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EDITORIAL
Debra Parnell

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Contributors
We very much welcome contributions to new paradigm on issues relevant to psychiatric disability support, psychosocial rehabilitation and mental health issues, but the editor retains the right to edit or reject contributions.

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EDITORIAL

National Disability Insurance Scheme: opportunities and challenges

Debra Parnell, VICSERV

With reform the order of the day, and all roads in the process leading to the National Disability Insurance Scheme (NDIS), it is timely to devote an issue of newparadigm to this topic. The NDIS became a reality on 1 July 2013, and already we are seeing changes in the policy, service system and organisational context of mental health at both the national and state levels, with issues emerging for services, participants and carers.

The launch of the NDIS heralds the most significant change to the human service system in Australia since the introduction of Medicare 30 years ago. Its development is an important step towards recognising the rights of people living with psychosocial disability related to mental illness as articulated in the United Nations Convention on the Rights of Persons with Disabilities. The change from block funding of support services to individualised disability funding – along with parallel changes to the funding and operations of health, mental health and primary health care sectors being driven by national health reform – presents both great opportunities and risks to people living with mental illness.

I am pleased that we are able to present diverse views and issues through this edition, including the perspectives of consumers and families of people with mental illness, the National Disability Insurance Agency (NDIA), agencies at the front line, and researchers who are considering the issues and implications for consumers as well as providers.

The scene is set for us with state, national and international perspectives. NDIA Board Chairperson, Bruce Bonyhady, provides an overview of the NDIS and some of the challenges for the inclusion of people with psychosocial disabilities, as well as the path ahead, while Frank Quinlan, CEO of Mental Health Council of Australia provides an overview of the urgent and complex issues emerging through the implementation of the scheme. Kim Koop, VICSERV CEO, places the NDIS launch in the context of reform in Victoria, and what this broad agenda may mean for services as well as consumers.

Participants at The Mental Health Services Conference (TheMHS) in 2013 may have heard Isabell Collins, CEO of the Victorian Mental Illness Awareness Council (VMIAC) present the consumer perspective of NDIS. She updates her views here, informed by a further six months of NDIS trials. Margaret Spinggay and Pat Sutton, Carer co-Chairs of the National Mental Health Consumer and Carer Forum, outline the development of the Forum’s Position Statement on Psychosocial Disability associated with a mental health condition and where its priorities need addressing in the NDIS.
Elizabeth Crowther and Laura Collister from the Mental Illness Fellowship Victoria identify some of the key issues that agencies face in delivering rehabilitation and recovery oriented services through their early experiences in the trial site in Barwon, and in discussions with consumers and carers through their NDIS Design Fund Project.

NDIS trials are being implemented across Australia, with the Hunter and Barwon sites having particular relevance for mental health services and consumers. In conjunction with international models and outcomes, there is much to inform the ongoing work and developments for the future. Tina Smith, from the New South Wales Mental Health Coordinating Council (MHCC), reports on the experience in the Hunter Valley, and Dr Therese Williams, Director of the Western Australian Centre for Mental Health Policy Research, discusses the growing body of practical experience in other countries that she studied as part of her Churchill Fellowship project.

University of Melbourne academic Dr Lisa Brophy and her colleagues provide an overview of Mind’s current research project which considers the implications of the NDIS from the perspective of people with psychosocial disability, and how they can influence the development of the current service system through improved understanding of their preferences for psychosocial disability support.

These varied and in-depth considerations are rounded out with a new feature, we have introduced in this edition: a vox pop in which we ask key CEOs in the mental health sector in Victoria about their views on the opportunities and challenges presented by NDIS in the short and long term.

I’d like to thank the contributors who have made this a very interesting and stimulating edition of newparadigm and Eswen Chaffey, Policy Officer with VICSERV, for her tireless efforts to see the production progress smoothly. I hope you enjoy reading and considering the ideas presented through these articles, and that it prompts discussion for you and your colleagues.
NATIONAL DISABILITY INSURANCE SCHEME
The National Disability Insurance Scheme (NDIS) is being built on a combined total of more than 500 years of experience of the many no-fault accident compensation schemes in Australia.

However, extending these schemes to a much wider array of disabilities and taking a functional rather than a diagnostic approach to eligibility and assessment means the NDIS is being refined, redesigned and built as it is being expanded.

One of the key challenges is to ensure the NDIS is person-centred, able to respond to the diverse needs of participants, including co-morbidities such as psychosocial and intellectual disability, and takes account of functional impairments, rather than diagnostic labels.

Under the legislation, the scheme is designed to cover people with a significant and permanent disability that substantially reduces their ability to participate effectively in activities or perform day-to-day living tasks or actions.

This means that, for the first time in Australian disability policy, equity is at the centre of policy design. The NDIS will not discriminate based on cause or type of disability or where or how a disability occurred; need will determine support.

Yet it is also clear that this creates particular challenges in the area of mental health and psychosocial disability.

This article explores those challenges and how the current trials of the NDIS and the work of the National Disability Insurance Agency are seeking to address them.

The NDIS will not discriminate based on cause or type of disability or where or how a disability occurred; need will determine support.

**Rolling out the NDIS**

In 2011, the Productivity Commission called for an NDIS after conducting its largest inquiry ever. It compiled a 1,400-page report and — in language perhaps unusually colourful for economists — labelled the existing disability support systems unfair, fragmented, underfunded and inefficient. The case for an NDIS was and is clear. The NDIS is core government business and received support from both sides of politics. It is an exemplar of governments doing what people cannot do for themselves.

It is one of Australia’s most significant social policy changes so it is being trialled in sites across the country so the NDIA can learn from experience and apply the lessons in the full-scheme rollout.

These trials began at four sites on July 1 last year: Tasmania (for young people aged 15–24), South Australia (for children aged 0–14), and in the Barwon area of Victoria and the Hunter area of New South Wales (for adults up to 65).

