mental health
community coalition ACT Inc.

When the NDIS came to the ACT

A story of Hope and Disruption in the Mental Health Sector

JUNE 2018

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About this document

This report sets out to 'tell the story' of the impact of the introduction of the National Disability Insurance Scheme (NDIS) on the mental health sector in the Australian Capital Territory. It can be downloaded from https://mhccact.org.au/publications/

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About Mental Health Community Coalition ACT Inc.

The Mental Health Community Coalition of the ACT (MHCC ACT), established in 2004 as a peak agency, provides vital advocacy, representational and capacity building roles for the community-based not-for-profit mental health service providers in the Australian Capital Territory. This sector covers the range of not-for-profit organisations that offer recovery, early intervention, health promotion and community support services for people with a mental illness.

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

Our strategic goals are:

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

Acknowledgements

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MHCC ACT would also like to thank the service providers, consumers and carers who gave their time and shared their personal experiences of the NDIS, and by doing so, have added valuable insight to this report.

Acronyms

ACT	Australian Capital Territory
CHN	Capital Health Network
CMHA	Community Mental Health Australia (national coalition of state peak bodies for community mental health)
COAG	Council of Australian Governments
IFP	Individually Funded Package – see glossary
ILC	Information, Linkages and Capacity Building – see glossary
LAC	Local Area Coordination OR Coordinator – see glossary
MHCC ACT	Mental Health Community Coalition ACT
MHF	Mental Health Foundation – community-based NFP mental health service provider
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NFP	Not-for-profit – see glossary
NGO	Non-government organisation – can include for-profit and not-for-profit organisations
PHN	Primary Health Network
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities

Glossary and key concepts

Block funding

Block funding is where a service provider is funded by government to provide a defined support type to a defined number of people or as many people as they can.

Carer/Mental health carer

This refers to a person with a lived experience of supporting and caring for someone with a mental illness or mental health condition. Usually this is a family member or close friend.

Community mental health services

This refers to the range of government and non-government mental health support services. In simple terms, community mental health refers to mental health care delivered in community settings. These settings could be a residential facility in a neighbourhood street, a GP practice, a private psychiatrist's office, a clinic, a community-based day program, or a person's own home.

There is often confusion around the terminology regarding community, primary, secondary and tertiary mental heath care. A good discussion of what each of these represents can be found in 'Mental Health Council of Australia, Community Mental Health and Primary Mental Health Care Background Paper, July 2010[1].

See also 'Not-for-profit community-based mental health services'.

Consumer/Mental Health Consumer

This refers to a person with a lived experience of mental illness or mental health condition.

Continuity of support

In the context of the introduction of the NDIS, this refers to a principle stated by the Commonwealth Government that no one is to be left worse off as a result of the NDIS. Most states and territories signed agreements with the Commonwealth/NDIS to provide continuity of support services for people who had services prior to the NDIS, but who will not qualify for a funded package of services within the NDIS. However, as highlighted in a Community Mental Health Australia (CMHA) position paper: "To date (beginning 2018), there has been no clear articulation by any Government Department or the National Disability Insurance Agency (NDIA) about what continuity of support actually looks like in practice, or what the provider of last resort would look like and who the provider/s would be."[2]

Individually Funded Package (IFP)/ NDIS Plan

These two terms are more or less interchangeable, and are often referred to simply as a 'plan' or 'package'.

As the name suggests, this is the package of services and supports funded under the NDIS for a person found eligible under the Scheme. People eligible for IFPs must be able to demonstrate that their disability significantly affects their ability to take part in everyday activities. It is estimated that people with IFPs will represent ten per cent of people with disability in Australia once the Scheme is fully operational.

The concept of the IFP is one of the core premises around which the NDIS is designed. It is the collection of funded services and supports, individually tailored to a person with a disability by the NDIA. The plan is structured by the NDIA with the intent of enabling the person to conduct their life and engage in their community in accordance with their own needs, abilities and aspirations. The person then has choice and control in applying the funding allocated within their package.

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[1] Mental Health Australia website, Accessed on 8 June 2018 at https://mhaustralia.org/sites/default/files/imported/component/rsfiles/publications/Community_Mental_Health_and_Primary_Mental_Health_Care_Background_Paper_July_2010.pdf

[2] Community Mental Health Australia Position Statement – Continuity of Support - https://cmha.org.au/wp-content/uploads/2017/04/CMHA-Coninuity-of-support-position-statement-2018.pdf

An NDIS plan comprises three 'support budgets'[3]

- Core – daily activities; social, community and civic participation; consumables; and some transport,
- Capital – assistive technologies, home modifications
- Capacity Building – daily activity, choice and control, employment, social community and civic participation, health and wellbeing, home living, lifelong learning, relationships, support coordination.

'Reasonable and necessary' funding is allocated under each relevant budget depending on individual support needs.

The stated intention of the NDIS is that IFPs are to be planned collaboratively by the person with a disability and a planner from the NDIS. IFPs are to be reviewed annually, by a similarly collaborative process.

Information, Linkages and Capacity Building (ILC)[4]

The Information, Linkages and Capacity Building part of the NDIS is how the majority of people with disability in Australia will gain support through the NDIS. ILC provides information, linkages and referrals to connect people with disability, their families and carers with community and mainstream supports.

Unlike the rest of the NDIS, ILC does not provide funding to individuals. It provides grants to organisations to carry out activities in the community. Many of these activities are open to both people with disability and families. ILC supports people who have an NDIS plan as well as those who do not

People might find their way to ILC activities through a Local Area Coordinator (LAC).

Local Area Coordination/Coordinator (LAC)[5]

Local Area Coordination is delivered by NDIA 'Partners in the Community'. These Partners and the NDIA work to build and improve the way the NDIS is delivered to make sure it works for people with disability in the best possible way. Local Area Coordinators have three key roles:

- link people to the NDIS
- link people to information and support in the community
- work with the local community to ensure it is more welcoming and inclusive for people with disability.

National Disability Insurance Agency (NDIA)

The National Disability Insurance Agency (NDIA) is an independent statutory agency. Its role is to implement the National Disability Insurance Scheme (NDIS). As such, it makes decisions around the eligibility of potential participants, structure and funding of NDIS plans, registration of service providers, grants for ILC, selection of LACs and many other aspects of the Scheme.

Not-for-profit (NFP) community-based mental health services[6]

Community-based mental health services are the range of support and recovery services provided in a community setting, as distinct from a hospital. They are also referred to as 'community-managed mental health services'. While such support services can be provided by governments, this report only refers to those provided by the NFP sector, unless stated otherwise.

For the sake of brevity, this report will commonly refer to these support services as 'the community sector' or even 'the sector', 'NFP service providers', 'NFP organisations' or various combinations of these terms. Context will be provided to ensure that this terminology is clear throughout.

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[3] NDIS website, Understanding your NDIS plan and supports - Factsheet – Managing your NDIS funding package – Downloadable resource accessed as https://www.ndis.gov.au/participants/understanding-your-plan-and-supports.html

[4] NDIS website, FAQs – People with Disability. Accessed on 8 June at https://www.ndis.gov.au/ILC-FAQ-People-with-Disability.html

[5] NDIS website, Local Area Coordination. Accessed on 8 June 2018 at https://www.ndis.gov.au/communities/local-area-coordination.html

[6] Community Mental Health Australia, 2012, Taking our Place. Available on 8 June 2018 at https://cmha.org.au/publications/

NFP community-based mental health services can together be treated as a single sector of the mental health service-provision landscape. The providers of these services are MHCC ACT's key stakeholder group and are responsible for providing the bulk of services that are NDIS eligible in the ACT.

Community-managed services provide a critical gateway for people affected by mental illness to live valued lives in the community. They have led the way in establishing a recovery-oriented mental health service-delivery culture, and in countering the stigma and discrimination that results in social exclusion.

Community-managed services focus on provision of social supports that result in safe and stable accommodation, meaningful engagement in the form of employment, education and training, and other peer-based programs. These are particularly important to allow connection with, and participation in, the wider community. The types of support services offered include:

- helpline and counselling services
- accommodation support and outreach
- self-help and peer support
- employment and education
- family and carer support
- information, advocacy and promotion
- leisure and recreation.

Peer support and peer work[7]

Peer work does something unique and valuable - it harnesses the lived experience of mental ill-health and recovery to support others and foster hope.

Peer support is a system of giving and receiving help founded on key principles of respect, shared responsibility, and mutual agreement of what is helpful. Peer support is not based on psychiatric models and diagnostic criteria. It is about understanding another's situation empathically through the shared experience of emotional and psychological pain.

Informal peer support has always been provided by friends, family and peers. Over the last 10 years, however, the sharing of lived experience has been increasingly recognised as an integral, complementary part of the recovery journey in mental health. Formal recognition has led to increasing numbers of paid peer support roles and a diverse range of terminology, services, activities, practices, protocols, research and resources.

Psychosocial disability

This was not a term commonly used in Australia until its inclusion as one of the disabilities to be supported by the NDIS. The term is descriptive of a mental health condition that is sufficiently severe to amount to a functional disability.

The effects of psychosocial disability can be severe and the impact is frequently underestimated both for people with a psychosocial disability and for their carers. Psychosocial disability can cause social isolation and economic marginalisation that can spiral into crisis, homelessness, poverty and risk of harm through exploitation. This causes extreme hardship for mental health consumers and carers, placing an unfair burden on some of the most vulnerable members of Australian society.

Mental health assessments of people with a psychosocial disability often fail to identify disability support needs and mental health services are often not adequately funded to provide the full range of community-based supports needed by people with a psychosocial disability.[8]

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[7] Mind Australia website, Peer Work. Accessed on 12 June 2018 at https://www.mindaustralia.org.au/work-us/peer-work

[8] National Mental Health Consumer and Carer Forum, 2011, Unravelling Psychosocial Disability, Accessed on 1 June 2018 at http://nmhccf.org.au/sites/default/files/docs/nmhccf_psychosocial_disability_booklet_web_version_27oct11.pdf

Recovery

The concept of recovery has grown out of the mental health consumer movement. The term describes the personal process by which mental health consumers work through the challenges of mental health conditions, usually with the support of carers and/or service providers, to re-establish self-esteem, identity, and a meaningful role in society. Many describe their recovery as a process rather than an arrival at a fixed state, and most consider that sustained attention to their wellbeing and their management methods is integral to good recovery.

When mental health consumers and carers talk about recovery, they do not necessarily mean achieving a state without mental illness or the impairments and disabilities that can result. Very often this is not possible. Even for people whose mental health condition is well-managed, impairments and psychosocial disabilities can be long-lasting or intermittent. Recovery is about achieving an optimal state of personal, social and emotional wellbeing, as defined by each individual, while living with or recovering from a mental health condition.[9]

For example, different people's satisfactory 'recovery' might mean:

- episodes of mental illness are less severe or less frequent than a person has previously experienced, allowing them to remain and engage in their community
- getting well enough to return to their former employment, to enter different employment, or to return to the family home, or
- the absence of mental illness altogether.

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[9] Same source as for footnote 8 on Psychosocial disability

Executive summary

This report sets out to 'tell the story' of the impact of the introduction of the National Disability Insurance Scheme (NDIS) in the Australian Capital Territory (ACT). It concentrates on the trial period and the first year of full rollout of the Scheme in the ACT – a total of three years.[10]

This report is only about the NDIS as it pertains to mental illness and psychosocial disability and is shaped from the perspective of the ACT being the only whole-of-jurisdiction, whole-of-population NDIS trial site. This means the full impact of NDIS was tested and experienced in the ACT in a way that was unique among all the trial sites across the country.

The NDIS is a worthy initiative and one with the potential to improve the lives of thousands of people with disability, their families and carers. As such, it has the potential to contribute significantly to future economic growth and the wellbeing of all Australians. It is hoped that the NDIS will give people more access to, and choice and control over, services and supports – fundamental rights that have long been called for by people with disability.

> **NDIS has opened up scope and possibilities for clients, more opportunities to build capacity.**
> » Service Provider 3

> **I really hope that it can give him some normalcy back, give him choice and control in his life but have enough supports that he won't be on his own.**
> » Carer 2

One of the basic premises of the NDIS trials was that they would provide an opportunity to review the interactions between the NDIS and other service systems and consider any lessons arising. However, the NDIA have not publicly released any data or research around the trial sites and the learnings from them. The only systematic governmental review of the launch sites was in Western Australia (WA) where the WA Government requested a delay to the implementation of the Scheme while they evaluated the evidence from their trial sites of both the NDIS and a WA-specific service model. It has generally been left to the initiative of community organisations to report on their experiences as a trial site, in a similar way to this report.

The not-for-profit (NFP) community-based mental health sector experience of the introduction of the NDIS recorded in this report is a synthesis of the experiences of service providers, consumers and carers. It sets the scene with a short precis of the disability policy environment and the ACT environment before going on to outline common experiences across the ACT NFP community mental health sector and specific service provider, consumer and carer experiences.

The introduction of the NDIS is a massive change to the way disability support services are negotiated, structured and purchased in Australia. With such fundamental change comes major upheaval. As with many major policy reforms, the NDIS has had aspects that have worked well and those which have not. People's experiences of this change influenced how they felt about and interacted with the Scheme and the NDIA.

In the ACT, as with jurisdictions across Australia, a major impediment to the successful transition to the NDIS continues to be that the Scheme fails to cater adequately for the complexities and specificities of psychosocial disability as compared to general disability. This failing is reflected throughout the Scheme's framework, governance, implementation and management.

Strong local relationships and communication channels are critical to managing the host of practical issues and problems arising during the testing of a new system. During the trial period, the ability to call on familiar contacts in the ACT Government and the local NDIA for information or to discuss issues was helpful for community-managed organisations.

