensure that you are able to provide a recovery focused service has become harder due to time constraints as you are only funded for one-on-one (direct) funding, making sure you are out there seeing participants. Workers aren't able to put in as much time as they used to, time with participants is missed out. The hour or so doing research, gathering information to take to participants is really rushed: fact sheets, resources, gathering info on other services, mindfulness, hearing voices, mental health or also learning more for a worker re the mental health issue. In the past you were able to go 'I'd really like to learn more about this topic' and seek more information. That has been taken away. You need to be doing your one-on-one.



Consumer case study: Liam

Liam is in his early 20s and lives at home with his mother and sister. He has been receiving Mental Health Community Support Services (MHCSS) for a little over a year. Liam has a diagnosis of schizophrenia and says before he started with the service:

I was an absolute mess. I was having my episodes of schizophrenia all over the place. I was a horrible mess. I was hurting everyone around me: not physically, (but) frustrating them, making them angry. Just because I didn't have the social skills not to.

Liam's support worker explained the service's approach in working with Liam was to:

Look at what he values in order to think about what is most important to him and what he wants to work towards.

Liam said about his goals:

I wanted to be able to save money. I wanted to be able to feel like I was worth having on this earth. I wanted to feel complete.

Liam also had a decision he needed to make:

I had a car that I needed to make a really hard decision with: keep it, fix it or destroy it. They helped a lot. They showed me the options of what I had and put like a pros and cons list down and all that stuff. Even though it was still pretty even with 'let it go' or 'keep it' I was at least able to deal with it, sort of, when my dad forced my hand.

Feeling complete was helped by making those decisions easier. I still feel like I am missing some things, but I can't have everything. (With) saving money, they helped put plans in place that I didn't stick to at the time because my impulse control was horrible. Thankfully that is a lot better now though.

Liam said of his worker:

We just talk about them and do those little form things and write things down, make graphs, just stuff, it's so helpful, it really is.

His support worker feels that:

He is doing well, is able to identify recovery goals that he wants to work on. He is pushing himself to meet those goals and being involved in our groups.

One (goal) is independence and he is coming to community kitchen group, sharing recipes. Doing the Mindfulness group. Using these groups to advance his skills in those areas. Also using to learn social skills, interact with other people. He realises he struggles with social skills sometimes. He feels that he annoys people, and is using the group to observe others, learn how to communicate in a social setting.

Liam says:

I just find the groups that they run just amazing. I started a cooking group a few weeks back and it has been so much fun. Given me ideas for things to cook, learning basic skills and everything.

The support worker advised that Liam's parents, sister and girlfriend had discussed him and his goals with her. She said she had felt the need to intervene over some definite ideas that Liam's father in particular had about what his son needed:

While he talked to me about what he wanted for Liam I made sure he knew that I would be working on what Liam wanted for Liam. I would be happy to keep him updated and as much as Liam wanted he could be involved in the work and in the support.



I have had discussions with Liam about his family always lecturing him, and explored how that makes Liam feel and whether or not his family were aware of how their lectures make him feel. We are slowly approaching the topic of the way his family support him and how there can be more understanding between them to help him recover.

The Mental Health Community Support Service (MHCSS) uses the Collaborative Recovery Model (CRM) as its practice framework. It was developed by the University of Wollongong and focuses on increasing wellbeing and promoting psychological recovery. Liam's support worker talked about how the service uses the three main Collaborative Recovery Model (CRM) tools, the 'Camera', 'Compass', and 'Map':

The Camera is about identifying values, Compass is specific goals and setting them, looking at motivation levels and confidence: how you might over-achieve in that area or you might not quite reach the goal and what that looks like. Then there's the Map tool which really breaks down the goal into steps. It supports potential barriers, solutions to those barriers. We kind of work through these sheets either in conversation form without the sheet if that is what someone prefers or, if that is the best way to engage someone, we can sit there and do it with them. With Liam we reviewed, say, the Camera, which is his values. We have reviewed his old one and identified what some of his values are at the moment and which he would like to have more in focus in his life. First we had a discussion one time when I met him. Next appointment we did an activity to bring out what his strengths and values are and we entered them onto the Camera tool sheet. The next time I saw him we had another discussion about it. It is a long process and it depends what else comes up. If he just needs to talk through something that is going on for him that day then we don't get to it.

His support worker talked about how she responded to variations in Liam's mental health:

(There can be) subtle changes in his mental health. The last few times I saw him he seemed slightly lower in mood. He tends to pick himself up by the end of the session actually... What I am doing is responding to that by drawing out his strengths and allowing him to see how far he's come. That might be more of a focus that session than setting goals and looking into the future. The way I try and respond is to sit with him where he is at and continue showing him that I am hopeful and reminding him that he is hopeful because he is, he has a lot of determination.