From 1 July this year, the NDIS will commence throughout the ACT, the Barkly region of the Northern Territory and the Perth Hills area of Western Australia. Rollout of the full scheme across the rest of Australia will commence progressively from July 2016.

The sheer scale and logistical challenges of building the full scheme — once rolled out across Australia it will have an annual cost of $22 billion — makes it essential that it is accountable, transparent and financially sustainable.
Bridging the medical model of the health sector (which, for example, treats the symptoms of psychosocial disability) and the social model of the disability sector (which focuses on how a person can be assisted in participating in the community) is a challenge for both the NDIS and the health sector.

Most importantly it must also seek to address the unique needs and aspirations of thousands of people who have been failed by a succession of inadequate disability support systems.

Central to the solution to these challenges is establishing the NDIA as a learning organisation and recognising that everyone from consumers to service providers and subject experts have a valuable contribution to make to its co-design.

**Challenges for psychosocial disability support**

The concept of a permanent impairment, that is central to the framing of the NDIS, does not sit easily with the framework and language of recovery which are the basis of current best practice in mental health.

While the legislation specifically includes impairments that are episodic or vary in intensity, the intention is to focus on those people with significant and persistent support needs across their lifetime. This is necessary to ensure equity and the long-term sustainability of the scheme.

Similarly the NDIS cannot take on responsibility for medical or health needs. These remain the responsibility of the health system.

Bridging the medical model of the health sector (which, for example, treats the symptoms of psychosocial disability) and the social model of the disability sector (which focuses on how a person can be assisted in participating in the community) is a challenge for both the NDIS and the health sector.

It is vital that the disability and health sectors are coordinated and complementary in providing support to people with psychosocial disability – anything less is inefficient and not in the interest of the person concerned.

The NDIS has an ongoing role in supporting the community and carer support services that the Productivity Commission defined as Tier 2 services. These include the very necessary services for people affected by lesser or shorter-term functional impairment.

These community based services, which are not based on individualised packages, are particularly important in the area of mental health, as they can prevent the development of mental illness into full psychosis and psycho-social disability.

The ACT launch in July this year will be the first experience in moving a whole jurisdiction from a state or territory-based disability support system to the NDIS. This is expected to shed further light on the best way to go about establishing and supporting the connections between the NDIS and these community-based Tier 2 services.

Through all of this, the NDIA is committed to working with the mental health sector through ongoing dialogue with industry experts as well as participating in specific events and research.

**Looking to the future**

The staged implementation of the NDIS means the NDIA is learning valuable lessons and building a rich evidence base of what works for people and cost drivers. There is still a lot more work to do, as the NDIS builds from launch sites to 460,000 participants when the full rollout is complete.
In late 2012, before my appointment to the NDIA, I addressed the VICSERV annual general meeting, because of the importance I saw in engaging with key participants in the mental health sector. In October last year, as Chairman of the NDIA, I convened a ‘Roundtable on Mental Health in the NDIS’. This panel of experts and industry leaders will meet again later this year.

The Mental Health Council of Australia has also received funding through the scheme to run a series of NDIS workshops for the mental health sector.

The NDIA will be regularly reviewing and updating procedures, guidelines and the way in which the scheme works to ensure it is fair, equitable and financially sustainable.

The knowledge and contribution of those involved in psychosocial support at this critical launch stage – whether through formal feedback and input or simply familiarising yourself with the NDIS so you can inform your friends, colleagues or loved ones – will help ensure its future success.

I look forward to feedback and engagement from the community managed mental health sector to ensure that the NDIS best meets the needs of people with significant and persistent psychosocial disability and works seamlessly with the mental health sector.

How it works
The scheme works on an insurance principle, the idea being that anybody can be affected by disability. It might be from birth or it might be acquired later in life.

One of the most important elements of these insurance principles is that the NDIS will seek to minimise costs of support and maximise opportunities over participants’ lifetimes and invest in people through evidence-based early intervention.

The NDIS is therefore very consistent with best practice in mental health.

The scheme covers people with a significant and permanent disability that substantially reduces their ability to participate effectively in activities or perform day-to-day living tasks or actions.

People aged over 65 will be covered by the existing aged-care system and will not be able to access NDIS support. Those who are under 65 when they make a successful access request will be able to choose whether to stay with the NDIS or transfer to the aged-care system when they turn 65.

The NDIS will enable people with disability and their families, for the first time in the history of disability support in this country, to have choice and control over the implementation of their reasonable and necessary supports.

Where people might have difficulty accessing the NDIS or cannot manage their own supports independently, there is provision in the legislation for them to be supported in these activities too.

Accessing the NDIS and further information
The NDIA website, www.ndis.gov.au, is the first port of call for information about the NDIS.

It outlines when the scheme will roll out in each area and the My Access Checker allows prospective participants to check their ability to access the scheme.

The website is continually updated with new information so it is helpful to check in regularly to keep up-to-date or, even better, sign up for our regular newsletter.

Once a person has been determined as able to access the scheme, an NDIS planner will listen to their goals and aspirations, and work with them to determine the most appropriate, reasonable and necessary supports that will help them achieve these goals.

Plans are designed to enable participants to engage in education, employment and their community and become independent, to the best of their abilities, and receive necessary equipment.

These plans include capacity building to help people learn skills needed to enter the workforce and live more independently.

For example, plans to date have included 1-3 hours a week of intensive, one-on-one lessons about handling money or cooking, or help in identifying and entering mainstream employment.

If a person does not meet access requirements for an individual plan, Agency planners and local area coordinators will help them find and connect to community supports, activities and organisations.
NDIS and state mental health reform: opportunities and risks for Victoria

Kim Koop, Chief Executive Officer; VICSERV

Phasing of current PDRS clients into the NDIS in the Barwon launch site and the commencement of new funding and service agreements could significantly change the face and nature of mental health support (and treatment) services in Victoria and across Australia.

Community-managed mental health service providers in Victoria are experiencing an extended period of uncertainty.