Some productive collaboration took place between the NFP community mental health sector and the ACT government and local NDIA office during the ACT trial of the NDIS. In general, however, the sector has not felt that they are regarded as genuine partners in the ongoing development of the NDIS. Too often service providers

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[10] The trial period went from July 2014 through to September 2016; full national rollout began in July 2016. The three month overlap of these two stages of NDIS implementation proved problematic for the ACT – more detail in body of the report.

felt as if they are viewed as self-interested when they have attempted to work constructively with the NDIA in particular, but at times also with the ACT government. This approach has meant that the Scheme has often not capitalised on the breadth and depth of expertise of the sector.

In the ACT, as with other jurisdictions, the pace of NDIS implementation has been too fast for effective change-management, and it has led to the disappearance and shortage of services. The Scheme's yardstick for implementation being on outputs (number of entrants), rather than outcomes (plan quality), exacerbated these problems. This is summarised well in the following statement:

> *The Scheme's rollout is outpacing the readiness of people with disabilities, disability service providers, local area coordinators and the National Disability Insurance Agency to achieve its stated aims, and its sustainability hinges on its interface with mainstream public and community services, which is a minefield of competing priorities and jurisdictional ambiguities across federal, state, territory and local government.*[11]

The withdrawal of ACT and Commonwealth Government funding for some highly effective programs has led to service gaps and also created problems for continuity of support. For the consumers and carers affected this has increased their social isolation and undermined their mental health. The phasing out of programs such as Day 2 Day Living, Personal Helpers and Mentors (PHaMs) and Partners In Recovery (PIR) have been particularly harmful in the ACT. This is neatly summarised as follows:

> *We are also hearing that service gaps are appearing in and around the Scheme. Within the Scheme service delivery gaps relate to poor alignment of participant needs with NDIA plans, and multiple barriers to actualising participants' plans. These gaps both stem from a lack of NDIA expertise and understanding of the unique needs and challenges associated with psychosocial disability. Further, as funding from existing programs is transferred into the Scheme, people who are outside of it are losing the services for which they were previously eligible. There is significant concern that the existing services whose program funding will be transferred to the NDIS will leave people without support when they are forced to close. In the ACT where Partners in Recovery (PIR) was terminated as the NDIS was introduced it was estimated that 63 PIR participants would not be eligible for the NDIS out of a total of around 160 previously accessing PIR. Services for this group of people living with psychosocial disability are drying up in order to fund the NDIS.*[12]

The pricing framework of the NDIS is undermining workforce expertise and service offerings in the ACT, as in other jurisdictions. For psychosocial disability services the pricing structure has reduced providers' resources and presented real challenges to working within a recovery framework. It has placed a downward pressure on wages, which has negatively affected organisations' capacity to attract, retain, train and develop a workforce that can deliver safe, quality outcomes.

The NDIS pricing framework is inadequate to cover increased administrative costs and corporate overheads for organisations providing services under the NDIS. There is significant cost- and risk-shifting to service providers in particular, but also to consumers and carers. In order to address the cost-shifting, service providers have had to rely on their other programs cross-subsidising NDIS services or funding from reserves or debt. Managing risk has been challenging as the constraints on resources make it difficult to implement recognised best-practice approaches to service provision. There was also no Quality and Safeguards NDIS Framework in place during the trial phase and beginning of national rollout.

Consumers and carers are reporting mixed results when it comes to whether or not their lives are better off under the NDIS as compared to previously. Some are definitely finding the NDIS has changed their lives for the better; some have experienced great improvements one year only to have their quality of life eroded again by significant cuts in their Individually Funded Package (IFP) the next year. Others are definitely feeling worse off. While this is difficult to quantify, four things are clear:

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[11] Associate Professor Helen Dickinson, Director, Public Service Research Group, UNSW Canberra Public Service Research Group, et al, Submission to the ACT Legislative Assembly Standing Committee on Health, Ageing and Community Services Inquiry into the implementation, performance and governance of the National Disability Insurance Scheme in the ACT March 2018. Accessed on 1 June 2018 at https://www.parliament.act.gov.au/__data/assets/pdf_file/0017/1190510/Submission-49-UNSW-Public-Service-Research-Group.pdf

[12] Associate Professor Jennifer Smith-Merry et al, The University of Sydney, January 2018, Mind the Gap: The National Disability Insurance Scheme and psychosocial disability – Final report: stakeholder identified gaps and solutions, p.9. Accessed on 1 June 2018 at https://cmha.org.au/publications/

- navigating the NDIS is complex and time-consuming, even for the best informed and supported consumers and carers
- too many consumers and carers are being left feeling worse off
- carers have very little support they can claim in their own right
- those seeking support outside of the NDIS are left with far fewer service offerings than they had before the NDIS.

Despite the vast challenges involved with the implementation of this change, community-managed organisations continued to support people with a lived experience of mental illness during times of fundamental restructuring, fluctuating and insecure funding, large increases in administrative workloads and crucial information failings. This is not without cost as many organisations in the ACT are now experiencing unprecedented financial insecurity. Organisations have had to fundamentally change their business model. Some have withdrawn proven supports and one organisation went as far as deregistering from the NDIS in order to survive this change.

The NDIS is still evolving and changing and is a long way from being a finalised, embedded product across Australia. Crucial information and learnings about the implementation of the Scheme during the trial periods have not been transparently collected or analysed by the NDIA. In the ACT, this has meant that valuable lessons learnt during the trial have been at best ignored or, at worst, totally reversed.

As spelt out in the conclusions of this report, there are many challenges to be addressed before the NDIS can reach its potential and meet its objectives. Notwithstanding this, MHCC ACT, service providers, consumers and carers continue to work with determination to try and ensure that the NDIS leads to the positive changes for people with psychosocial disability that were originally envisioned. The NFP community-based mental health sector also keeps working to ensure that the NDIS is treated as one part of an overall mental health system in which all people in need of support for mental illness have access to effective services regardless of whether they have an NDIS package.

> *[We have been] involved in many wonderful outcomes for people with NDIS plans and can see the potential of what a "good plan" can achieve for someone living with a psychosocial disability. Having a reasonable spread of funded activities, including a focus on capacity-building activities, allows the participant and the provider to keep a recovery focus to the support provided.*[13]

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[13] Woden Community Services' (2017) Submission to the Joint Standing Committee of the NDIS: the provision of services under the NDIS for people with psychosocial disabilities relation to a mental health condition accessed on 16 March 2017 from https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/MentalHealth/Submissions

Development of this report

This report is based on information form a range of sources. Importantly, it relies heavily on first-hand accounts of the experience of the NDIS in the ACT during the trial period and for the first twelve months of the full national rollout. Quotes from first-hand experiences are used extensively throughout the report in support of report themes.

Some of the information in this report can be found in submissions made by MHCC ACT to Commonwealth and ACT Governments inquiries including:

- Joint Standing Committee on the NDIS Inquiry into the provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition, 2017.
- Productivity Commission inquiry into NDIS Costs, 2017.
- Senate Standing Committees on Community Affairs Inquiry – Delivery of outcomes under the National Disability Strategy 2010-2020 to build inclusive and accessible communities, 2017.
- Australian National Audit Office Performance Audit - Decision-making controls for sustainability - NDIS access, 2017.
- ACT Legislative Assembly inquiry into the implementation, performance and governance of the National Disability Insurance Scheme, 2018.

First-hand experience was gathered in several ways, including stakeholder meetings and interviews. A specific interview process was conducted by MHCC ACT during August – November 2016 and again during September – December 2017. Interviewees self-nominated, and separate questionnaires were designed to capture the unique experiences of service providers, consumers and carers (Appendix 2).

Unless already in the public domain, quotes from service providers, consumers and carers are identified using a numeric rather than their name in order to ensure confidentiality – e.g. (Service Provider 8).

Introduction

The introduction of the NDIS in the ACT, first as a trial site, and then as part of full national rollout, has been a story of hope and disruption. This report records the experiences of the ACT NFP community-based service providers, consumers and carers on this journey – a journey which has encompassed experiences ranging from elation and transformation through to frustration, bewilderment and disappointment. This report focuses only on the psychosocial disability aspects of the NDIS[14]. It is also shaped from the perspective of being the only whole-of-jurisdiction, whole-of-population NDIS trial site. This means the full impact of NDIS was tested and experienced here in a way that it was not in any other trial site.

All major reform involves hard work and upheaval. What made the NDIS process particularly challenging in the ACT was its immense scope and that it took place in the context of ongoing reform impacting the mental health sector, particularly the introduction in 2015 of Primary Health Networks (PHN), the National Mental Health Commission (NMHC) Review of Mental Health Services in Australia (2014) and the government response to this (2015), and the development of the 5th National Mental Health and Suicide Prevention Plan (2017). As a result, the introduction of the NDIS compounded existing reform fatigue and disruption.

The Disability Policy Environment

While the development of disability policy has a long history in Australia, the policy environment leading to the introduction of the NDIS can most recently be traced back to July 2008, when the Australian Government ratified the Optional Protocol of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). The UNCRPD includes people with psychosocial disability and aims to:

> *promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.*[15]

The Council of Australian Governments (COAG) is an important vehicle for Australia meeting its requirements under the UNCRPD. The National Disability Strategy 2010/2020 is the first time in Australia's history that all governments have committed to a unified, national approach to improving the lives of people with disability, their families and carers, and to providing leadership for a community-wide shift in attitudes. This Strategy was endorsed by COAG in 2011.

The National Disability Strategy is structured under six broad policy outcome areas:

1. inclusive and accessible communities
2. rights, protection, justice and legislation
3. economic security
4. personal and community support
5. learning and skills
6. health and wellbeing.

A revised National Disability Agreement between the Commonwealth and States and Territories was agreed to by COAG in July 2012.[16] Changes were made to the National Disability Agreement to reflect the policy direction concerning community-based care outlined in the National Health Reform Agreement (2011). The National Disability Agreement's five strategic areas are to:

1. build the evidence base for disability policies and strategies
2. enhance family and carer capacity
3. develop strategies for increased choice, control and self-directed decision-making
4. maintain innovative and flexible support models for people with high and complex needs
5. develop employment opportunities for people with a disability.

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[14] While MHCC ACT recognises there is a certain commonality of experiences with other areas of disability, there are also some very specific challenges fitting psychosocial disability into the NDIS model.

[15] Article1, UNCRPD at https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-1-purpose.html

[16] National Disability Agreement, Accessed at https://www.dss.gov.au/disability-and-carers/programmes-services/government-international/national-disability-agreement

The establishment of the NDIS relates to the third strategic area: developing strategies for increased choice, control and self-directed decision-making.

National Disability Insurance Scheme (NDIS)

In August 2011, the Australian Productivity Commission released its landmark report on disability care and support.[17] The report was highly critical of the care and support available to people with disability and their families and carers within Australia and argued for the need for deep and far-reaching change. The main recommendation of the report was the setting up of a national insurance scheme to improve the quality and enhance the equity of disability service-provision across Australia.

The Commonwealth and State and Territory governments signed agreements that formalised transition arrangements from the old system of disparate state- and territory-based arrangements to the new NDIS. The Intergovernmental Agreement for the NDIS Launch was signed at the COAG meeting of 7 December 2012. The *National Disability Insurance Scheme Act 2013* gave birth to the new Australian NDIS and established the National Disability Insurance Agency (NDIA) to manage the Scheme.

The NDIS is a social insurance model for funding and delivering long-term disability services and support to people with severe or profound disabilities. It is based on the premise that all citizens have a right to good health and social support regardless of their economic circumstances. A social insurance approach is one that shares the costs of disability services and supports across the community. It adopts:

> *…insurance principles that estimate the cost of reasonable and necessary supports, promote an efficient allocation of resources based on managing the long-term costs of supporting people with disabilities and their carers while maximising the economic and social benefits. This would involve consistent application of eligibility criteria, and the timely and efficient delivery of reasonable and necessary supports, including early intervention.*[18]

The NDIS represents a fundamental change to how supports and services for people with disability are funded and delivered across Australia. It empowers people with disability to have more choice and control over the services and supports they use to achieve their goals.

In April 2013, the COAG released '*Principles to determine the responsibilities of the National Disability Insurance Scheme (NDIS) and other service systems*'. This document states that the Commonwealth and State and Territory Governments agree that the principles outlined in this document will be used to determine the funding and delivery responsibilities of the NDIS. The Principles outlined that the NDIS trial sites would provide governments with an opportunity to review the interactions between the NDIS and other service systems and consider any lessons arising out of launch. The Governments would also use this information to amend the Principles and table of supports.

Within this document they also defined the responsibilities of the federal health system as well as the NDIS in regard to health and disability care and support. It explains that:

1. The health system will be responsible for
    a. supports related to mental health that are clinical in nature, including acute, ambulatory, continuing care, rehabilitation/recovery and early intervention, including clinical support for child and adolescent developmental needs, and
    b. any residential care where the primary purpose is for the inpatient treatment or clinical rehabilitation, where the service model primarily employs clinical staff.
2. The health and community services system will be responsible for supports relating to co-morbidity with a psychiatric condition where the co-morbidity is a clear responsibility of that system (e.g. treatment for a drug and/or alcohol issue).

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[17] Productivity Commission 2011, Disability Care and Support, Report no. 54, Canberra.

[18] Council of Australian Governments (2012) High-level Principles of a National Disability Scheme.

3. The NDIS will be responsible for non-clinical supports that focus on a person's functional ability, including those that enable people with mental illness or a psychiatric condition to undertake activities of daily living and participate in the community and in social and economic life.[19]

This highlights how essential it is that a clear understanding exists between the NDIA, the different levels of government and the NFP community mental health services sector around exactly where the roles and responsibilities of one end and those of the other start. The NDIS has caused a fundamental shift in how, where and by whom services and supports are provided – it is commonly referred to as the largest social policy reform since the introduction of Medicare. Clarity of roles is therefore essential to ensure that consumers and carers have sufficient access to supports and services to lead quality lives.