Liam values this positive approach:

They've just got all excited and everything and keep on telling me that I have come so far. It's a, like a, confidence boost. It's a temporary confidence boost.

Liam's support worker explained how she approaches her work with him and the balance between self-determination and duty of care,

When I began work with him he was struggling more to do activities of daily living like cleaning up after himself, cook, getting out of the house. And at that time I could have signed him up to a whole bunch of groups, made phone calls and pushed him into things. Instead I made him aware of the opportunities that are out there, told him of the groups at (organisation name). I let him decide what he wanted to do, make his own decisions, perhaps make some of his own phone calls to make that happen. It is hard to know how much support to give and how much you step back. I think that is always going to be a bit of a tension. On that note if someone is in crisis we will respond to that.

Liam said about his mental health over time:

There have been a few little craters but you know I just keep putting one foot in front of the other and just keep on going. Just helping me back up. They just listen as I ramble like I am so good. (Worker name) Is actually going to have a meeting with me and my psychologist to try



and collaborate everyone together. So rather than having individual people, it's a team working together.

The support worker advised that the service uses a variety of tools apart from the Collaborative Recovery Model, including a consumer risk assessment form and management plan which is completed with clients ever six months:

You sit down and do it together. It goes into any risks or thoughts or plans or symptoms relating to violence, suicide vulnerabilities and physical health. It looks at psychiatric history, physical health history, family relationships. We do this every six months with the client. From those risks you make plans: while they are well you do a plan of what to do when they become unwell. We do it together.

The service also uses the Cansas⁹ and Basis¹⁰ tools. These are measures of problems and symptoms used partly for research purposes. The support worker noted of the tools:

They can be beneficial because of the discussions that they prompt, (but) they can also be upsetting. People can opt out, they don't have to do them. They can stop, depending on why it is upsetting, we can approach that in a tactful way ... just be really sincere and supportive and encouraging. They are not about strength, more about the opposite: what is difficult in their lives. They can find ways of highlighting how well they are doing in their lives, can help to identify what they like to change in their lives.

The service uses a range of other tools around motivational interviewing and physical health although this is dependent on the person's mental health.

Liam's support worker said that he is a:

Very good example of the service working well for him. He has got some motivation and is very articulate. He is young and enthusiastic, pleasant to work with.

⁹ CANSAS is an assessment of need tool that is part of the Camberwell Assessment of Needs: These are questionnaires used to assess a wide range of problems potentially experienced by people who have with people with severe or long term mental health problems.

¹⁰ BASIS-32 is designed as a measure of the major symptoms and functioning difficulties experienced by people as a result of a mental illness.



Appendix Two: Methodology

The case studies in the Report were compiled from interviews with consumers and their support workers. The case studies used similar interview schedules for both consumers and workers and focused on:

- client needs
- goal setting processes
- changes in mental health and service provision over time
- involvement with family and clinical services
- outcomes for clients.

The worker interview has an additional question on what tools are used to support service delivery. The interview schedules are included in Appendix Two.

Consumer interviews on their experience of the National Disability Insurance Scheme focused on:

- What was their experience of the National Disability Insurance Scheme (NDIS) process?
- What was good or worked well about the process?
- What was not good or didn't work well about the process?
- Where they achieving what they want from the Disability Insurance Scheme (NDIS) service they are receiving?
- Had it made a difference to their lives?

Consumers were recruited for interviews by advocacy services and community mental health support services. Recruitment was on the basis of finding consumers who were interested in participating in the research and had experiences that highlighted the impact of the National Disability Insurance Scheme. Consumers were paid a \$40 honorarium for their participation in the project. Consumers' names have been changed to protect their identities. The names of services and workers have also been omitted for this reason.

A Consumer Information Sheet and Consent Form for the Project was developed using a National Mental Health and Research Council template. The researcher went through the information and consent process with each consumer before proceeding with the interview. The Information Sheet and Consent Form are included in Appendix Three. Each consumer was given a signed copy of the information Sheet and Consent Form.

The case studies included in Appendix One were written up and sent to consumers and workers for comment.