The reform of State Government mental health services has, after five years of planning, reached its penultimate stage and will become a reality in 2014. New service types and new contracts will be implemented and begin to reshape service delivery. Significant changes in the service provider landscape are also expected from July 2014.

In addition, the funding of PDRS services under the NDIS will become a reality at the Barwon trial site from May 2014. The agreement by the Victorian Government, through the Council of Australian Governments (COAG), to contribute all Psychiatric Disability Rehabilitation and Support Services (PDRSS) funding to the development of the NDIS signals a major shift in how support services are conceptualised and delivered in Victoria. Previously part of the state health system, these services will now be funded via the Commonwealth and with a disability focus.

This raises a number of concerns, not least of which is the possible loss of therapeutic or recovery oriented services for people with sub-acute support needs (proposed support clusters do not relate to current service types) and a split between these disability support services and the acute treatment sector. Many fear that the eligibility criteria for NDIS will exclude those people living with mental illness who rely on the current community supports, and that without these services they will fall through the gaps of the service system.

The release of Victoria’s priorities for mental health reform 2013 – 2015 late last year goes some way to setting out the State Government’s vision for mental health services in Victoria. This plan sets out a commitment to the NDIS and implies a development of the broader community services to meet the needs of people living with mental illness. Sadly the plan does not answer the vital question of how this will be achieved and what steps are being taken to avoid the feared or unintended consequences of transferring all PDRS services to the NDIS.

Time of uncertainty

We are currently in a state of readiness for reform but it will be some months before changes are enacted and until participants and stakeholders move to new arrangements. It will be at least mid 2014 before we really start to know how both the Victorian reforms and the NDIS will affect service delivery and the service system.
Service users, their families and carers have a wealth of lived experience to bring to the table. As ultimate beneficiaries of the NDIS their expertise must be incorporated in the design and ongoing refinement of the scheme if it is to truly meet their needs and expectations.

Phasing of current PDRS clients into the NDIS in the Barwon launch site and the commencement of new funding and service agreements could significantly change the face and nature of mental health support (and treatment) services in Victoria and across Australia. Victorian service providers are actively reviewing their business model and preparing for new service types with new workforces to match. At the same time service providers and consumers are advocating for a review of support clusters (and their pricing) to reflect the nature and complexity of contemporary mental health supports.

Of course we cannot underestimate the impact of the current federal political climate. The vast number of reviews being undertaken by the Abbott Government also compounds the uncertainty and feeds a growing concern as to which programs and initiatives will be prioritised and appropriately funded into the future.

Guiding principles for reform
For so long mental health advocates have promoted the rights of people who experience mental illness to a full range of services and to full citizenship. These concepts must be considered in our strategic thinking, planning and ultimately our service delivery.

It is also imperative that we extend, not overlook, our knowledge of the social determinants of good mental health and that we apply the social model of health in all of our future system design. There is evidence available that we can use to build effective and life affirming treatment and supports in the area of mental health. At this time of transition it is essential that we do not lose sight of this evidence, or fail to engage those with expert knowledge in the design of new services and review of existing supports.

Service users, their families and carers have a wealth of lived experience to bring to the table. As ultimate beneficiaries of the NDIS their expertise must be incorporated in the design and ongoing refinement of the scheme if it is to truly meet their needs and expectations.

We cannot underestimate the lack of understanding of, and stigma associated with, mental illness and psychosocial disability in the community and which can creep into our public policy and service delivery. It is essential that we seek to avoid this and that we use the opportunity the NDIS can give us to build a modern scheme that builds the capacity of people with psychosocial disability to take up full citizenship.

Risks for Victoria
Change in the service system could be an opportunity to build on strengths in our practice and to let go of old ideas and structures that do not serve the community. But this is only likely to be possible and deliver benefits for people with mental illness if we are vigilant in the planning, transition and implementation stages.

We have a strong starting base: Victorian community managed mental health services have developed over the past 30 years to be the most comprehensive and, in some cases, the most progressive in the country. The current rush to transfer these services to the NDIS is a risky strategy, one that could see significant service gaps develop as the NDIS focuses on those with “permanent disability” and while hospital networks focus on acute and crisis care.

Mental health stakeholder groups are watching the combined impact of state and federal reforms in Victoria with a high level of interest and growing concern.

One major concern is the role the hospital networks (clinical services) will be asked to play during the NDIS transition period and into the future. Without a comprehensive community service sector, case managers will be expected to take on even greater caseloads and an even greater variety of roles. It is also possible that hospital networks will become sub-contractors of a wider variety of mental health services. The delivery of PARC (prevention and recovery care) services is an example of sub-contracting in the Victorian context. Hospital services have been subject to productivity measures over many years and are already stretched to their capacity. How they will define their role and adapt to a post NDIS world is yet to be seen.

The questions of how agencies will retain their expert knowledge and their specialist mental health workers, through the transition are also key issues. The contention that the reform of Victorian community services over the next three years will prepare services for the NDIS is only true if it is accompanied by a workforce transition plan that is
The contention that the reform of Victorian community services over the next three years will prepare services for the NDIS is only true if it is accompanied by a workforce transition plan that is appropriately resourced and well constructed. There is no evidence that this will be the case.

Workshops seeking to engage key mental health stakeholders across Australia were begun by the NDIS in February 2014. NDIS has contracted Paul O’Halloran, a clinical psychologist with the Western Sydney Mental Health Services, to bring together a paper articulating the key issues. These are positive steps forward and it is hoped they will create a two-way flow of information and lead to a ‘co-design’ of scheme elements to ensure that services truly meet the needs of people who experience psychosocial disability as a result of enduring mental ill health.

Consumers, families, community service organisations and staff in hospital networks are all seeking clarification on how the service system will be configured and how it will function in 2014 and beyond.

VICSERV will continue to work with our members, service providers and other peak bodies in the Barwon launch site, and with the Mental Health Council of Australia and Victorian Department of Health, to assess the implications of all current reforms on the Victorian health system and community sector.