The NDIS was introduced in stages – initially in trial sites (using a number of different models) around the country, and then through a progressive national rollout starting in July 2016. The trial sites rolled out as follows:

- The first trial began in July 2013 in South Australia (for children aged 13 and under), Tasmania (for young people aged 15 to 24), the Barwon region in Victoria and the Hunter area in New South Wales.
- The Perth Hills in Western Australia, the ACT and the Barkly Region in the Northern Territory joined the launch in July 2014.
- The Nepean Blue Mountains area of New South Wales started in July 2015.

The NDIS and psychosocial disability

Psychosocial disability is not a term that was commonly used in Australia prior to the advent of the NDIS. Instead, people with psychosocial disability were generally supported within a recovery framework, focusing on their strengths, and building hope of living a contributing life according to their individual circumstances, desires and abilities. The inclusion of psychosocial disability in the NDIS was hard fought for and welcomed. Its inclusion led stakeholders to believe that the level of support they had long been seeking, would finally be achieved.

Unfortunately, the NDIS has not been shaped with a sound understanding of how to deliver sustainable, recovery-oriented services to people with psychosocial disability. This is important because psychosocial disability differs to other sorts of disability in several important ways:

> *Psychosocial disability differs from physical and sensory disabilities in important ways, which may affect people's ability to seek and access services through the NDIS, and their eligibility for them. People with a psychosocial disability may be less likely than people with other types of disability to identify themselves as disabled and seek support. Affirmative action may be needed to encourage them. People with a psychosocial disability often live with additional complex issues such as homelessness and poor physical health. They may have little or no contact with health and community services and therefore may not be readily identified as potential NDIS clients. The core NDIS term "significant and permanent disability" is problematic in relation to psychosocial disability which, in line with the episodic nature of mental illness, may fluctuate over time, and is particularly at odds with the notion of recovery, which maintains that people who live with mental illness of any severity or duration can seek to live well on their own terms. The National Disability Insurance Agency (NDIA), which manages and administers the NDIS, has clarified that episodic illness may be considered permanent. However, people must be judged to be disabled at the time of applying if they are to qualify for NDIS support, and this may further conflict with recovery principles. Finally there can be a conflict between the primacy of participants' "choice and control" – which suggests their existing service providers should not be a part of individual service planning under NDIS – and the value of having service providers with their knowledge of someone's needs as part of the planning conversation.*[20]

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[19] Council of Australian Governments, 2013, Principles to determine the responsibilities of the National Disability Insurance Scheme (NDIS) and other service systems p. 4

[20] Mental Health Commission of NSW – The NSW NDIS and Mental Health Analysis Partnership Project – Insights from the first two years of the NDIS rollout in the Hunter Region – October 2015 Accessed on 8 June 2018 at https://nswmentalhealthcommission.com.au/resources/the-nsw-ndis-and-mental-health-analysis-partnership-project

There are several key reasons why psychosocial disability is not an easy fit with the NDIS. Firstly, and most obviously, the language and approach to disability used around the NDIS has required a huge adjustment in mindset for people with psychosocial disability. To participate in the Scheme they must focus on their deficits, and prove that they have a significant, serious and life-long disability. Further, they have to demonstrate this on an annual basis as part of their NDIS Plan review process. This has proven to be a significant barrier to access and engagement for many people. For those who have managed to navigate this, it is frequently reported to be detrimental to their wellbeing, and to their sense of hope in recovery.

Secondly, there has been a demonstrated lack of understanding and expertise in psychosocial disability among NDIS staff, especially those associated with the formation and review of IFPs. This has resulted in people being falsely rejected from entering the Scheme, or, if they do become a participant, receiving plans and plan reviews which do not meet their needs.

Thirdly, the interaction of two fundamental elements of the Scheme – pricing and the way supports have been defined – have proven problematic for delivering effective support services under the NDIS for people with psychosocial disability. Evidence shows that people with psychosocial disability are best supported by recovery-oriented services, delivered by staff with qualifications and experience in working with the complexities of severe mental illness[21]. The ability to provide this type of support is constrained by an inadequate pricing model and structural rigidities with the Scheme. Reports, submissions, personal accounts from consumers and carers, and the experience of countless service providers, have all stated that delivering true recovery-oriented services within the NDIS framework is very difficult at best, at worst impossible, and certainly not sustainable.

Working within a recovery framework requires staff to have the time and competence to build a relationship based on trust and understanding; they need to know how to work with a person even in a situation where their mental illness is making it nigh impossible to go about the most basic daily tasks such as getting of bed, taking medications and food shopping; or even just opening the door of their house to a trusted support worker. The role defined as Support Coordination in the NDIS – which pays for a worker to connect a participant with the supports defined in their NDIS plan – is certainly useful and important. But a participant with psychosocial disability also needs someone in a role akin to a 'case manager' – currently not funded under the NDIS – someone they know and trust, with a focus on outcomes and an understanding of how that person is travelling on their recovery journey. They also need a support team that can respond quickly if their mental illness intensifies or they go into crisis. This is also not well catered for under the NDIS.

The majority of service providers have the necessary expertise to work within a recovery framework, and want to do so. But they are prevented from doing so by the structural rigidities within the NDIS framework, and by funding levels that do not pay enough for the recruitment, retention and further development of sufficiently qualified and skilled staff.

These issues are summarised well in an article about a recent report covering similar issues:

> *"While the NDIS is an exciting reform for people with disability, its current structure does not fit easily with the lived experience of people with psychosocial disability," Smith-Merry* [Associate Professor, University of Sydney] *said.*
>
> *"What this report shows is that people with psychosocial disability have significant problems accessing and being accepted into the Scheme, and that plans are not meeting their needs…*
>
> *The report also found that organisations with expertise in psychosocial disability were "collapsing, merging and selecting not to engage with the NDIS due to an inability to provide effective services within the NDIA costing structure".*
>
> *With organisations losing staff with expertise in psychosocial disability because of inadequate NDIA funding,* [Amanda] *Bresnan* [CEO of CMHA] *said issues around costing and market failures needed to be confronted*[22]*.*

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[21] Commonwealth of Australia, 2013, A national framework for recovery-oriented mental health services: guide for practitioners. Accessed on 8 June 2018 at http://www.health.gov.au/internet/main/publishing.nsf/content/mental-pubs-n-recovgde

[22] Luke Michael, Probono Australia, 'New report highlights gaps for people with severe mental illness', 31 Jan 18. Accessed at https://probonoaustralia.com.au/news/2018/01/new-report-highlights-ndis-gaps-people-severe-mental-illness/

The ACT experience of the NDIS

This part of the report is about the experience of the NDIS trial and the first year of the full rollout in the ACT. It is arranged as follows:

- mental health services in the ACT
- activities that were undertaken to support service providers, consumers and carers during the transition to the NDIS
- the common experiences of service providers, consumers and carers
- specific service provider experiences, issues and concerns.
- specific consumer and carer experiences, issues and concerns

The ACT was the only whole-of-jurisdiction trial site for the NDIS. The ACT has a number of characteristics which make it an ideal testing-ground. It is small in geographic size, it is essentially one city with one government, and its population is relatively well-educated and affluent. Given these attributes, the ACT has fewer and lesser variables than other sites. These conditions would allow the Scheme to be implemented with relative ease, and the trial would expose and demonstrate flaws which could be anticipated for the rest of Australia, where the challenges of implementation would be greater.

The Productivity Commission[23] estimated that nationally 57,000 people with psychosocial disability would be eligible for the NDIS. This is around 14% of the number of people with intellectual, physical, sensory or psychiatric disabilities who have significantly reduced functioning, and who the Productivity Commission estimated would need individual support packages. While there was no information available on how this number was calculated, it was estimated that around 900 people with a psychosocial disability in the ACT would be eligible for an NDIS individual package[24].

The rollout in the ACT started in July 2015 and was staggered over a period of two years with a different age group becoming eligible to apply every quarter (see table in Appendix 1 for ages and timing of the transition). Officially the NDIS Trial period finished at the end of June 2016. However, there was still a large number of people with psychosocial disability that had not accessed the NDIS. These were in age groups scheduled to transition into the Scheme in the later months of the trial, but by this time there had been major delays to entering the Scheme.

By the end of June 2017[25] in the ACT:

- There were 6327 eligible NDIS participants of which 5878 participants had an approved plan.
- Twelve per cent of all ACT participants with an approved NDIS plan had a psychosocial disability as their primary disability (the highest of any jurisdiction).
- Around a quarter of all participants over the age of 25 with an approved NDIS plan had a psychosocial disability as their primary disability.

Mental health services in the ACT[26]

The ACT Government provides mental health services directly and through partnerships with community organisations in the ACT. Some mental health services are also provided by the Federal Government through the ACT's PHN, named Capital Health Network (CHN), and the Department of Social Services. The services provided range from prevention and treatment to recovery and rehabilitation, social inclusion, and acute and sub-acute services.

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[23] Productivity Commission 2011, Disability Care and Support, Report no. 54, Canberra.

[24] ACT Government submission (2018) to the Standing Committee on Health, Ageing and Social Services', Inquiry into the implementation, performance and governance of the National Disability Insurance Scheme in the ACT, Canberra, accessed on 2 May 2018 from https://www.parliament.act.gov.au/__data/assets/pdf_file/0005/1190498/Submission-36-ACT-Government.pdf

[25] NDIA (2017) *ACT Dashboard – 30 June 2017* from https://www.ndis.gov.au/about-us/information-publications-and-reports/quarterly-reports.html

[26] The information in this section is based on yet to be published data collected for CHN by Furst, MC., Salanas, J-A., Xu, T., Salvador –Carulla, L. It will be published as 'The Integrated Mental Health Atlas of the Capital Health Network. Mental Health Policy Unit, Brain and Mind Centre, Faculty of Health Sciences. University of Sydney'

CHN commissioned an inventory of available services in the ACT specifically targeted for people with a lived experience of mental illness. The data was collected between June and November 2016. This coincided with the end of the NDIS trial in the ACT, and the beginning of full national Scheme rollout – a period when NFP community-managed mental health services in the ACT were in a state of flux. The data was collected through both face-to-face and telephone interviews. Thirty-three of the 36 organisations (92%) identified as providing services to people with a lived experience of mental illness in the ACT participated in the study.

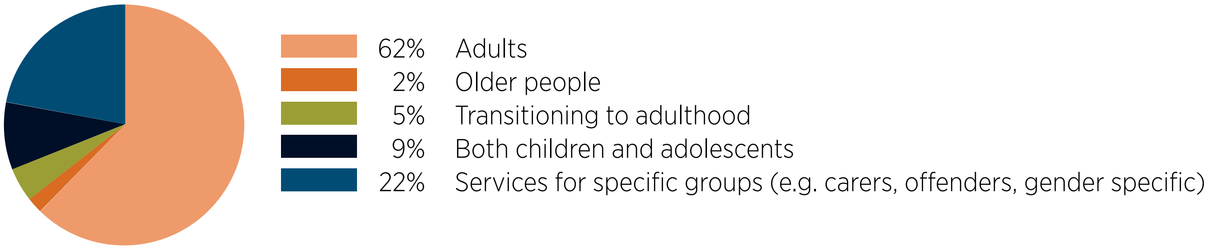
On-going changes to key areas of service-delivery during the collection period meant that some services were unable to provide relevant service or planning information to the researchers. These changes included: service closures; changes to service delivery; as well as a lack of clarity over funding, including current payments to services and ongoing funding, and over the future structure of the workforce. Around a third of services in the ACT could not provide a stable management plan.

In total, 40 of a total of 122 programs, provided by 110 care teams across the 33 service providers, were without organisational or temporal stability at the time of interview. This was almost one third of the total number of programs, and represented one half of programs provided by non-government organisations (NGOs), which include NFPs. This high proportion of programs lacking funding stability demonstrates a fragility in the system at this time, particularly in the NFP community mental health system, where most of these services are based.

There was also change to the type of care provided by some services, as illustrated in the case of a provider of supported accommodation finding that under NDIS plans, shorter, recovery-focused stays were giving way to longer stays with less emphasis on recovery principles.

At the time there were 110 services with 122 main types of care. Most of the types of care were directed at adults (62%) with a lot smaller numbers specifically directed to children and adolescent (9%) or those transitioning to adulthood services (5%).

Main types of care by target population



A number of areas were identified in which there was a lack of services for people with a lived experience of mental illness in the ACT. These include acute and non-acute alternatives to hospitalisation, acute and non-acute health-related day programs, employment-related services, and culturally and linguistically diverse services.

Activities that supported the transition

Although the transition experience was a challenging one, there was a genuine commitment in the community sector to working together in a concerted attempt to ensure the Scheme was successful. Eighteen months prior to the commencement of the ACT NDIS Trial the ACT Government formed an NDIS Taskforce. This was charged with using NDIS Sector Development funds and ACT Government funding to undertake a range of activities to help the disability and mental health sectors prepare for and implement the NDIS. Importantly, the Taskforce included a Mental Health Specialist Officer. The Taskforce quickly began to work collaboratively with the ACT office of the NDIA and the relevant peak bodies: National Disability Services ACT (NDS ACT), MHCC ACT, Carers ACT, and the ACT Mental Health Consumer Network.

Prior to commencement of the trial, the Taskforce oversaw implementation of several preparatory initiatives, including:

- a trial of small self-directed funding grants to individuals to purchase services and supports
- Community Conversation sessions with groups of potential NDIS recipients
- workshops on business essentials, international experience of implementing personalised funding, and other topics.