The original methodology has been modified as it proved more difficult than envisaged to locate and recruit suitable consumers for some aspects of the research. Unfortunately, no consumers who have been declined National Disability Insurance Scheme (NDIS) support or withdrew from the process were able to be interviewed. Services have advised that this may be due to a reluctance of consumers to retell their stories and feelings of vulnerability about their situations. It was also more difficult than envisaged to locate consumers outside of the National Disability Insurance Scheme (NDIS) trial to compare with National Disability Insurance Scheme (NDIS) funded consumers for case studies. This was due to the extension of block funding, which meant consumers who had transitioned to the National Disability Insurance Scheme (NDIS) were still able to access services and skills from state funded community mental health support services relatively recent recommissioning of state funded services with significant organisational changes to catchment and clients.



Appendix Three: Information Sheet and Consent Forms

Participant Information Sheet/Consent Form

Health/Social Science Research - Adult providing own consent

Title	VICSERV NDIS Project
Short Title	Case Studies
Project Sponsor	Caz Healy – Strategic Project Manager
Coordinating Principal Investigator/ Principal Investigator	Leonie Kenny
Location	Melbourne/ Geelong

Part I What does my participation involve?

I Introduction

You are invited to take part in this research project, which is called VICSERV National Disability Insurance Scheme (NDIS) Project. You have been invited because you are a client of **XX**. Your contact details were obtained *from [provide details]*.

VICSERV is the peak organisation representing community mental health support services such as **XXXX**.

This Participant Information Sheet/Consent Form tells you about the research project. It explains the processes involved with taking part. Knowing what is involved will help you decide if you want to take part in the research.

Please read this information carefully. Ask questions about anything that you don't understand or want to know more about. Before deciding whether or not to take part, you might want to talk about it with a relative, friend or worker.

Participation in this research is voluntary. If you don't wish to take part, you don't have to.

If you decide you want to take part in the research project, you will be asked to sign the consent section. By signing it you are telling us that you:

- understand what you have read
- consent to take part in the research project
- consent to be involved in the research described
- consent to the use of your personal and health information as described.

You will be given a copy of this Participant Information and Consent Form to keep.



2 What is the purpose of this research?

- The aim of the project is to understand the types of services you receive from XX. VICSERV is researching this to understand how services might be different between the current standard Community Mental Health Support Services (MHCSS) and the new National Disability Insurance Scheme (NDIS) services.
- By understanding how services are provided VICSERV hopes to be able to describe the main differences to ensure that the services provided are what people need to live well in the community.
- The research is for the purpose of describing how different people experience their services and is funded by a grant from the Victorian Government.

3 What does participation in this research involve?

- The Consent form will be signed prior to any interviews being performed.
- When the consent is agreed our researcher will contact your worker to discuss the types of questions that will be asked.
- Your worker will discuss this with you and arrange a time for you to meet with our researcher. The researcher will ask a series of questions about the types of support that you receive and what works well for you. The interview will take about 30-45 minutes.
- Our researcher will also ask similar questions of your worker – about the types of support you receive and what works well for you.
- The researcher will take notes and also make an audio recording of the interviews.
- You can choose a place to meet that suits you best

This research project has been designed to make sure the researchers interpret the results in a fair and appropriate way and avoids study researchers or participants jumping to conclusions.

There are no costs associated with participating in this research project, however you will be paid an honorarium of \$40. You may be reimbursed for any reasonable expenses associated with the research project visit.

4 Other relevant information about the research project

- We hope to interview up to 14 people who will also be taking part in the case study project overall.
- We will interview four people in one to one interviews and then 6-10 people in small groups.



5 Do I have to take part in this research project?

Participation in any research project is **voluntary**. If you do not wish to take part, you do not have to. If you decide to take part and later change your mind, **you are free to withdraw from the project at any stage**.

If you do decide to take part, you will be given this Participant Information and Consent Form to sign and you will be given a copy to keep.

Your decision whether to take part or not to take part, or to take part and then withdraw, will not affect your routine care, your relationship with professional staff or your relationship **with XX**.

6 What are the possible benefits of taking part?

We cannot guarantee or promise that you will receive any benefits from this research; however, possible benefits may include that mental health service delivery continues to meet people's needs.

There will be no clear benefit to you from your participation in this research.

7 What are the possible risks and disadvantages of taking part?

You may feel that some of the questions we ask are stressful or upsetting. If you do not wish to answer a question, you may skip it and go to the next question, or you may stop immediately.

If you become upset or distressed as a result of your participation in the research project, the research team will be able to arrange support. Any counselling or support will be provided by qualified staff who are not members of the research team. This counselling will be provided free of charge.

Whilst all care will be taken to maintain privacy and confidentiality, you may experience embarrassment if one of the group members were to repeat things said in a confidential group meeting.

8 What if I withdraw from this research project?

If you do consent to participate, you may withdraw at any time.