I am not an expert on the National Disability Insurance Scheme (NDIS), but I do have some 20 years of experience as an advocate for people with a psychosocial disability. This experience has taught me many things, including to be very cynical when it comes to reform. Australia has undergone at least two decades of mental health reform but still the consumer community is having to complain about issues it has raised from the start. Why is this so? Because, too often, those in positions of power believe they know what is best for the consumer community.

So what do consumers want and can they be delivered through the NDIS?

**What consumers want**

Consumers want to be treated like everyone else, they want to be heard, they want their mental illness to be secondary to their personhood (holistic individuality) and they want a life free of discrimination and stigma. They want access to individualised and holistic mental health services and to not have to wait until they are in dire straits. They want services to fit in with their needs and wants, not vice versa. They want meaningful work and permanent, appropriate and affordable housing. They want a home, not just a room. They do not want to have to live in poverty.

They want to be able to make friends and enter into relationships and not have their mental illness get in the way of how other people think about them. They want drop-in services to be funded. They want to be treated with respect and dignity. They want to have fun. They want people to listen to them when they express concern about the side effects of medication and be willing to do something about it.

They want to be seen and treated as an equal partner to the community in which they live and, at the same time, recognise the normality of their desire to retain contact with and to use psychiatric disability services. They want to be discharged from services when they are ready, not when the service decides they are. They want more focus on the quality of service delivery than on throughput and outcomes.

Consumers want their lived experience of mental illness recognised as an equal area of expertise to that of service providers and as essential for respectful and responsive service delivery.

Consumers don't want models of practice or theoretical ideas to override their unique humanness, so that they get lost in the model or the theoretical principle. They want involuntary detention and treatment to cease being a habit of practice and to be only used as a last resort. They want services to talk with them, not at them and, finally, they do not want others to decide what is best for them – they want to decide that for themselves.
The role of the NDIS

Consumers don’t necessarily need an NDIS program to be implemented for these issues to be addressed and resolved. My concern is that, with the introduction of NDIS, these issues will be lost or, more than this, that the NDIS may add other issues of concern.

For example, NDIS legislation allows for consumer files to be handed over to the NDIS without the consent of the consumer. How disrespectful is that? Additionally, without any discussion with the consumer community, a decision was made to transfer state government funding of the psychiatric disability rehabilitation and support (PDRS) sector to the NDIS program. What does that say about the respect government has for its own policies on consumer participation? The consumer community has long held to a basic tenet: “Nothing about us without us.” Where is the respect for this?

Choice, eligibility, responsibility

The current NDIS rhetoric indicates that people with a disability will be able to choose the services they use. But will they, in fact, only be able to choose the services that have been decided and established for them? In other words, are we merely transferring funding from the states to the Commonwealth and offering only programs largely the same as those that currently exist?

In addition, it is distinctly possible that those who currently receive a PDRS service may not be eligible for that service in the future. Given the complete transfer of funding proposed, what will happen to them?

While Victoria provides the most advanced level of PDRS services in Australia, it is not without its problems. The Victorian Government has said it is committed to addressing issues of concern to the consumer community. But what will happen when funding is transferred and these issues become the responsibility of another government? It is also of concern that funding transferred from the PDRS sector may not be corralled to ensure it only goes to those with a psychiatric disability.

I was very excited when I first heard about the NDIS. I thought it would mean that people with a psychosocial disability would be able to access support they currently cannot afford, like massage therapy, gym membership, yoga classes, alternative therapies and, dare I say, the occasional visit to a brothel. Anecdotally, we know young men are taking their lives because of the side effect impact of medication on their sexual life, and many people with a psychosocial disability suffer from what one consumer termed “tactile deprivation”.

I was disappointed to read recently that brothel therapy is off the NDIS agenda because it is not regarded as an essential service.

Notwithstanding this, it is my firm view that people with a psychosocial disability should not be treated differently to other members of the community nor receive services in a different mode to those who don’t have a disability. It is my view that the PDRS program should not become part of the NDIS but rather remain part of the specialist service system, with the NDIS providing services which could greatly improve their lives and aid their recovery.

Mutual Support and Self Help (MSSH) and drop-in services are prime examples of services that aid recovery largely because they help put the personhood back into the person. Put simply, clinical services treat the diagnosis, PDRS services deal with the disability, and MSSH and drop-in services provide the opportunity to mix with people with similar experiences, develop friendships, have time out from the illness and disability and ‘be themselves’. Are we now going to make consumers pay for that privilege?

Expectations and access

While it is said that the NDIS will give people a choice, those of us who work in mental health know only too well that we have, more often than not, conditioned people with a psychosocial disability to not expect much out of life or services. In order for them to truly choose, much work is going to need to be done to ‘un-condition’ people from their low expectations of life. We will also need to condition staff to stop deciding for the consumer community. Who is going to assist people to develop a better sense of self and entitlement so that they eventually genuinely choose what they want?
The NDIS is a major reform. It needs to be implemented thoroughly, inclusively of the people it is mostly going to affect, and slowly to ensure we get it right.

As with any service, the ability to provide that service rests heavily on the funding provided. In Victoria alone, according to the Boston report1, we have some 50,000 people who are regarded as having a serious mental illness who get no access to treatment or care whatsoever. Are we going to have sufficient funding to not only meet the needs of the people we currently see but all those we haven’t even met yet?

It also begs the question: how are we going to identify people who have never accessed services and those who have been wrongly discharged from services given their isolation from the community mental health system?

Criteria of eligibility

This raises the issue of the criteria that are going to be used to establish an individual’s right to the NDIS. If it is true that only 60-100,000 places are to be put aside for people with a psychosocial disability, then this will not cover even one state or territory. If that is the case, then clearly the criteria are going to exclude people rather than include them. If we transfer the PDRS sector funding to the NDIS then what services are going to be available to people who don’t meet the criteria. There is a clear risk that many people who receive a service today may very well not do so in the future and, given the complete transfer of funding, will have nowhere else to go.