Once the NDIS Trial commenced additional support was funded, including:

- business investment packages of up to $50,000 and other programs assisting organisations to implement strategic business change
- small grants for individuals to prepare and plan for the NDIS
- a workforce awareness tool with NDIS factsheets and information
- NDIS engagement and planning support for harder-to-reach groups
- dedicated programs for Aboriginal and Torres Strait Islander people
- planning and wellness support for carers of NDIS participants
- "Ready4" portal and program of business support tools and resources.

One of the projects that the ACT NDIS Taskforce supported was the "Your Voice, Your Choice" program which was funded by the Commonwealth Government NDIS Sector Development Fund. The program was delivered in partnership by Wellways, Imagine More and Community Connections and ran from May 2015 until December 2016. This was a community education program designed to raise awareness about the NDIS, including how to access it and how to benefit from the opportunities it provides. The program worked to:

- raise awareness about the NDIS among people who have traditionally not engaged with the disability or mental health service systems
- increase the ability of people with disability, including psychosocial disability, to consider what constitutes a good life for them by enabling/encouraging them to set life goals and objectives and make informed decisions
- support people with disability to maximise the opportunities to exercise choice and control over the supports and services in their lives
- assist families in their primary supporting roles from a perspective that respects and promotes the agency of the person with a disability to exercise control and choice in their life.

Within the program a number of different activities were planned to assist people to understand the NDIS including workshops, one-on-one and community conversations, inter-agency networking and producing digital stories. Part way through the program, a change was made to focus on community conversations and one-to-one supports rather than group sessions. It was found that information delivered in a group format did not provide the space or time for people to work through the information and increase their confidence/capacity to navigate the NDIS.

As the peak body representing community-based mental health service providers, MHCC ACT played a valuable role in working with and fostering an attitude of cooperation between the ACT Government, the local NDIA, the NDS, mental health service providers, consumers and carers with the aim of facilitating the best possible transition to the NDIS. The key ways this was achieved were in influencing policy development, participating in steering groups, communication and collaboration activities, and organising workshops.

Influencing policy development

MHCC ACT coordinated community sector responses to NDIS policy development processes including the Information, Linkages and Capacity Building (ILC) aspect of the Scheme, and the first pricing review. MHCC ACT also led stakeholder participation in two CMHA projects – one on individual supports for people with psychosocial disability, the other on the workforce implications from the NDIS.

On behalf of stakeholders, MHCC ACT wrote to all levels of government calling for urgent action to address key concerns around the implementation of the NDIS and its application to psychosocial disability. Submissions were also written to a number of parliamentary and government committees and commissions.

Communication and collaboration activities

MHCC ACT implemented a Weekly NDIS Update e-newsletter communicating with the broad sector on developments, events, opportunities for influencing policy development, media reports and research. The e-newsletter was sent out to around 700 subscribers for around two years; more recently it has become part of the MHCC ACT general e-newsletter.

MHCC ACT collaborated with ACT Government, the local NDIA, ACT Mental Health Consumer Network, Carers ACT and NDS to hold regular forums so that the community mental health sector could interact directly with the main players in the Scheme. Topics were driven by forum attendees – for example, access and engagement, getting plan-ready, making NDIS plans work, and working collaboratively. One of the notable achievements of this was that the local NDIA office agreed to trial specialist psychosocial disability planning teams – service providers noted a marked improvement in NDIS plans during the time that these teams were in place.

As the peak organisation for NFP community-based mental health services in the ACT, MHCC ACT participated in the steering groups of two ACT Government-funded NDIS projects: ‘Values in Action’ on organisational transformation, and ‘Opening Doors’ on engaging Aboriginal and Torres Strait Islander communities in the NDIS.

MHCC ACT helped organisations to learn about and assist clients to navigate the NDIS by bringing together front-line NDIS workers to learn from each other. The Mental Health Services NDIS Champions Group was a small group of experienced mental health recovery workers, representing a variety of organisations. Members shared experiences and resources, raised operational issues, worked together to find solutions for their clients and informed MHCC ACT of what was happening on the ground.

Organisation of workshops

At the request of the NDIS Champions Group, MHCC ACT organised workshops on the cultural changes required to make the NDIS successful. Front-line workers were not used to negotiating and discussing the costs of services with clients and did not know how to structure service agreements with clients. Often clients didn’t understand the parameters around the funding in their packages. Due to demand, the first workshop was repeated for a second time.

- NDIS Psychosocial Disability Individual Funding Packages Implementation. The focus of this workshop was on:
  - how to best align clients’ ‘life goals’ with the suite of services available in the community,
  - business sustainability, and
  - how to have conversations with clients about money.
- Developing Sustainable Services in the NDIS Framework. The focus of this workshop was on the opportunities and challenges the NDIS presents:
  - the impact of NDIS entry processes on service delivery,
  - preparing to report against client outcomes,
  - managing participants’ expectations, and
  - increasing staff understanding of their changing roles.

Common experiences across the ACT NFP community-based mental health sector

The experience of navigating the NDIS environment both in trial and full rollout varied between service providers, consumers and carers, and will be discussed further on in this report. Despite these differences however, there were also some commonalities of experience and recurrent themes shared between these different groups. These included:

- communication difficulties
- the challenge of continual changes, reversals and upheaval in the community sector
- problems with planning and reviews of IFPs.

Communication difficulties

Communication difficulties were a facet of all the issues raised by service providers, consumers and carers and are elaborated on in the different sections of this report.

It needs to be highlighted that one of the major frustrations that service providers, consumers and carers all mentioned was the inability to contact people in the NDIA to seek clarity about aspects of the Scheme, or information on access requests, plans or reviews. They mentioned things like phone calls being commonly on hold for periods exceeding 45 minutes and that the calls regularly dropped out, requiring the person to begin again. Stress associated with this frustration was exacerbated by having to re-explain often sensitive issues. The financial cost associated with this lost time affected participants and service providers.

Emails were also often not answered for weeks and even months. NDIA staff were regularly reluctant to give specific verbal or written information and would not commit to specific timeframes.

> **I thought that the planner that held the meeting would be contactable after the assessment, but it's been pretty impossible for consumers to contact anyone at NDIS.** » Service Provider 1

> **It's been frustrating because you do spend a lot of time on hold and then things sometimes don't work. Communication has not been helpful or easy to read. The people who work for the organisation [NDIA] assume all the admin stuff has happened as it should. They told me to go on the portal but not how to access the portal. They assumed I had received information that I hadn't.** » Consumer 5

> **They have been really lovely when I could get through to a person, but none of them seem to have any of the necessary knowledge to help.** » Carer 2

Continual changes and upheaval

Carers, consumers and service providers all recorded varying degrees of confusion, stress and anxiety around the process of change from the existing system to the NDIS. Everyone was prepared to encounter problems during the introduction of a new way of doing things. However, the magnitude of the difficulties exceeded even the best prepared.

The experience of those trying to build new business models and navigate new ways of providing and accessing services was indicative of a poor change-management process, particularly on the part of the NDIA, but also at all levels of government more generally. This instability was exacerbated by the fact that a substantial part of the NDIS was still being built while it was being trialed and implemented – and to an extent this is still the case at the time of finalising this report.

Of particular concern to service providers, consumers and carers were the regularly changing eligibility criteria, system and administration errors, and confusing access and assessment procedures. The pace of change exacerbated these concerns as service providers, carers and consumers struggled to digest information fast enough to keep up. Many mentioned finding it difficult to find consistent information and reliable education to help access and effectively utilise the NDIS. The reliability of the information was also a concern for service providers, consumers and carers.

> **[NDIA] give inconsistent information. We felt we couldn’t rely on it and we still don’t feel confident to give out some information to consumers in case it changes.** » Service Provider 1

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

> **One of the most challenging problems is that everyone is learning the system, so it’s difficult to get the right information. I’ve heard there is a lot of variation between different NDIS planners. Some accept evidence that others don’t, so it’s challenging.** » Consumer 2

> **The communication and constant change was pretty confusing, really ad hoc communication as they changed on the run, enormous amounts of change. You would just settle in and it would change again.**
> » Service Provider 6

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

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

The ACT trial site process of transitioning people into the NDIS according to age brackets led to a bottleneck effect for mental health consumers. Primarily this was due to the bulk of people with psychosocial disability falling within the last age groups to transition across to the NDIS. While three months was originally scheduled to move individuals from each age group into the Scheme, the reality was that it took longer and backlogs grew over time. This compounded the bottleneck effect for mental health consumers.

The impact was an increase in anxiety and confusion for the community sector as the NDIA struggled to both process the growing number of applicants and manage the complexity of a high number of people with psychosocial disability as their primary diagnosis. By the end of the trial period and the beginning of national rollout many NDIS applicants were being told they would have to wait in excess of six months for their NDIS plan to be fully processed.

Compounding the difficulties faced at the end of the trial period was that it overlapped with commencement of the national rollout (July 2016) by three months. At national rollout, the ACT NDIA office also took on responsibility for south east New South Wales. By this stage, first NDIS plan reviews were also being initiated for those in the ACT who had transitioned early into the NDIS. From late 2016 an alarming number of people were finding that their second plans contained significant funding cuts, and this in turn meant a lot of people were returning to the NDIA for a review, increasing the NDIA workload and freezing the funding available in the person’s plan.

The final stages of the ACT Trial also coincided with a major collapse of the NDIS service payments portal[27] – which, among other things, left many service providers without payment and many participants without the ability to purchase supports, in some cases for many months.

The other thing that happened at this time was the sudden announcement by the NDIA that they had hit the target number for ACT NDIS trial participants, and that no more people would be able to enter the Scheme. This announcement took the ACT Government and the sector entirely by surprise. It also caused much anxiety, particularly among people waiting to enter. Although the rationale for this announcement was never adequately explained, it was ultimately resolved fairly quickly. But this was another of too many unnecessary and poorly-managed aspects of the rollout of the NDIS in the ACT.

Alongside the process of transitioning people into the NDIS according to their age, was a process for the withdrawal of identified ACT Government block funding from NFP community-based service providers. Put

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[27] PwC (2016) National Disability Insurance Scheme MyPlace Portal Implementation Review – Final Report, from https://www.dss.gov.au/sites/default/files/documents/09_2016/pwc_review_of_the_ndia_myplace_portal_implementation_-_final_report.pdf

simply, programs that were assessed as serving a clientele who would largely be eligible for the NDIS would have their ACT Government funding gradually transitioned to the NDIS. The transition of funding was aligned with the periods when program participants became eligible to transition to the NDIS according to the transition schedule. This initially appeared reasonable as the NDIA originally guaranteed that a person would have an individual package within 28 days of being found eligible for the NDIS.

As already noted, in practice participants' packages took a great deal longer to finalise than anticipated. Delays in transitioning people into the NDIS, the inconsistencies and inadequacies of NDIS plans necessitating plan review, and the NDIA practice of freezing the entire plan's funding if a review was requested, meant that too often a person did not have a functioning NDIS plan until long after their nominal transition date. Even when plans were appropriate, it would often take weeks or months to secure the support services defined in them. In the meantime, block funding for the programs people had been accessing continued to be withdrawn. In too many cases this left people without supports, or service providers continuing to support people without funding to cover those supports. To their credit, the ACT Government eventually responded to the concerns of service providers by providing funds to cover supports during delays in transition in some circumstances.

> **The ages and stages rollout was sensible. But the reduction of block funding that coincided with the stages was not great because there were individuals not allowed in the Scheme, yet funding was cut to their program.** » Service Provider 5

> **Gradual introduction by age was inefficient because the majority of people [with psychosocial disability] are in one age group.** » Service Provider 4

> **In the ACT trial site, people were introduced in by ages and stages, and the biggest cohort came at the end. We were already behind. Capacity to transition was reduced by that.** » Service Provider 6

Adding to all this, the ACT Government NDIS Taskforce was effectively wound up at the commencement of national NDIS rollout. This meant that during the last stages of transition – when the largest proportion of mental health consumers were entering – there was no local government mental health spokesperson to support the community sector.

Individual Funding Packages (IFP) – problems with planning and reviews

There are a number of steps involved in an individual NDIS participant achieving an appropriate IFP. The key parts of this process include pre-planning, plan interviews and, where necessary, review of initial plans. Additionally, participants in the Scheme are required to undertake an annual review of their NDIS plan. The experience of these processes in the ACT was too often problematic, including experiences of inconsistency in information and packages, packages not meeting key support requirements, and long delays. The NDIA offered little transparency around these issues and service providers found it difficult to know where to go to raise concerns and find solutions in the best interests of their clients.

Despite this, there are many positive examples of the impact of good, consistent planning with appropriate funds to support the goals set by clients. One of the positive aspects of the Mental Health Services NDIS Champions Group facilitated by MHCC ACT was the opportunity to discuss examples where consumers were experiencing good outcomes.

> *.... [We've been] involved in many wonderful outcomes for people with NDIS plans and can see the potential of what a "good plan" can achieve for someone living with a psychosocial disability. Having a reasonable spread of funded activities, including a focus on capacity-building activities, allows the participant and the provider to keep a recovery focus to the support provided.*[28]

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[28] Woden Community Services' (2017) Submission to the Joint Standing Committee of the NDIS: the provision of services under the NDIS for people with psychosocial disabilities relation to a mental health condition accessed on 16 March 2017 from https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/MentalHealth/Submissions

> **It [NDIS] has made an enormous difference to my life. I can now relax and be more of a parent than a service provider/supporter/financial provider. I have feared dying and not being around to support my son, but now I know he will be supported for life.** » Carer 4

Many of the systems put in place for engaging with the NDIS were not designed to meet the needs of people with psychosocial disability, many of whom are highly marginalised and disadvantaged. A willingness to engage with government, access to Information Technology systems such as the MyGov website, and the requirements to have conversations with unfamiliar people, including sometimes over the phone, are just a few examples of the sort of systemic impediments built into the system.