If you decide to withdraw from the project, please notify a staff member or member of the research team before you withdraw.

A member of the research team will inform you if there are any special requirements linked to withdrawing.

If you do withdraw, you will be asked to complete and sign a 'Withdrawal of Consent' form; this will be provided to you by the research team.

When the researcher has written the case study they will give you a copy to review to ensure that they have understood your story accurately.



9 What happens when the research project ends?

The case studies will confidentially be written up and a report on people's experience with the NDIS will be given to government. A worker at XXX can give you a copy of the report when it is published.



Part 2 How is the research project being conducted?

10 What will happen to information about me?

- All the information and data collected will be non-identifiable.
- The information will be kept at VICSERV and only the Researcher and VICSERV Manager will have access to it.
- It will be stored for three months and then destroyed.
- We are asking you to provide consent for this project only.

By signing the consent form you consent to the research team collecting and using personal information about you for the research project. Any information obtained in connection with this research project that can identify you will remain confidential. Your information will only be used for the purpose of this research project and it will only be disclosed with your permission, except as required by law.

The personal information that the research team collects and uses is the information from the interviews with you and your worker.

It is anticipated that the results of this research project will be published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that you cannot be identified.

In accordance with relevant Australian and/or Victorian privacy and other relevant laws, you have the right to request access to the information about you that is collected and stored by the research team. You also have the right to request that any information with which you disagree be corrected. Please inform the research team member named at the end of this document if you would like to access your information.

Any information obtained for the purpose of this research project that can identify you will be treated as confidential and securely stored. It will be disclosed only with your permission, or as required by law.

11 Complaints and compensation

If you suffer any distress or psychological injury as a result of this research project, you should contact the VICSERV research team as soon as possible. You will be assisted with arranging appropriate treatment and support.

12 Who is organising and funding the research?

This research project is being conducted by Leonie Kenny who has been employed to VICSERV to undertake this project.

It is being undertaken by VICSERV through a grant from the Victorian Government.



13 Further information and who to contact

The person you may need to contact will depend on the nature of your query.

If you want any further information concerning this project or if you have any problems which may be related to your involvement in the project, you can contact VICSERV on 95 17 9000 or your worker at XXXX:

Project contact person

Name	Caz Healy
Position	Strategic Project Manager - VICSERV
Telephone	9517 9000

For matters relating to research at the site at which you are participating, the details of the local site complaints person are:

Complaints contact person

Name	<i>[Name]</i>
Position	<i>[Position]</i>
Telephone	<i>[Phone number]</i>
Email	<i>[Email address]</i>

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about being a research participant in general, then you may contact: The VICSERV CEO on 9517 9000



Consent Form - *Adult providing own consent*

Title	VICSERV NDIS Project
Short Title	Case Studies
Project Sponsor	Caz Healy – Strategic Project Manager
Coordinating Principal Investigator/ Principal Investigator	Leonie Kenny
Location	Melbourne/ Geelong

Declaration by Participant

I have read the Participant Information Sheet or someone has read it to me in a language that I understand.

I understand the purposes, procedures and risks of the research described in the project.

I have had an opportunity to ask questions and I am satisfied with the answers I have received.

I freely agree to participate in this research project as described and understand that I am free to withdraw at any time during the project without affecting my future care.

I understand that I will be given a signed copy of this document to keep.

Name of Participant (please print)	_____
Signature	_____
Date	_____

Declaration by Researcher[†]

I have given a verbal explanation of the research project, its procedures and risks and I believe that the participant has understood that explanation.

Name of Researcher [†] (please print)	_____
Signature	_____
Date	_____

[†] An appropriately qualified member of the research team must provide the explanation of, and information concerning, the research project.

Note: All parties signing the consent section must date their own signature.



Form for Withdrawal of Participation - *Adult providing own consent*

Title	VICSERV NDIS Project
Short Title	Case Studies
Project Sponsor	Caz Healy – Strategic Project Manager
Coordinating Principal Investigator/ Principal Investigator	Leonie Kenny
Location	Melbourne/ Geelong

Declaration by Participant

I wish to withdraw from participation in the above research project and understand that such withdrawal will not affect my routine care at **XXX**, or my relationships with the researchers.

Name of Participant (please print)	_____
Signature	_____
Date	_____

In the event that the participant's decision to withdraw is communicated verbally, the Senior Researcher must provide a description of the circumstances below.

--

Declaration by Researcher[†]

I have given a verbal explanation of the implications of withdrawal from the research project and I believe that the participant has understood that explanation.

Name of Researcher (please print)	_____
Signature	_____
Date	_____

[†] An appropriately qualified member of the research team must provide information concerning withdrawal from the research project.