One of the criteria for eligibility is that a disability should be permanent. How is this going to fit with the principles of recovery? How will young people who have only just been diagnosed get access to the NDIS? Will people with a psychosocial disability be penalised because its impact on their daily living and ability to participate in the community will differ at different times? Who will decide what the level of impact should be?

As a consumer from Geelong recently said: ‘On the one hand you have to fight to be seen as well enough to get out of hospital and, on the other hand, you have to fight to be disabled enough to be eligible to get a service with the NDIS.’

Conclusion

The NDIS is a major reform. It needs to be implemented thoroughly, inclusively of the people it is mostly going to affect, and slowly to ensure we get it right. People with a psychosocial disability deserve genuine input to the NDIS policy framework but that seems to have been sadly lacking. Indeed, one could suggest that the only people with a disability who can have a say about the NDIS are those who have access to a computer.

In speaking about the NDIS, I tell the story of Mary, a woman very disabled by schizophrenia. Mary has told me that life is supposed to be about enjoyment but, with a mental illness, it is about endurement. The NDIS needs to be about the individual, recognising their worth as a human being and affording them the opportunity to eradicate the ‘endurement’ in their life in order to embrace the enjoyment of life. Sadly, unless we work together, the NDIS could very well add to the ‘endurement’ of life, in total contrast to its original intent.

The VMIAC is the peak Victorian non-government organisation for people who have experience with a mental illness or emotional distress.

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Psychosocial disability: the urgent need for reform in assessment and care

Margaret Springgay, South Australian Carer representative and Deputy Carer Co-Chair of the National Mental Health Consumer Carer Forum*
Pat Sutton, Carer’s Australia representative on the National Mental Health Consumer Carer Forum#

Psychosocial disability associated with mental illness is a new and evolving concept, resulting from the interaction between people with impairments and attitudinal and environmental barriers present in society.

In 2010 the National Mental Health Consumer Carer Forum (NMHCCF) formed a working party to develop a Position Statement on Psychosocial Disability associated with a mental health condition. Launched in 2011, its development was driven by the need to draw attention to the significant and ongoing functional disabilities of people with severe mental illness, inform the Productivity Commission’s work in scoping a National Disability Insurance Scheme (NDIS) and argue for the inclusion of psychosocial disability as a condition to be covered by the NDIS.

Despite four National Mental Health Plans, two National Mental Health Policies and 11 National Mental Health Reports, numerous national surveys of mental health have demonstrated time and again the significant unmet needs of the same group – those with enduring mental illness and complex needs. There is no doubt that people with psychosocial disability and severe mental illness fall into this category.

The NMHCCF Position Statement attested to the fact that the psychosocial disability support needs of people with mental health conditions have been overlooked for too long. The mental health system is not designed to provide disability support. Nor has it been able to initiate the strategic development of mechanisms to address psychosocial disability support needs, despite three decades of national documentation calling for urgent reform in this area.

The NDIS and psychosocial disability

Two important reports were commissioned by the Federal Government in the lead up to the NDIS. The first was done for the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) in 2009 by PricewaterhouseCoopers on costs and funding models for a national disability insurance scheme. In describing people with severe ‘core activity limitations’, it found that those with psychosocial disability were the second largest group, at 206,000, following those with physical conditions, at 223,000.

The second commissioned report was written by the Productivity Commission and completed in 2011. In its initial draft the Commission identified between 149,800 and 206,000 people with a severe or profound core activity limitation occurring as a result of a mental health condition. However this was revised to 57,000 in the Final Report, which also stated:

Psychosocial disability: the urgent need for reform in assessment and care

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Psychosocial disability associated with mental illness is a new and evolving concept, resulting from the interaction between people with impairments and attitudinal and environmental barriers present in society.

In 2010 the National Mental Health Consumer Carer Forum (NMHCCF) formed a working party to develop a Position Statement on Psychosocial Disability associated with a mental health condition. Launched in 2011, its development was driven by the need to draw attention to the significant and ongoing functional disabilities of people with severe mental illness, inform the Productivity Commission’s work in scoping a National Disability Insurance Scheme (NDIS) and argue for the inclusion of psychosocial disability as a condition to be covered by the NDIS.

Despite four National Mental Health Plans, two National Mental Health Policies and 11 National Mental Health Reports, numerous national surveys of mental health have demonstrated time and again the significant unmet needs of the same group – those with enduring mental illness and complex needs. There is no doubt that people with psychosocial disability and severe mental illness fall into this category.

The NMHCCF Position Statement attested to the fact that the psychosocial disability support needs of people with mental health conditions have been overlooked for too long. The mental health system is not designed to provide disability support. Nor has it been able to initiate the strategic development of mechanisms to address psychosocial disability support needs, despite three decades of national documentation calling for urgent reform in this area.

The NDIS and psychosocial disability

Two important reports were commissioned by the Federal Government in the lead up to the NDIS. The first was done for the Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) in 2009 by PricewaterhouseCoopers on costs and funding models for a national disability insurance scheme. In describing people with severe ‘core activity limitations’, it found that those with psychosocial disability were the second largest group, at 206,000, following those with physical conditions, at 223,000.

The second commissioned report was written by the Productivity Commission and completed in 2011. In its initial draft the Commission identified between 149,800 and 206,000 people with a severe or profound core activity limitation occurring as a result of a mental health condition. However this was revised to 57,000 in the Final Report, which also stated:
The Australian Government has undertaken modelling to estimate the number of individuals with ‘severe, persistent and complex’ needs. These are individuals who:

• have a severe and enduring mental illness (usually psychosis)
• have significant impairments in social, personal and occupational functioning that require intensive, ongoing support
• require extensive health and community supports to maintain their lives outside of institutional care’.

With the current difficulty in estimating the number of people in Australia with a mental illness and associated psychosocial disability, collection of data using the term psychosocial disability should also be identified as part of national data collection.