Many service providers reported spending months working with individuals to help them overcome their reluctance, anxieties and misapprehensions about engaging with the NDIS. In the most difficult examples, special arrangements were sometimes negotiated with the NDIA. For a period during the trial phase, for example, the NDIA implemented the concept of "mirror plans" whereby current supports were simply reflected into an NDIS plan for the first year, bypassing the challenges of the pre-planning and planning process. This approach could be seen as a pre-cursor to the "My First Plan" concept used during the first stages of full national rollout (from which time there was no further use of "mirror plans").

There were a number of key issues that people had to deal with around the planning processes. One of these issues was a reported lack of consistency with IFPs. This occurred internally within a package – meaning that the different components were inconsistent thereby making it difficult to implement. It also occurred between packages for people with very similar functional capacity meaning that according to their IFPs, one person could be effectively supported, while the other could not. These discrepancies occurred both in terms of the total value of the package and the allocation of supports within the different parts of a package.

Another big issue was a lack of appropriate expertise among NDIA staff. On the whole, consumers, carers and service providers found that the NDIA staff associated with the planning process demonstrated a poor understanding of the specifics of supporting people with a psychosocial disability. Particular concern was reported about the lack of contingency plans and flexibility in IFPs for crisis situations or if the participant needed an increase in support due to an episodic period of mental ill-health.

People also found the information provided by NDIA staff about the NDIS was inconsistent. Consumers reported being given inconsistent information about the content and scope of their packages during the planning process. There was a lack of clarity around the supports funded under the NDIS, as well as confusion about the role of mainstream services such as clinical services in regard to the NDIS.

The gathering of evidence for the NDIS Access Request Forms was problematic for most people. ACT clinical mental health services took time to understand and effectively provide information needed for the forms. General Practitioners often didn't understand what was required of them or have the information needed to complete the forms. General Practitioners also reported feeling uncomfortable describing a client's condition as a permanent disability.

To complete the required forms, people wanting to enter the NDIS found they needed to book long appointments with their General Practitioner. Such appointments are often difficult to obtain. They are also costly, particularly given that there is no specific Medicare service code available to reimburse any of the cost. To help alleviate these issues the ACT Government and NDIA produced a simpler form specifically for people with psychosocial disability. This helped inform revision of similar national NDIS forms.

The experience of providers, consumers and carers showed that outcomes for a participant were almost guaranteed to be more appropriate if a participant was supported by a formal or informal advocate through the planning process. The ACT Government made some specific funding available to assist in this process during the trial. Service providers were also able to provide some advocacy supports with what was left of block funding. Notwithstanding this, service providers still reported spending large numbers of unfunded hours preparing some of their clients to access the NDIS.

> **Clients didn’t feel supported by their doctor to access NDIS.** » Service Provider 1

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

> **It is better than before, but funding for my [NDIS] plan is in the wrong areas.** » Consumer 1

> **I believe they [the NDIA] should have employed people with lived experience of disability rather than people getting these jobs with no understanding or experience what it would take for people with disabilities to have full lives.** » Carer 3

> **The amount of bureaucracy! Families have enough trouble surviving and they can’t wait for six months because of bureaucracy.** » Consumer 5

> **Interpretation of [NDIS] plans especially for people with psychosocial disability is complex.**
> » Service Provider 1

> **If NDIS went and communicated with your support network first before starting from scratch that could be really useful.** » Consumer 4

Following consultation and feedback from the ACT community mental health sector, the ACT NDIA Office set up specialist planning teams during the ACT trial to allow for deeper expertise in the planning process for the different types of disability. Anecdotal evidence showed that this improved the situation - IFPs became less inconsistent and more appropriate to the needs of the person with psychosocial disability. Fewer IFPs needed to be sent back for review.

However, the concept of disability specialist teams was abandoned at the beginning of national rollout. At the time of writing consideration is once again being given to specialist teams. This was a valuable lesson learnt during the ACT trial, however it is regrettable that it was not recognised at the time for its value and common sense.

> **Planners don’t have skills to plan and assess people who have psychosocial disability – they are not listening to consumers.** » Service Provider 2

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

The NDIS plan review process in the ACT has had significant difficulties since the full rollout of the Scheme commenced. In the first six months of the full rollout, due to backlogs of work in the NDIA, reviews were postponed or plans were rolled over depending on the period in which the first plan commenced. This, of course, caused more stress and worry for all involved around the continuation of funding, when a review would be scheduled and what process would be used for the review.

Once the NDIA commenced the NDIS plan reviews, another issue emerged. Significant cuts in plans were experienced by participants with no evidence provided as to why this decision was made by the NDIA. Providers have stated that some of the clients that they were seeing daily under their first plan now only receive minimal support under their reviewed plan. These are clients who have not had any significant changes to their needs or circumstances in the intervening time, so it can be assumed that they are now left without access to the full range of supports they require.

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

As well as the significant cuts to NDIS plans, the review process was problematic for a number of reasons including:

- the lack of an authentic review of the efficacy of the existing plan – what worked, what did not, and where and how changes could be made
- failure on the part of the NDIA reviewer to adequately acknowledge or refer to the evidence provided for the review
- the blanket transition to a local area coordinator (LAC) for support connection when most people with a psychosocial disability generally need more specialised support than the LACs could provide
- unused funds being treated as evidence of not having been needed when planning next IFPs, without any regard for the reasons why funds were not spent
- NDIS plans being approved by the NDIA without an opportunity for participants to review them
- no ability to make small amendments to plans, as had been possible in the trial.

A number of additional communication issues arose during the plan review process, including:

- the review interviews being very brief, superficial conversations
- the interviews being conducted by phone calls instead of face-to-face meetings
- review phone calls received with no prior notice to the participant
- NDIS staff failing to explain what the call was for, or to establish whether the timing of the call was appropriate for the person
- people not knowing or being informed that they could have a support person present at the time of the call.

Given the import of the outcome of the review, service providers, carers and consumers all raised concerns about the appropriateness of using a phone call for the plan review process. People with psychosocial disability often take a long time to build relationships and trust – a phone call from an unknown person is therefore counterintuitive and not the best way to gain the information needed to review a plan.

A phone call is also a difficult interface for a person to make their needs known and understood, to refer to supporting paperwork, or to effectively engage with the reviewer and be sure they have been properly listened to and understood. It is also difficult to verify the integrity of the caller in an age where phone scams are commonplace. On 30 May 2017, the NDIA itself posted a warning on its website about a "potential scam involving people who claim to be from the National Disability Insurance Agency attempting to defraud National Disability Insurance Scheme participants by telephone". People with psychosocial disability are particularly vulnerable in this regard.

> **It stared out being a really wonderful exciting adventure, but now it's not. We are in crisis.** » Carer 3

Consumers and carers had a great deal of hope around the NDIS – and reasonably so given the enormous value of the initial premises of the Scheme. They anticipated more choice and a better quality of life. The reputation of the NDIS has been damaged by the extent of problems and disappointments people have experienced in trying to navigate it. There was a cruel irony in people experiencing such transformation and seeing possibilities open before them during their first NDIS plan in the ACT; only to see this vanish with no explanation after their first NDIS plan review resulted in a significant funding cut.

Service providers themselves reported finding it distressing that they were constrained by resources from providing adequate and appropriate support to some people in need. Where possible, service providers stepped into the breach and at their own cost supported people who were left in this situation, and sometimes in crisis as a result. The decision to do this for extended periods caused financial upheaval for many service providers.

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

> **We also discovered from the second planner that unspent funding is used as a baseline for a new plan, resulting in punishment for not using all funding. The planners did not ask us why all funding was not used, but when we provided the reasons, it was reassessed. This is worrying as NDIA states that participants are not to be penalised for not using funding and there are many reasons why people do not use funding, especially in a first plan, in the first year of a new scheme.** » Carer 1

> **I think it's going to get worse. Because they keep cutting plans back, it will leave more people in crisis.**
> » Carer 3

Service Provider Experiences

The introduction of the NDIS is a massive social reform. It has required huge cultural and business-model changes for service providers. Yet service providers saw the NDIS as a positive step towards meeting the support needs of individuals with a psychosocial disability and providing them the choice and control over these supports. They also accepted that the transition to the NDIS from block-funded services would be disruptive.

> **It was never going to be easy, but external problems made it worse.** » Service Provider 4

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

As well as the common issues mentioned in the sections above such as continual changes, planning issues and communication problems, service providers dealt with a number of concerns during the transition to the NDIS. These included:

- transfer of risk to service providers
- adapting to and accessing a new online system for billing services
- concerns around the NDIS pricing structure
- service gaps and closures
- building recovery into NDIS plans
- increasing unfunded, unbillable work
- a number of concerns around workforce, including a downward pressure on wages and therefore qualifications, and increased casualisation.

Risk Transfer

A significant issue that was raised by service providers in the transition to the NDIS was the transferring of risk to service providers. As well as the risks associated with planning and pricing issues discussed elsewhere in this report there were also a number of other risks that the service providers experienced.

There was often an unreasonable lag between when changes were implemented and when detailed written advice was available to NDIS participants and providers. When this happened, risk was shifted to service providers to correctly interpret a verbal briefing ahead of official documentation. There was also often little or no warning of forthcoming changes which meant that neither participants nor providers had time to adequately prepare for the changes. For example, only one week of notice was given ahead of the closure of the NDIS Portal for end of financial year 2015/16. This left providers with insufficient time to process their invoices for services rendered, leaving them months in arrears.

> *For example any delays in putting in place plans or reviewing plans which leads to consumers and then providers not receiving payment, leaves providers in a position of having to make a decision to provide services and not be paid.*[29]
>
> *The service and financial risk has been left squarely at the feet of the service provider, particularly given the inconsistency of plans. The service risk is presented through lack of communication from the planner and through the client. WCS believes the introduction of the Scheme has shifted the financial burden to service delivery agencies*[30]

Service providers were also provided with little or no information from the NDIA about their clients. Previously this information was accumulated as part of the process of establishing a relationship with the client, understanding their goals, and determining how best to support them. Under the NDIS the client comes with funding for a service but no background information. Further, funding in NDIS plans does not provide for the ‘two support workers to attend’ policies, which most organisations regard as best practice when assessing new clients. This shifts risk to organisations, potentially putting workers and clients at risk.

Adapting to and accessing a new system

The extent of change required within organisations cannot be underestimated. As was to be expected with such a massive transition, service providers felt a lot of pressure in not only working to assimilate and adapt their own organisations to the NDIS, but also to work with consumers and carers to help them transition to the new system.

Administration of the Scheme by the service providers required a change of mindset for organisations – for the first time they needed to have conversations with clients about the cost of the services they access, and what that means for the rest of a person’s plan. Negotiating what can and cannot be purchased as part of a person’s NDIS plan, and explaining the distinction between funds which the person has been provided for services through the NDIS as distinct from personal finances, were among the many new skills needed by organisations in an NDIS workforce. These required time to develop and time to implement.

Organisations undertook extensive work assisting consumers with pre-planning and testing eligibility as well as supporting them to find and access services once they had entered the NDIS. During the transition many organisations were still block-funded to provide services, and some of the NDIS transition work was supported with this source of funding. This, however, was a temporary solution to a complex and time-consuming process which remains largely unfunded.

The work involved a number of steps or actions, including:

- identifying people who could be eligible for the NDIS
- supporting and educating clients while they gained confidence to engage with the NDIS
- helping clients with the Access Request Forms and testing their eligibility.

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[29] Community Mental Health Australia (2017) Submission to Joint Standing Committee on the NDIS – The provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition from https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/MentalHealth/Submissions

[30] Woden Community Services Submission to the Joint Standing Committee of the NDIS: the provision of services under the NDIS for people with psychosocial disabilities relation to a mental health condition; accessed on 16 March 2017 from https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/MentalHealth/Submissions ..

Then, if eligible:

- helping with the pre-planning for their planning interview, and
- when an NDIS plan arrives:
  - helping them to understand the plan,
  - advocating on their behalf if the plan was inadequate, internally inconsistent or contained mistakes,
  - implement the plan,
  - assist the person to access services.
- supporting people who were ineligible including examining the reason for ineligibility, reviewing evidence, and appealing the decisions if appropriate
- continuing to support people for whom it was inappropriate to test eligibility while coping with diminishing block funding.

> **…so what I have at the moment is four incomprehensible lines of stuff I can get and I don't really know what that means… I can see how it's useful to have room for interpretation, but it is incomprehensible. It's written so that I can interpret it how I want, but I have no idea what that means.** » Consumer 5

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

> **Get as much help and information as you can before you start the process, expect it to be painful and put aside a lot of time to get the forms in.** » Carer 2

Outreach services aimed at identifying and supporting people with psychosocial disability to test whether they are eligible for the NDIS are time-intensive and expensive to provide. In short, those types of vital services disappeared fast under the NDIS. With the removal of block funding and the relatively low hourly rates offered by the NDIS, service providers simply could not afford to continue to provide this sort of service.

The timing for the withdrawal of federal and territory block funding for programs supporting people with severe mental illness did not, in practice, adequately line up with the rate at which people entered the NDIS (see discussion above in section on continual changes). The withdrawal of funding also did not adequately take into account the fact that not all participants, particularly in federally-funded programs, were eligible for the Scheme.

It was not uncommon for service providers to spend weeks, and sometimes months, supporting clients to build confidence in engaging with the NDIS. Most of this work was unfunded by the NDIS and only made possible by using the remains of block funding, cross-subsidising from other areas of the organisation, or through access to one of the special funding packages provided by the ACT Government during the trial period.