Note: All parties signing the consent section must date their own signature.



Appendix Four: Interview Schedules

VICSERV NDIS Case Study Client Interview

Purpose and consent

Thank you for making the time to participate in this project.

Before we start I will go over the participant information sheet and consent form with you. This explains the purpose of the project and ensures we get informed consent.

Please feel free to ask questions at any point.

Questions

4. Can you tell me about yourself and your life before you started with (service name)?

Areas to cover: mental health, family background and support, clinical management, needs on referral and, if National Disability Insurance Scheme (NDIS) funded, whether you were an existing community mental health service client and what services you were receiving.

5. Can you describe how your goals and/or needs were identified when you first came to the service? What worked well? Where there any issues with this process?

Areas would like to cover: how assessment undertaken, tools utilised, what worked well and if any issues with process?

6. How well do you think the funded service meets your goals and/or needs? Is the service providing any supports or services that are not funded?

Areas to cover: Differences between National Disability Insurance Scheme (NDIS) funding and current funding. Does funded support meet actual needs? Is the service providing unfunded support?

7. Have there been changes in your mental health, needs or goals over time? How has your (organisation name) worker responded to this?

Areas to cover: Changing needs and/or goals and if so flexibility to respond.



8. Does your worker have any involvement with your family? Has this been of benefit? Have there been any issues or challenges?

Areas to cover: Family liaison: benefits and issues/challenges

9. Does your worker have contact with your GP or clinical mental health service? Has this been of benefit? Have there been any issues or challenges?

Areas to cover: coordination with clinical mental health services: benefits and issues/challenges,

10. Are you achieving what you want from the (service name)? Has the service helped to make a difference to your life?

Areas to cover: Impact of service: has client been able to achieve their goals and any improvements in client's life as a result of the service.

11. Do you have anything you would like to add?

Thank you for your participation



VICSERV NDIS Case Study Worker Interview

Purpose and consent

Thank you for making the time to participate in this project.

Before we start I will go over the participant information sheet and consent form with you. This explains the purpose of the project and ensures we get informed consent.

Please feel free to ask questions at any point.

Questions

1. Can you tell me about your client and their life before they started with your service?

Areas to cover: mental health, family background and support, clinical management, needs on referral and, if National Disability Insurance Scheme (NDIS) funded, whether they were an existing Psychiatric Disability and Rehabilitation Support Service (PDRSS) client and what services they were receiving.

2. Can you describe how your client's goals and/or needs were identified when they first came to the service? What worked well? Where there any issues with this process?

Areas would like to cover: how assessment undertaken, tools utilised, what worked well and if any issues with process?

3. How well does the funded service meet the goals and/or needs of your client? Are you providing any support or services that are not funded?

Areas to cover: Differences between National Disability Insurance Scheme (NDIS) funding and current funding. Does funded support meet actual needs? Is the service providing unfunded support?

4. Have there been changes in your client's mental health, needs and/or goals over time? How have you responded to this?

Areas to cover: Changing needs and/or goals and if so flexibility to respond.



5. Do you have involvement with your client's family? Has this been of benefit to your client? Have there been any issues or challenges?

Areas to cover: Family liaison: benefits and issues/challenges.

6. What contact do you have with this client's GP and/or clinical mental health service? Has this been of benefit to your client? Have there been any issues or challenges?

Areas to cover: coordination with clinical mental health services: benefits and issues/challenges.

7. Do you think your client has achieved what he/she wanted from your service? Do you think that your service has made a difference for this client?

Areas to cover: Impact of service: has client been able to achieve their goals and any improvements in client's life as a result of the service.

8. What tools and processes have been used with this client to support service delivery?

Areas to cover: assessment, goal setting, risk management, monitoring and review.

9. Do you have anything you would like to add?

Thank you for your participation



VICSERV NDIS Project Consumer Experience Interview

Purpose and consent

Thank you for making the time to participate in this project.

Before we start I will go over the participant information sheet and consent form with you. This explains the purpose of the project and ensures we get informed consent.

Please feel free to ask questions at any point.

Questions

1. What was your experience of the National Disability Insurance Scheme (NDIS) process?
2. What was good about the National Disability Insurance Scheme (NDIS) or worked well about the NDIS process for you?
3. What was not good about the National Disability Insurance Scheme (NDIS) or didn't work well about the NDIS process for you?
4. Are you achieving what you want from the National Disability Insurance Scheme (NDIS) service you are receiving? Has the service helped to make a difference to your life?
5. Do you have anything you would like to add?

Thank you for your participation