The NDIS is currently being trialled in four sites, and has established seven shopfronts and other satellite sites. The trial has started the transition of thousands of people from existing service systems into

The Position Statement defines psychosocial disability as:

‘a term applicable to mental health to describe the disability experience of people with impairments and participation restrictions related to (mental) health conditions. These impairments and restrictions include reduced ability to function, think clearly, experience full physical health and to manage social and emotional aspects of their lives’.

It goes on to say:

‘the best outcome for people experiencing such disability will be achieved through supports that mitigate the effects of impairment or participation restriction and enhance the social and environmental opportunities to expand their capabilities.’

It is important to note that psychosocial disability is particularly common among people with psychotic disorders.

If people do not understand how the system works and what they can reasonably expect then you can guarantee disappointment, frustration, cynicism, dispute and increased reliance on the judicial and political systems.

If you are not sure how the system works and what you can reasonably expect, you will be disappointed, frustrated, cynical, dispute and increased reliance on the judicial and political systems.

The role of cognition

Assessing what the particular impairments are is key to putting in place the services that will enable a person to improve their functioning and match both their needs and choices. This is particularly true of psychosocial disability associated with mental illness because some of the disabilities, such as cognitive impairment, can be diverse and make it extremely difficult to engage with the individual.

Families and carers of people with severe mental illness and psychosocial disabilities have first-hand knowledge of the resulting impairments and the consequences on lives of those with complex impairments. Mental disorders constitute the leading cause of disability burden in Australia in the following age cohorts: 15 to 44 years (36 per cent, followed by injuries at 17 per cent); 0–14 years (23 per cent, followed by 18 per cent from chronic respiratory disorders).

Cognition is increasingly being recognised as a key contributor to functional outcome and as an important aspect of psychotic disorders. A recent study based on a meta-analysis of international literature over the past 10 years found that substantial, generalised cognitive impairment in schizophrenia is global and consistent over decades around the world. The research analysed data from 100 studies.
and included close to 10,000 people with schizophrenia and a similar number in the control group. The mean age of both groups was between 18 and 50 years. The most consistent finding was overall, generalised impairment across neuropsychological measures that persists in every clinical state and across lifespans. The domains measured included, for example:

**Executive functioning:** An umbrella term for the management (control) of cognitive processes to enable planning, problem solving and execution of plans.

**Working and episodic memory:** Has been described as the temporary ‘online’ storage and the subsequent retrieval of information – for example, a first date or first day at school. This includes prospective memory which is remembering to do future tasks – for example, take medication and attend appointments.

**Visuospatial/problem solving:** The sense of ‘whereness’ in relation to one’s environment, and in the relation of objects to each other, or judgment of spatial objects.

**Sustained attention:** An example is the act of reading a newspaper article or participating in discussion. One must be able to focus on the activity of reading/discussing long enough to complete the task. Problems occur when a distraction arises. A distraction can interrupt and consequently interfere in sustained attention.

Neuropsychological performance was significantly impaired in the schizophrenia group across all measures tested and all domains.

**Barriers to assessment**

There are many barriers which will need to be overcome in the assessment process of someone with severe mental health conditions and psychosocial disabilities. These barriers have historically led to so many of this group of people not receiving adequate support in the community. It has also largely contributed to our ongoing reliance on acute hospital services and crisis-driven service delivery.

One particular barrier is how to address those with the condition of anosognosia, a neurological deficit caused by severe mental illness itself, particularly psychotic disorders, which leads to a lack of awareness, or lack of insight by the individual that they are sick or disabled. It is not a considered choice by the individual, but a symptom of their illness and it is believed to be the single largest reason why these individuals do not take their medications. Anosognosia affects approximately 60 per cent of people with schizophrenia and 40 per cent of those with bipolar disorder and has been found to be predictive of a poorer course of illness, of higher relapse rates and poorer psychosocial functioning.

It is denying the nature of the illness itself when this group continues to be marginalised in the community because they are ‘difficult to engage’ or are ‘unable to have goals and drive their own care’. It is essential to overcome barriers which have historically made it extremely difficult for them and their families to access support services. This will require the experience of the individual’s family or the individual’s support network or both to be a focal point when assessing the criteria for entry into the NDIS of people with severe mental illness and psychosocial disabilities, particularly those with anosognosia, and also when assessing the support services.

Mental health carers are hopeful that a life-long approach by the NDIS and a commitment to life-long support for people with psychosocial disabilities will ensure that people with psychosocial disabilities will not continue to be marginalised because they are too difficult. Rather, they will walk alongside people with psychosocial disabilities, ‘fit into care’ and their lives will improve.

And it will take the burden away from families: why else are carers always asking ‘what happens when I’m not here?’

**Priorities ahead**

There are some ‘must do’ steps prior to the roll-out of the NDIS next year. First up is to prepare people about the scheme. If people do not understand how the system works and what they can reasonably expect then you can guarantee disappointment, frustration, cynicism, dispute and increased reliance on the judicial and political systems.

The NDIS is designed to bring resources and decision-making closer to people and their families. Government will have a more direct relationship with the people. Individualised funding will enable people to organise their own care if they are able and choose to do so.

Experience in other countries such as the US showed that approximately 80 per cent of their funding programs go through a host agency. Other countries have had similar experiences.

Whichever funding system is in place, assessment of an individual’s capacity is paramount as is the involvement of an individual’s family or carer when capacity is compromised – as is often the case with severe mental illness.

Policy and research reports in Australia have supported the demands of individuals and community groups for a better system of care than is currently available. The NDIS design started with the framework of the person, their capacity, their circumstances and the elements that all citizens need to have in place to build good and safe lives. Working with people and their families and identifying the gaps in capacity is essential in order to overcome the current failure in meeting the citizenship needs of people with severe mental health conditions associated with psychosocial disabilities.

What families want from the NDIS is a life-long approach to support that will lead to a better quality of life for people with severe mental health conditions and psychosocial disabilities and also for their families and carers.