> **It's costing us from two perspectives, we have services that we were running under block funding that aren't applicable under NDIS, but we know they are valuable so we are continuing them at our own costs. And the other NDIS services are not breaking even yet, but we are hoping it will work out in a couple of months. Our Board is happy to go along with this as long as they can see we are working towards it becoming viable and it is valuable to consumers.** » Service Provider 4

> **I think the ACT Government were very naive in phasing out funding in the ages and stages. There is such a large potential to leave people behind, high and dry, and now service providers struggle to support people who haven't got in [to the NDIS].** » Service Provider 6

Pricing Concerns

Concerns about the unrealistically low levels of prices available under the NDIS for psychosocial disability have been raised since before the trial began in the ACT. In the ACT (as in other jurisdictions) it has been exceedingly difficult to engender any real comprehension within the NDIA of the validity of these concerns.

The widespread view among service providers is that the current price limits are not sufficient to recover costs, let alone provide any opportunity to invest in the quality of service. They do not allow for the level of staff needed to deliver high-quality recovery-focused services to people with psychosocial disability, nor the flexibility to respond effectively to participants with high needs and the episodic nature of severe and persistent mental illness.

Increasingly, service providers are changing their model of service-provision in the interests of business sustainability. The NDIS framework imposes some real dilemmas for service providers in terms of the time they spend engaging in direct support work with their clients and the time spent doing administration associated with the Scheme. For example, where support workers previously would expect to spend an hour in direct support for a client, and perform the administration for that hour at a later time, an hour funded by the NDIS now requires the worker to complete all travel and administration within that hour, leaving less time for direct service delivery with the client.

> **[We used to have] 75% direct contact [working] with clients whereas now that is 95-100% for NDIS workers. [Now we have to] write case notes during the session and get the client to co-sign it. Spend 20 minutes in transport, 10 minutes note-writing [which means we are] only left with 30 minutes of interaction. The implication is that you run the risk of having a lower level of documentation and accountability because less time can be spent making sure good notes are written.**
>
> » Service Provider 5

This particular change in procedure is not without positives, however, as some clients have felt empowered by the increased transparency of being present while their records are being written.

> **Working with clients to change work practices – including the write-up of notes for each client, so all admin tasks are done with client at the visit – we found that this is empowering for the client, they know what is going on their records, what services are being ordered and paid for.**
>
> » Service Provider 3

There is the well-publicised case in the ACT of the service provider, 'Just Better Care' which provides disability support services. They made the decision to deregister from providing agency-managed NDIS plans, and now only provide services for self-managed NDIS participants. This change gives Just Better Care greater flexibility in service offering and pricing. The decision was driven from the perspective of both values and business viability as they had lost $200,000 in the previous year providing NDIS services. The General Manager of Just Better Care in the ACT, Rob Woolley, described NDIS prices as "*a bargain basement rate for what is expected to be a platinum quality service*"[31].

The widespread view in the community sector is that when it comes to psychosocial disability, the Scheme has not been well-informed and reflects a lack of understanding of what is involved in delivering effective support to people with psychosocial disability. Current NDIS prices make it difficult to attract quality staff and is causing significant disruption and service gaps in the sector (discussed further below).

> **The impact from the implementation of NDIS has been significant. Prior to NDIS, our organisation was block-funded for 35 participants and our client load that we successfully serviced was 70 participants. Our service provided temporary accommodation and a case manager for persons with a psychosocial disability, to assist them with the reintegration and recovery process. Under the current NDIS system, our program could not be fully funded as it wasn't considered that the supported accommodation and the community program would be financially viable under individual supports.**
>
> » Service Provider 4

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[31] Norman Hermant, "We have grave concerns": there could be trouble ahead for the NDIS if the ACT's problems go national, 6 January 2017 accessed on 25 September 2017 from http://www.abc.net.au/news/2017-01-03/ndis-there-could-be-trouble-ahead-after-problems-in-act/8157662

Despite all this, organisations in the ACT have been committed to finding ways to make the NDIS work. This has included cross-subsidising from other areas of their operations, as mentioned above, in adapting and accessing the new system.

Service gaps and closures

In the ACT, as in other jurisdictions, there were a number of Commonwealth- and ACT Government-funded community-managed mental health services whose clients were regarded as likely to be NDIS eligible. The number of people in these programs who applied for the NDIS and were found ineligible was quite low in the ACT relative to other States and Territories. However, the end of block funding for these services has meant they are no longer available to people who still need them now or in the future. This particularly affects people who are ineligible for NDIS packages. But it also affects people who are NDIS participants, but whose key psychosocial rehabilitation supports are not funded in their NDIS package.

> **There are a group of people who are never going to apply, and for this year we have agreed to try and support them out of our own funding, but it's not sustainable.** » Service Provider 4

In the ACT, all ACT Government-funded service providers were told they must test clients' eligibility for the NDIS regardless of whether they thought they would be eligible, or whether the clients were willing to engage with the NDIS. Only in cases where clients' eligibility had been tested and they were found ineligible would the ACT Government guarantee continuity of funding for support. This caused many issues. In particular it exacerbated the already dramatic increase in unfunded administrative work required for the NDIS, and time involved engaging people who for a variety of reasons did not want to be part of the NDIS.

> **A lot of people have refused to apply, and they are possibly worse off.** » Service Provider 1

> **Ones who are eligible are better off than before, ones who aren't eligible are worst off.**
> » Service Provider 4

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

> **Perhaps they could have thought of a stronger contingency plan for people who aren't eligible, what that means for them. Some people I see as quite deserving have been not found eligible.** » Consumer 2

One of the consequences of the transition of government-funded community-managed mental health services to the NDIS has been the loss of vocational programs, group-based programs and drop-in style social participation supports. Some examples of the type of services which closed were a café and gardening service vocational program and a highly valued group drop-in centre. These services were found by their respective providers not to be viable within the NDIS framework.

The services which have been lost were primarily designed to help participants to overcome social isolation and increase their connections to the community. Participants were assisted to access services and participate economically and socially in the community, increasing their opportunities for recovery. Given that a tendency towards social isolation and disability in social and community settings is a very prevalent characteristic of serious mental illness, this loss is keenly felt.

> **Certain components will be the same but others won't exist. Outreach will look different. Supported accommodation will look different. [The] landscape will look very different.** » Service Provider 2

> **Clients in groups [that rely on block funding] are going to be so significantly disadvantaged.**
> » Service Provider 6

Providers were aware that delivering fewer group activities increased the risk of reducing social participation opportunities for people with psychosocial disability. Increasing individual choice and control is crucial. But this does not mean that a person with a psychosocial disorder is best served living in a world entirely made up of one-to-one relationships. Most people enjoy and benefit from access to community spaces and activities as well. People need more than a paid friend or cleaner. The disappearance of community spaces isolates people, removes an effective component of the recovery journey and increases the possibility of a person's symptoms worsening. Community spaces have also provided a very effective mechanism for 'soft', less threatening, outreach services.

CASE STUDY:

Rainbow – Psychosocial Rehabilitation and Social Inclusion Program[32]

The history of Rainbow started approximately 15 years ago when consumers and carers combined with the ACT Government to develop a program that would facilitate psychosocial rehabilitation and social inclusion in a safe environment. The Rainbow program was unique. It was managed by the Mental Health Foundation (MHF) but designed and driven by consumers and based on a peer-support model and recovery principles. It used structured and unstructured programs – all designed by consumers – which gave people a safe environment in which they could create a sense of community, connect with supports, and develop a range of skills for living in today's society.

The introduction of the NDIS in 2014 and the corresponding decreasing funding of the program by the ACT Government, catapulted MHF into a situation necessitating a review of the program to determine how it would remain true to its mission and viable. MHF informed and brought consumers and carers as well as the ACT Government on board with the identified issues arising from the introduction of the NDIS.

Over two years the key stakeholders worked with the MHF to find a viable solution. This included changing the programs and location of Rainbow. The change was difficult for some participants as it shifted their paradigm to a new environment. A core group of 20 participants maintained regular attendance, as well as others who attended less frequently. These people worked with the organisation during the transition to the NDIS funding model.

The main issues resulting in the closure of Rainbow were that the new funding model was slow in implementation and the ACT Government ceased funding prior to complete transition of participants to the NDIS. Rainbow participants found the process very difficult and lengthy. The timeframe for the majority of them to become NDIS participants did not come through until the 2nd quarter of the 2016-7 financial year. However, the ACT Government stopped financial support of The Rainbow on 1 July 2016. This meant that the MHF was left to independently cover the costs of the program.

MHF lobbied the ACT Government for ongoing funding during the transition period to the NDIS, but with no success. There came a point at which the MHF Board had to make a business decision about how long it was able to continue the service with minimal revenue. Ultimately the MHF Board made a decision in October 2016 that this situation was not sustainable and that the Rainbow would close on 23 December 2016.

Source: Mental Health Foundation ACT

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[32] This is an edited version of a case study included in the 28 April 2017 MHCC ACT submission to the Senate Standing Committee on Community Affairs Inquiry into the Delivery of Outcomes under the National Disability Strategy 2010-2020 to Build Inclusive and Accessible Communities

Recovery Principles

A recovery approach maintains that people living with a mental illness can live a fulfilling, meaningful and contributing life with the appropriate clinical management and community supports. It also means that people can live independent lives, not dependent upon services that absolve them from responsibilities of daily life. Recovery principles and a strengths-based approach are the basis of the services provided for people with mental illness in the ACT.

Service providers report that the NDIS framework makes it difficult to build recovery into a participant's IFP. Instead many see the NDIS as too much like a 'maintenance model' – in other words, the focus is on maintaining the status quo and keeping people out of hospital rather than building the capacity of participants to achieve their goals and potential while living in the community. This has proven a contentious issue when attempts have been made to raise it with the NDIA. The change to increase consumer choice and control under the NDIS is genuinely positive. But such change must be done in tandem with the substantial evidence-base in, and community sector experience, knowledge and understanding of how to deliver, recovery-oriented services to people with psychosocial disabilities.

> *In testing eligibility for NDIS people must describe their deficits and the debilitating effects that the condition has on their lives. This in itself is a demeaning introduction to the Scheme which doesn't encourage a description of what people have done to overcome their conditions. Moreover, people feel that if they present too positively, they won't receive the supports that they need. So they must dwell on and go into great detail about the limitations that mental illness imposes on them, rather than focusing on what they can do with support. This access model is totally at odds with best-practice recovery approaches.*[33]

> **A big challenge because NDIS doesn't fund recovery, it funds specific tasks.** » Service Provider 5

> **[Recovery is] at odds with NDIS goals. We just focus on the goals put forward in NDIS plan and don't consciously think too much about the goals of a recovery model.** » Service Provider 1

However, despite the challenges, many service providers are committed to ensuring that recovery principles continue to be the basis of the support that they offer to their clients. They believe that rehabilitation and recovery services must be part of a continuum of support for people living with a mental illness.

> **Our organisation's values are around recovery. We have not lost this focus as we are trying to incorporate recovery principles in the model of care. Choice and control is about recovery. We've revamped the model of care to maintain the principles and maintain the way the person lives within this, but still operating in a disability model.** » Service Provider 2

> **…recovery is about capacity-building which is what the NDIS is about. Need to educate the staff to educate the clients. Need to put requests for services (or inclusion into plans) into recovery focus so the clients can take ownership of their services. For example one client said that it will be good getting the NDIS, as they could get a cleaner in to do the housework. The reply to that was no, the person would be coming in to teach you how to take care of your home.** » Service Provider 3

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

Unbillable administrative, financial and background work

Another area that is a cause of concern for service providers is the large amount of unbillable administrative, financial and background work needed to operate within the NDIS. Service providers have all highlighted the significant increases in administrative costs due to the complexity of managing the Scheme. As discussed elsewhere in this report, these costs have been exacerbated due to the Scheme being implemented while it was still being built, and problems with a lack of accessible, transparent, real-time information coming from the NDIA.

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[33] Woden Community Services Submission to the Joint Standing Committee of the NDIS: the provision of services under the NDIS for people with psychosocial disabilities relation to a mental health condition accessed on 16 March 2017 from https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/MentalHealth/Submissions.

The process of NDIS billing is complex and organisations needed to implement new systems to deal with this. The costs in doing so were compounded by:

- little help from the NDIA on how to set up systems
- continual changes to both the system and codes needed for billing
- prices being fixed and services predetermined meaning that service providers were unable to charge the true cost of providing a particular service
- a radical upgrade to the portal which failed, leaving organisations unable to process any accounts
- information being lost by the NDIA, requiring that providers resubmit.

A very concerning consequence of the associated increase in administrative work is the movement of experienced staff away from face-to-face support work where they make the most difference in someone's life, to spending more time behind a desk.

> **Much more admin time and paperwork. No real reduction in work tasks, only an increase.**
> » Service Provider 1

> **We had to employ a bookwork company to do the basics, and we're now having them do payroll so the finance officer can do other stuff – 7 hours per fortnight. NDIS administration is 30% of our costs, not the 9% provided for by NDIS.** » Service Provider 2

> **The ratio of time to admin has gone up about 10-15% because we are trying to bill effectively - billing each client is work we have never done before.** » Service Provider 4

> **We've had to bring in more admin staff, a new full-time equivalent to do billing and stuff. We tried to avoid this by getting the workers to do billing but they find it hard. It's a significant change in how they work. Doing large amounts of admin, doing work sheets, recording each hour they do and billing it, does take away from their previous work focused on recovery of individuals.** » Service Provider 6

> **Changed the way admin is done, practice is daily and reporting and billing cycles. Transferring admin tasks down the line. We have to trust people are doing it properly so when audit happens we will be okay.** » Service Provider 4

Workforce concerns

The NFP community services sector is known for its relatively low wages and limited career structures. Indeed, in the ACT in particular, one of the community sector's biggest difficulties has been in attracting and retaining well-qualified and experienced staff given the more competitive salaries and conditions offered by the government sector.