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Peter does not understand or acknowledge that he has mental illness or diabetes, and he regularly informs RDNS of this, but they do not give up calling him. Their service is reliable, regular, persistent and assertive when this is necessary. Peter knows that they won’t ever give up on him!

Benefits of reliable, regular, persistent and assertive support

The following story of exemplary service delivery to the son of one of this article’s authors, Pat Sutton, is included to demonstrate the approaches that could be adopted by the NDIS to meet the needs of people with psychosocial disabilities which have never been available through mental health services.

My son, Peter, has schizophrenia with anosognosia and his serious condition has prevented him from working, living independently, or even having friends. Despite his extensive psychosocial disabilities, Peter continues to receive no independent living support from mental health and community services. We have been told on several occasions that ‘he does not fit into a recovery-oriented support service’ as he is ‘unable to drive his own care or articulate and work towards his own goals’. Peter has been trialed in three supported residential facilities over the last three years, but each placement failed, as the facilities were unable to provide adequate infrastructure and the care required to keep him safe. Therefore, Peter remains living with my husband and myself. We have supported Peter for 23 years and, as we are now ageing and struggling to support him, we anxiously await an ideal placement.

When Peter developed diabetes about six years ago, mental health services relinquished responsibility for his physical health care, despite the fact that his diabetes occurred as a result of antipsychotic medications and he refuses to regularly see a GP. Our family struggled to support him for about 18 months. Following one long general hospital admission, he fortunately was referred to and visited by a district nursing service for follow-up.

Benefits of reliable, regular, persistent and assertive support

After several months of working with Peter on a daily basis, the RDNS understood that he doesn’t believe that he has diabetes – any more than he believes that he has a mental illness. They also realised that he would not be able to manage his diabetes himself.

Having taken the time required to establish a good relationship with him, they installed a telephone link with a screen attached (called a virtual hospital). He could see them and they could actually observe Peter injecting his own insulin, via the camera. They now phone him twice a day to do this and discuss his blood sugar levels that he records himself over the course of each day. Because of his poor memory, they continue to repeat suggestions about his diet. They visit Peter and the family at home once a week or fortnight to discuss his progress, and liaise with a GP about his treatment. Peter waits by the phone at 8am and 5pm every day.

RDNS are very proud of Peter’s efforts and describe him as highly motivated, despite the fact that his verbal communication is almost nil. The family has been included in both the initial assessment and on-going care.

This demonstrates the importance of service providers and support workers being able to overcome the barriers which exist when a person has a severe mental illness and psychosocial disabilities. Peter does not understand or acknowledge that he has mental illness or diabetes, and he regularly informs RDNS of this, but they do not give up calling him. Their service is reliable, regular, persistent and assertive when this is necessary. Peter knows that they won’t ever give up on him!

References

2. PricewaterhouseCoopers (2009), Disability Investment Group, National Disability Insurance Scheme – Final Report, Department of Families, Housing, Community Services and Indigenous Affairs, Canberra, p. 4
3. Productivity Commission (2011), Disability Core and Support, Report no. 34, Canberra
4. Ibid, Appendix M, p.2
8. Ibid
11. Ibid
Further unravelling psychosocial disability: experiences from the NSW Hunter NDIS launch site

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The Hunter Launch Site Project

The transitional implementation of the NDIS at the Hunter launch site in New South Wales over the next three years is an important opportunity to consider how the NDIS will impact on people with mental health issues and/or psychosocial disability.

The Mental Health Commission of NSW has partnered with the Mental Health Coordinating Council (MHCC) – the peak body for non-government community managed organisations (NGOs/CMOs) working for mental health in NSW – to explore and analyse the introduction of the NDIS from a mental health and community sector perspective in the Hunter Launch Site Project.

The project looks to better understand what the NDIS will mean for people living with mental illness and the organisations that support them. Of particular interest is how the NDIS will reconcile essential philosophic differences between the mental health and disability sectors with regard to recovery oriented practice and workforce development.

It will make recommendations on how psychosocial disability should be best understood and included under the NDIS in terms of access and eligibility, existing community sector and public mental health programs, safeguards and workforce appropriateness. It will consider the wider NDIS and health services interface, especially as this relates to the unmet physical health needs and high prevalence of substance use by people living with mental illness.

Finally, it will consider how the needs of people living with psychosocial disability related to mental illness are being met within the NDIS and how they can be better met. The project is focused on adults aged 18 to 64 years, as this is the Hunter launch site target group, but it will also consider the psychosocial rehabilitation and disability/recovery support needs of both younger and older people.

Around 20 MHCC member organisations provide a range of Commonwealth and state funded programs in the three LGAs that make up the Hunter NDIS launch site. The project has met with consumers, carers and member agencies to better understand their experiences and needs in relation to the introduction of the NDIS.

NDIS in the Hunter

The Hunter launch includes ‘Tier 3’ individualised funded disability support packages for around 10,000 people, as follows:

- 2013-14: 3,000 people in the Newcastle Local Government Area (LGA) (2,673 ‘existing’ clients and 327 new)
- 2014-15: 5,000 people in the Lake Macquarie LGA (2,748 ‘existing’ clients plus 2,333 new)
- 2015-16: 2,000 people in the Maitland LGA (1,200 ‘existing’ clients and 830 new).

‘Existing clients’ mean people currently in receipt of disability support services funded by the NSW Department of Family and Community Services (Ageing, Disability and Homecare) who are transitioning to the National Disability Insurance Agency (NDIA). New clients will include some people receiving Commonwealth funded mental health programs, including:

- Personal Helpers and Mentors (PHAMS) – 100 per cent ‘in-scope’ for the NDIS
- Partners in Recovery (PIR) – 70 per cent ‘in-scope’
- Mental Health Respite – 50 per cent ‘in-scope’
- Day to Day Living program (D2DL) – 35 per cent ‘in-scope’.