Since 2007, MHCC ACT in partnership with the ACT Government have developed the community mental health support workforce through initiatives aimed at increasing staff qualifications[34]. This resulted in most staff at the beginning of the ACT NDIS trial having at least a Certificate IV in Mental Health, with many more having other qualifications including social work or nursing degrees.

The introduction of the NDIS, however, effectively places downward pressure on qualifications because the relatively low prices for support services set by the NDIS framework has in turn translated into lower wages. Across the NFP community sector, this has led to a workforce that is less skilled and more casualised, making it difficult to deliver the full range of quality recovery-oriented services required to support people with psychosocial disability. This is especially the case for those people with the greatest need.

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[34] MHCC ACT 2012, 'A real career: a workforce development strategy for the community mental health sector of the ACT'

> **There's now a two-tier system in the sector, NDIS casual workers on one side and management and block-funded services on the other side … Certificate II for NDIS, Certificate IV for anything else. Other areas may require a bachelor degree or higher.** » Service Provider 5

> **Our key workers, while the expectation is they have a minimum of a Certificate IV, generally had tertiary level qualifications. But we can't afford [to hire at that level] anymore.** » Service Provider 6

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

> *The NDIS pricing schedule also does not allow for the same level of supervision of staff to ensure adequate support for them, and for exploring ways to better engage and support clients.*[35]

This issue is well summarised by this extract from a submission to the ACT government inquiry into the NDIS in the ACT:

> *Many of the block-funded programs which did not transition into the NDIS are based on the premise that those not eligible for the NDIS don't need regular ongoing support. This however is not the case for many individuals and families dealing with complex and challenging situations.*
>
> *The other issue around the workforce is particularly in regards to specialist workers to support people with psycho-social disabilities. The transition into the NDIS saw the movement of a large portion of skilled and experienced mental health workers away from NDIS funded services. With providers having to significantly reduce wages to come in line with the NDIA pricing, many workers left the sector or changed roles which left people with psycho-social disabilities without familiar and skilled workers to support them. The long-term impact of the NDIA pricing is the deskilling of a critical specialist workforce. Support workers are operating even more independently in the field, with less training, support and experience.*[36]

Along with the difficulty of employing and retaining suitably qualified staff, the service providers also mentioned that they are experiencing a number of other workforce issues including:

- staff having to change the nature of their work with less time spent working directly with clients and more time behind a desk doing administrative work
- staff leaving because the redefinition of the type of work they do gives them less job satisfaction or is not in keeping with their values
- increase in staff stress and people leaving due to the insecurity of their employment
- change to a more transactional relationship between staff and management because of the commodification of services under the NDIS.

> **We have brought in a few workers with casual contracts … brought in some lower employment classifications. We haven't had any redundancies and hope we don't have to.** » Service Provider 4

> **The other shock that is coming – as a sector we like to have good relations with our staff and it will likely become a more businesslike, transactional relationship.** » Service Provider 5

> **The burn-out of staff is a very human cost. There's a lot of anxiety in workforce about future of jobs and pay rates.** » Service Provider 5

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[35] Woden Community Services Submission to the Joint Standing Committee of the NDIS: the provision of services under the NDIS for people with psychosocial disabilities in relation to a mental health condition, Accessed on 16 March 2017 from https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/MentalHealth/Submissions ..

[36] Catholic Care Canberra and Goulburn (2018), ACT Legislative Assembly Inquiry into the implementation, performance and governance of the National Disability Insurance Scheme in the ACT, accessed on 6 June 2018 at https://www.parliament.act.gov.au/__data/assets/pdf_file/0004/1190515/Submission-55-Catholic-Care.pdf

> **We have been forced to put people on fixed-term contracts – maximum of 6 months for the new staff employed, all casual. That's to give us a door out if we need it to reduce staff. We have taken a risk because we have moved a lot of permanent staff over to fixed-term contracts, but we aren't sure if we can keep them even though we want to.** » Service Provider 6

Useful preparation and training for the NDIS

Service providers found that initially the information and training coming from the NDIA and the ACT Government was a very helpful start to preparing for the changes in transitioning to the NDIS.

As the trial progressed, the information coming from the NDIA was at times dense and badly communicated, making it difficult to understand. The volume of new information was often also too high. Another problem which arose throughout the trial and beyond was the continually changing information provided by the NDIA. This was confusing and costly for service providers and their clients, and very hard to keep on top of.

Service providers' feedback on what preparation and training had been the most useful to keep abreast of the changes were:

- workshops and presentations by third parties including the ACT NDIS Taskforce
- participating in open forums with other service providers, like the National Disability Services CEO Forums
- groups which allowed service providers to share their understandings and provide a collective sense of clarity around process and procedures such as the MHCC ACT NDIS Champions Group
- training and workshops put on by MHCC ACT.

> **The NDIS task force was a really good decision. I don't know if they were 100% effective, but it has made the transition much better than it would have been otherwise.** » Service Provider 5

Consumers' and carers' experience

The introduction of the NDIS was a major upheaval for consumers and carers, even for those people who had played a major part in advocating for psychosocial disability to be included in the Scheme. In general, it was viewed as a way for people with psychosocial disability to have greater choice and control over their lives and the way that they contributed to their families and communities. Consumers and carers have experienced many of the issues and impacts discussed in the rest of this report, often with detrimental results.

> *A client has had such a difficult time with the NDIS that their suicide ideation and self-harming behaviours have both significantly increased.*[37]

The issues within the NDIS which were of particular concern to consumers and carers included:

- barriers caused by the deficit-focus of the NDIS when testing eligibility
- people viewing the Scheme with extreme caution and distrust due to a history of negative interactions with government services
- carers being excluded from NDIS processes, in particular not being consulted during the planning phase
- the lack of specific support for carers, particularly the withdrawal of carers' services, which have not been replaced with anything else.

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[37] ADACAS Advocacy (2018) - Legislative Assembly for the Australian Capital Territory, Standing Committee on Health, Ageing and Community Services, Inquiry into the implementation, performance and governance of the National Disability Insurance Scheme in the ACT, accessed on 6 June 2018 from https://www.parliament.act.gov.au/__data/assets/pdf_file/0003/1190505/Submission-43-ADACAS.pdf

Issues with the eligibility criteria and willingness to access the Scheme

Eligibility criteria for the NDIS creates many barriers to entry for people with psychosocial disability. Testing eligibility and the planning process also produced unpredictable results.

Despite a tendency for the NDIA to dismiss the significance of the deficits-focused language around aspects of the NDIS, the reality for many people is that having to prove enduring severe disability is a barrier. On average, people with psychosocial disability do not associate with having a disability and many do not even relate to having an illness at all. Instead, care and support for people with psychosocial disability has historically been strengths-based – guided by what a person can do – and focused on recovery.

> **I had mixed feelings about the first access form because it seemed very negative and you needed to have a permanent disability with functional impairments. I had been right into the recovery concept so I was a bit shocked, but then I started to get the benefits of having a plan. I never fit into a service properly, when I'm well I don't need any supports and when I'm unwell I'm too unwell to do anything but inpatient services so I was kind of happy about getting something that was now tailored to me.**
> » Consumer 4

> **Others [clients] have chosen not to apply at all. It's too stressful, they don't want to prove their disability. We have generally focused on strengths and how to enhance them rather than proving disability. It literally turns things upside down from the support model.** » Service Provider 6

> **There is also struggling with the idea of having a dysfunction permanently, and acknowledging that and identifying as that and wearing that label. For me being a NDIS participant carries that label, and then there's having to deal with the assumptions that other people make about you because of that label.** » Consumer 5

> **It maybe works really well for physical disability, it's possibly a kind of hidden discrimination against psychosocial disability because it is invisible how the psychosocial disability affects you. It pushes the patient/carer model.** » Consumer 4

One of the assumptions in the design of the NDIS is that people with disability will actively seek to participate in the Scheme. For numerous reasons, this is not always the case for people with a psychosocial disability. Many people with psychosocial disability have a long history of interaction with government services, and past negative experiences can leave people suspicious of government processes, particularly when they involve change. Furthermore, the nature of some types of mental illness can make it difficult for a person to trust others.

Building trust in relationships and systems is therefore critical to success in supporting a person's recovery journey. Trust often takes a lot of time and effort to develop. Service providers report that in practice, it can often take months or even years for people with mental health issues to develop trust and be confident that service providers are working towards them having a better life. The NDIS was not implemented in a way that built relationships of trust with consumers and carers, which caused many of them a lot of anxiety and acted as a barrier to access.

> **Even with all the knowledge and support I had from being a well-known advocate in the area it was still a very anxious, overwhelming experience. Because we have been in the system for over 10 years, we were very distrusting and cynical based on past experience of promises broken.** » Carer 1

> **Why does the opinion of a planner override a doctor or psychologist?** » Consumer 1

> **I have a long history of service providers not knowing what to do with me because my needs and diagnosis are so unique, and I don't know if people can do anything. I don't know if the NDIS is any different from what I had before, and they don't seem truly committed to tailoring supports.**
> » Consumer 5

> **It took me a while to really see the benefit of the NDIS, and it's made me feel a lot more hopeful. It's a totally different feeling having a service try to meet my needs rather than me trying to fit into the services provided.** » Consumer 2

> **It might help some people to have workers, but for a lot of people I think that would be very intrusive and scary.** » Consumer 4

> **I believe my son has all the support services he will accept. His condition does not allow him to have a cleaner or someone who would be able to touch his food.** » Carer 4

> **The planning meeting was really daunting because you have someone who you don't know, you're unsure of their qualifications or their right to judge your state and how much funding you get.** » Consumer 5

Role of carers

The general impression from carers is that the NDIS has been built and implemented without understanding of the value and enormity of the role they play in ensuring the person they care for can live a valued and contributing life. Many reported feeling ignored by NDIS processes and that their input was not respected or valued.

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

It was the stated intention that no one would be left worse off as a result of the NDIS. In direct contrast to this intention, however, funding for carer supports has been gradually transitioning into the NDIS, despite the fact that the Scheme does not provide support for carers in their own right. Importantly this includes the 2011-12 Australian Government 'Mental Health Respite: Carers Support Program' which provided relief from the caring role through in-home or out-of-home respite or social and recreational activities, counselling, practical assistance, social inclusion activities, case management, and education, information and access. It also funded community mental health promotion.

> **There have been a lot of cuts to what Carers ACT can fund now, so you have to pay for everything since the NDIS. We used to get counselling free.** » Carer 1

> **We are more supported but in the sense of being carer-specific supported, the things that were provided for free don't exist anymore … A lot of the respite places that existed for carers before have closed down, and while that doesn't affect me it affects other carers. Some can't afford even the $5 it used to cost for counselling let alone the cost it is now.** » Carer 1

> **I am very new to being a carer, I don't know where to start with getting respite or support. I talked to Carers Australia but they said there isn't much they can provide me, let alone for free. I may have to access counselling or something in the future but for now I have my friends and family.** » Carer 2

Carers feel that at the same time they were losing the little support and respite they once received, their role as a carer has become more difficult as a result of the NDIS. The more common reasons for the increased difficulty include:

- it is often challenging to find the services provided for in the NDIS plan of the person they care for
- there is a lot more time now required to undertake the paperwork and other administrative requirements of the NDIS – to the extent even of having to reduce their working hours or in some cases resign from the paid workforce
- carers are invariably still the ones providing care when the person they care for experiences a worsening of their mental health condition or a crisis.

> **Even with all the services and supports there is still need for a carer … the [NDIS-funded] support is still mostly 9-5 so it comes down to us after hours. Crises still occur whether we are there or not and it is still traumatic.** » Carer 1

> **Not if it's after hours. It would still come down to us. Last week, there was a situation which we managed. He has two lots of medication, one in the morning and one at night which makes him drowsy. He took the wrong medication in the morning and we had to go around and take care of him. In crisis I think it still comes down to the carer.** » Carer 1

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

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

Rocky roads to a better life

Consumers and carers both acknowledge that they have had to overcome significant hurdles to participate in the NDIS. As already discussed in this report, this includes the time spent gathering information to use to apply to the Scheme, uncertainty around how the NDIS works, and the confusing (or non-existent) information received from the NDIS. However, they also acknowledge that where the NDIS is working well, it was changing their lives for the better.

> **I'm feeling better than I ever have before. They definitely responded to my needs last plan – about 90 per cent. I'm hoping this next one does the same thing.** » Consumer 3

> **Yes, it was really positive to have our perspective and our insight into the experiences of my son's illness acknowledged up front. It relieves a lot of the burden (I keep saying that but I don't like that word). It removes a lot of the things we had to do before [in] caring for him, it takes a lot of the worry and anxiety away but we still have to monitor and oversee. But it's still a help to get all his support. It's a wonderful thing because we don't feel like a charity case anymore.** » Carer 1

> **It has given me and my ex-husband, two other sons and their families' peace of mind, it has taken the pressure from us, we are now able to meet and enjoy life as a family.** » Carer 4

Conclusion

The introduction of the NDIS was greeted with much excitement. It is a new way of providing individualised support for people with permanent and significant disability, their families and carers. The Scheme offers more choice and control and a lifetime approach to a person's support needs, representing a break from previous welfare approaches. It aims to empower people with disability to use funds given to them to purchase services that reflect their lifestyle and aspirations.

The NDIS is the only national scheme of its kind in the world. It is the biggest social reform in Australia since the advent of Medicare. Such a fundamental reform to the way disability support services are negotiated, structured and purchased in Australia was expected to be challenging. It clearly requires a massive restructuring of business models as well as deep cultural change around the purchasing and provision of support services.

The questions then are whether the introduction of the NDIS in the ACT, first as a trial site and then as part of full national rollout, is giving people affected by psychosocial disability better outcomes than in the past? Is it giving consumers more control and choice in the way they are supported to live their lives as valued and contributing members of society? Is it enabling carers to more freely participate in the workforce and community, and to look after their own wellbeing as well as contribute to that of the person they care for?

Time is still required before we know what the completed Scheme will look like, and before the transition is completed in every jurisdiction in Australia. Only after all that will we be able to properly answer these questions.

The introduction of the NDIS has caused massive disruption across the mental health sector in the ACT. At the time of finalisation of this report, it is clear that some fundamental challenges remain before NDIS objectives can be met. At the ACT Legislative Assembly public hearings for its inquiry into the implementation, performance and governance of the NDIS in the ACT in May 2018, MHCC ACT stated that "*at the moment [we have] the sense that the level of disillusionment and disengagement with the shaping and implementation of the NDIS is high, and we feel strongly that this needs to be changed.*"[38]

While the number of participants with an approved NDIS plan in the ACT had grown to 5,978[39] early in 2018 (13 per cent of whom listed psychosocial disability as their primary disability), it was also reported that for the first time people were leaving the Scheme in numbers greater than those joining the Scheme for the same period.[40] Given that these are people who have been established by NDIS eligibility criteria to have severe and enduring functional disability, this development is concerning and the reasons behind it need to be explored.

The two years of the trial and the first year of full rollout of the NDIS has proven a difficult time for the whole ACT NFP community mental health sector. A fundamental issue is that the NDIS framework does not adequately cater for the complexities and specificities of psychosocial disability. While some useful things were achieved through collaboration between the NDIA, the ACT Government and the community sector during the trial period, too often the concerns of NFP service providers, consumers and carers fell on deaf ears, and lessons learnt during the trial period were abandoned once the Scheme progressed to full national rollout.

The NDIS pricing framework continues to cause problems in the provision of psychosocial disability supports in the ACT. It is driving an increased casualisation of the workforce, and a downward pressure on qualifications and wages. The ACT will not be well served into the future by financially vulnerable organisations, which are being driven to employ a low-skilled workforce with a high churn rate, delivering a narrow range of highly commodified services. Nor by organisations which do not have the capacity to outreach into the community, support people whose needs are the most demanding, or respond flexibly and quickly to people's changing needs on a day-to-day basis. Implementation of the recommendations in the 2017 Productivity Commission report on National Disability Insurance Scheme Costs[41], would improve things to some extent.

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[38] Legislative Assembly for the Australian Capital Territory, Standing Committee on Health, Ageing and Community Services, Inquiry into the implementation, performance and governance of the National Disability Insurance Scheme in the ACT – MHCC ACT evidence, Tuesday 15 May 2018, transcript of evidence, accessed 31 May 2018 from http://www.hansard.act.gov.au/hansard/2017/comms/health08.pdf

[39] NDIS Quarterly Reports – ACT Dashboard as at 31 March 2018 https://www.ndis.gov.au/medias/documents/dashboard-act-mar-18-pdf/dashboard-act-march-18-pdf.pdf

[40] Sherryn Groch, Canberra Times, 30 May 2018, "There are now more Canberrans leaving the NDIS than there are joining it."

[41] Productivity Commission 2017, National Disability Insurance Scheme (NDIS) Costs, Study Report, Canberra.

Consumers and carers report that where the NDIS is working well, it is changing their lives for the better. However, even those with positive outcomes find the processes involved to be overly bureaucratic, time-consuming and deficits-focused. But there are also too many consumers and carers feeling that they are worse off than they were before the Scheme was implemented.

The NDIS was never intended to replace the mental health system. People with mental illness and psychosocial disability need both. There will always be areas of overlap and soft boundaries between health, disability and social services. With the introduction of the NDIS, and the blurring of mental illness and disability, the confusion has become an impediment to recovery-oriented, person-centred services. There is also a growing perception among some people that the NDIS is the new mental health system – except that it leaves people out. The distinctions and relationships between health, disability and social services need to be clarified and clearly articulated.

There are many challenges ahead with regards to the NDIS as it applies to psychosocial disability. These appear to apply equally to the rest of Australia as they do to the ACT. Key concerns include ensuring that:

- the rollout of the NDIS is driven more by outcomes and less by outputs. The narrow focus on target entry numbers to the Scheme is currently undermining its integrity
- there is a comprehensive mental health system in place for all. Only about 10 per cent of people with serious and enduring mental illness are expected to participate in the NDIS when it is fully rolled out[42].
- the boundary between the NDIS and the mental health system is clarified – a person-centred approach is needed to ensure people do not miss out on vital services nor are bounced between systems when they encounter issues
- the NDIS addresses the specificities of psychosocial disability, including the episodic nature of mental illness and the importance of relationships based on trust
- the NDIS workforce is qualified, experienced and skilled in working with people with psychosocial disability – organisations need to be able pay wages commensurate to the attraction and retention of such staff
- the NDIS framework builds the capacity of service providers to provide strong recovery-focused supports for participants with psychosocial disability
- the provision of specific support for carers (in their own right) to ensure they are not left in a worse position due to the NDIS
- the continuing existence of a diversity of viable providers in the NDIS marketplace
- a genuine and more transparent partnership approach is taken by the NDIA with consumers, carers and service providers in the interest of optimising outcomes and minimising costs associated with the NDIS
- a simpler, less bureaucratic approach is taken to the administration of the Scheme as it affects carers, consumers and service providers
- all work associated with the NDIS is billable and appropriately funded.

Consistent with reports from other jurisdictions in Australia, the ACT NFP community mental health sector continues to deal with a concerning number of issues relating to the implementation of the NDIS. Throughout this report MHCC ACT has drawn on information and feedback from people with psychosocial disability, their carers and the NFP community-based organisations that provide services to support them. The experiences shared and the themes that have emerged in this report make it clear that change is needed in the approach to the Scheme, the way it is being structured and finetuned, and the way it is being implemented.

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[42] Parliamentary Library, The National Disability Insurance Scheme: a quick guide (updated 3 March 2017) – accessed from https://www.aph.gov.au/About_Parliament/Parliamentary_Departments/Parliamentary_Library/pubs/rp/rp1617/Quick_Guides/NDIS

The ACT Human Rights Commission (ACT HRC) summarised the current state of the NDIS in the ACT in this way:

> *At this time, the ACT HRC considers the intent of the scheme, as set out in the legislation, is yet to be fully realised in the ACT. The ACT HRC has identified a number of key factors that impact on the full achievement of these outcomes, as follows:*
>
> - *The current NDIS processes are complex, bureaucratic and not user-friendly;*
> - *There is a lack of accessible complaints management and resolution, particularly in relation to NDIA decisions;*
> - *There is a lack of assistance to access and navigate the system, which places an increased burden on informal supports and other service systems, and results in some vulnerable people not accessing the scheme;*
> - *The approach to plan approval appears to be to apply standardised or benchmark levels of support rather than consideration of the individual's reasonable and necessary supports as required by the legislation;*
> - *Delays in processes, inaccessibility of NDIA staff and limited accountability of the NDIA impact on participants' outcomes;*
> - *The developing disability services market in the ACT is not yet able to fully meet participant's needs and deliver quality supports across the sector.*[43]

At the time of finalising this report, there are signs that the ACT government and the NDIA might be recognising and responding to some of the issues highlighted here and in other places. The ACT Government is undertaking an inquiry into the NDIS in the ACT. As reported in the Canberra Times on 24 May 2018,

> *The ACT Government is to be commended for the work of its inquiry into the local roll-out of the National Disability Insurance Scheme. Hopefully federal politicians and public servants with direct connections to the troubled care provider[s] are sitting up and taking notice. One of the most alarming outcomes of the hearings, which are being conducted by a parliamentary committee, is little appears to have changed since the release of an interim Productivity Commission report, commissioned by the Treasurer, Scott Morrison, almost 12 months ago.*[44]

In the lead-up to the 2018-19 budget the ACT government has also made a number of announcements of investment in the ACT mental health sector, including in many community-based services as well as in assisting people to navigate the NDIS. The NDIA is trialling a new psychosocial access pathways approach. It is also developing resources and information to assist people with psychosocial disability.

However, change is mostly slow and incremental, and it will take time for improvement to be felt. There is also still much uncertainty in the NFP community mental health sector around organisations' capacity to continue providing particular programs and support services to people who need them. As more time passes without fundamental and effective change – at least as it applies to psychosocial disability – it is hard not to conclude that the NDIS as it is being implemented will continue to erode many aspects of the ACT NFP community mental health sector.

Despite the challenges involved with the implementation of such a major policy reform, the ACT NFP community-based mental health sector remains committed to making the NDIS a success for participants. Service providers have also done what they can to provide continuity of support to people who need support regardless of whether they are NDIS participants. This has often been unfunded work and comes with risk to their future viability.

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[43] ACT Human Rights Commission, ACT - ACT Legislative Assembly Inquiry into the implementation, performance and governance of the National Disability Insurance Scheme in the ACT - https://www.parliament.act.gov.au/__data/assets/pdf_file/0019/1190521/Submission-62-ACT-Human-Rights-Commission.pdf

[44] The Canberra Times, Opinion, 'ACT NDIS inquiry is necessary and important', 24 May 2018 https://www.canberratimes.com.au/national/act/act-ndis-inquiry-is-necessary-and-important-20180523-p4zh2q.html

It is well documented that an investment in the mental health and wellbeing of the Australian population leads to strong positive returns[45]. Baulking at the costs associated with mental illness today only means higher costs emerging later in other parts of our society.

MHCC ACT, service providers, consumers and carers continue to work with determination to try and ensure that the NDIS leads to the positive changes for people with psychosocial disability and their carers that were originally envisioned. We also remain committed to working with government to ensure there is a mental health system in the ACT that gives all people in need of support access to a broad range of timely, effective, recovery-oriented mental health support services.

> *There is an extraordinary level of commitment to the success and sustainability of the NDIS (and to preserving the core principles of the scheme) shared by governments, people with disability and their families and carers, providers of disability services and disability advocates.*[46]

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[45] The most recent comprehensive study on this was undertaken by Mental Health Australia and KPMG – "Investing to Save" May 2018 accessed from https://mhaustralia.org/publication/investing-save-kpmg-and-mental-health-australia-report-may-2018

[46] Productivity Commission 2017, National Disability Insurance Scheme (NDIS) Costs, Study Report, p.8 Canberra, accessed from https://www.pc.gov.au/inquiries/completed/ndis-costs#report

Appendix 1
Transitioning into the National Disability Insurance Scheme[47]

Transition Period	Youth (Age or Academic Year)	Adults (Date of Birth)
2014		
From 1 July	Children born on or after 1 July 2012 People who completed school between 2008-13 and received a Post School Options package funded by the ACT Any resident of a group home who on 1 July 2014 was born on or after 1 July 1992	Born between 1 July 1949 and 30 June 1950 Residents of a group home whose youngest resident on 1 July 2014 was born on or after 1 July 1992
On or after 1 October	Children born between 1 July 2010 and 30 June 2012 Children not expected to start school in 2015 or 2016 Students expected to complete secondary school in 2014 Any resident of a group home who on 1 July 2014 was born between 23 August 1989 and 30 June 1992	Born between 1 July 1950 and 30 June 1951 Residents of a group home whose youngest resident on 1 July 2014 was born between 23 August 1989 and 30 June 1992
2015		
On or after 1 January	High school students (Years 7-12)	Born between 1 July 1951 and 30 June 1954 Residents of a group home whose youngest resident on 1 July 2014 was born between 24 October 1983 and 22 August 1989
On or after 1 April	Children enrolled in Kindergarten, or school years 1–6	Born between 1 July 1954 and 30 June 1955 Residents of a group home whose youngest resident on 1 July 2014 was born between 29 October 1981 and 23 October 1983
On or after 1 July		Born between 1 July 1955 and 30 June 1958 Residents of a group home whose youngest resident on 1 July 2014 was born between 3 November 1978 and 28 October 1981.
On or after 1 October	Remaining children under 15 years	Born between 1 July 1958 and 30 June 1965 Residents of a group home whose youngest resident on 1 July 2014 was born between 19 May 1974 and 2 November 1978
2016		
On or after 1 January		Born between 1 July 1965 and 30 June 1974 Residents of a group home whose youngest resident on 1 July 2014 was born between 24 February 1974 and 18 May 1974
On or after 1 April		Born between 1 July 1974 and 30 June 1987 Residents of a group home whose youngest resident on 1 July 2014 was born between 14 June 1967 and 23 February 1974
On or after 1 July		Born on or after 1 July 1987 Residents of a group home whose youngest resident on 1 July 2014 was born between 18 August 1956 and 13 June 1967

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[47] It was estimated that each transition period would last for three months from the starting date shown in the table.

Appendix 2
Interview process

Specific set of interviews with consumers, carers and service providers about their experience of the NDIS

This interview process undertaken by MHCC ACT captured the self-reported experiences of six service providers, five consumers (one of whom chose not to apply for the NDIS but was eligible) and three carers.

Separate sets of questions were designed to capture the unique experiences of service providers, carers and consumers, with a modified consumer set of questions used to capture consumers who chose not to apply for the NDIS.

Participants were recruited on the condition that they had a psychosocial disability, they cared for a consumer with psychosocial disability or they were a service provider for services marketed to consumers with psychosocial disability. Participants were recruited through direct invitation and open invitation advertised throughout the sector. When participants nominated to participate they were provided with an information sheet and informed consent was confirmed at the beginning of interviews.

Interviews were conducted over 11 weeks in 2016, with a follow-up for additional perspectives approximately a year later. Interviews took around 2 hours to complete and were transcribed using a laptop.

Consumer and carer participants were reimbursed for their time.

Interviews were analysed using a qualitative approach.

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