New clients can be from any of the three LGAs and a number of people with psychosocial disability related to mental illness have been found eligible. This includes people who had been, or still are, ‘residing’ inappropriately in acute and sub-acute hospital facilities due to a lack of access to appropriate and/or sufficient community based services and housing.

Former boarding house residents with mental health issues in the Newcastle LGA who were successfully transitioned 13 years ago into supported accommodation and who access community based activities were among the first of the existing clients to transition to the NDIA along with PHAMS and D2DL clients. In the first week of the launch, 360 new clients were also referred to the NDIA in the Hunter.
Referral, eligibility, assessment and care planning

Issues around priority of access are beginning to emerge. For example, staff at Hunter New England Mental Health (HNEMH) have identified a large number of people who could be referred to the NDIA, however their capacity to do so has been hampered by the large volume of psychosocial assessment information required and the priority focus on acute and sub-acute mental health treatment.

Issues have also arisen around funding levels for clients, with some allocations revised down for existing clients as they are transitioned. These are being revisited with NDIA Support Planners where they do not seem to align with a person’s current needs. This discrepancy may stem from the NDIA’s practice to keep ‘registered providers’ (including those currently providing services to transitioning clients) at a distance, including not requesting client information from them or allowing them to participate in assessments. This practice was intended to ensure the person’s ‘choice and control’ regarding service selection was not compromised by the input of their current service provider. However, the NDIA is increasingly seeing the value of more ‘collaborative practice’ with existing psychosocial disability and recovery support service providers. This is amid concern that some clients do not identify to NDIA Support Planners all the support services they require and/or currently use, underestimate their support needs, and/or may not disclose involuntary mental health orders (for example, forensic status, Community Treatment Orders) and/or other potential duty of care/dignity of risk issues.

The Hunter is the only 2013-14 adult NDIS launch site that also has a Partners in Recovery (PIR) program. PIR is an important and innovative new national mental health program that focuses on outreach to adults with serious mental health issues and many of these will also likely be NDIS eligible. Referrals to PIR commenced in November and the staff and other financial resources it provides are thought to help accelerate new referrals to the NDIA. The referral, eligibility, assessment and care planning pathways between PIR, public and community sector mental health services, and the NDIA are complex but are beginning to be identified through fortnightly meetings of PIR, HNEMH and the NDIA.

Need for ongoing dialogue

Early experiences indicate the need for a range of human service workers – both mental health specific and other – to better understand the similarities and differences between acute/sub-acute episodes of mental illness and psychosocial disability and how these may co-exist. However, the project has identified that much of the Hunter NDIS learning is happening in silos for individual workers, programs and organisations. To address this, the project held a Community Sector Forum in October 2013 which shared the experiences of about 30 participants of the first three months of the NDIS. The Mental Health Council of Australia (MHCA) also attended to discuss national perspectives of the NDIS and its 2013–14 Mental Health Capacity Building Project.

The forum identified how much the whole process remains a learning experience for all involved: community sector mental health programs are learning to varying degrees through NDIS implementation and the NDIA is also learning about mental illness, psychosocial disability and recovery support from the mental health sector.

It revealed that organisations are at varying levels of ‘NDIS readiness’ and want to learn from and with one another, even though the ‘business’ environment is increasingly competitive. An important outcome of the day was agreement to have ongoing bi-monthly reflective practice meetings and to open these up to others who may wish to participate (that is, to establish a Hunter NDIS and Mental Health ‘Community of Practice’). The NDIA, HNEMH and MHCA have been invited to attend and provide regular updates at these events.

The project followed up in November with a management workshop to explore organisational readiness for the NDIS, run by Peter Gianfrancesco, former Chief Executive of Norwich and Central Norfolk Mind in the United Kingdom, who shared experiences of the introduction of personalised budgets in the UK. The workshop focused on how to maximise learning from the Hunter launch site and to support organisational readiness in an increasingly competitive market-based economy, thus reinforcing the need to establish a Community of Practice. The workshop was repeated in Sydney for others outside of the launch site to encourage them to reflect on their organisational readiness. Sector and organisational readiness for the NDIS was also considered during MHCC’s August Regional Forums and December ‘Big Issues’ Day and Annual General Meeting.

Hunter NDIA has recently identified a worker who will serve as a key liaison in working across mental health and psychosocial disability issues. It has also created an internal Mental Health Reference Group to review all mental health related transitions and new referrals. The aim of this group is to establish benchmarks around eligibility and access, and consistency in assessment and care planning processes. Variability in these processes to date suggests a need for the NDIA to become more skilled in working with people living with psychosocial disability and recovery support needs.

NDIS Tier 3 ineligibility

The issue of what psychosocial rehabilitation and recovery support services might be available for people who are not NDIS Tier 3 eligible, including families and carers, is critically important. For example, people who are occasionally or frequently acutely mentally unwell but have no or little residual disability when well will typically not be eligible for NDIS Tier 3.

Prior to the NDIS, community sector services for people with mental illness were already acknowledged to be at capacity and underfunded. With most federal funding for community sector mental health support programs being ‘in scope’ for the NDIS there is a risk that people not eligible for Tier 3 may miss out on existing federally funded community supports. State and territory jurisdictions have variable approaches to, and share a high level of concern about, this situation. In NSW, no Ministry of Health state funded mental health programs have been deemed ‘in scope’ for NDIS.

This situation may be revisited through the review of the Bilateral Agreement between the Commonwealth and NSW and/or via the NSW Health Grant Management Improvement Program that is underway. Some tensions are emerging regarding the NDIS eligibility of people currently receiving state funded community sector mental health programs: clarification is much needed. Continuing with ‘ad hoc’
approaches to mental health sector development through the guise of NDIS individualised funding will not be sufficient to address the aspirations of either the National or NSW Mental Health Commissions.

**Next Steps**

The work undertaken at the Hunter launch site over the next three years will help to inform both NSW and national directions for people with high levels of psychosocial disability and the community organisations that provide services to them. It is estimated that, by 2018, 57,000 Australians living with psychosocial disability will benefit from NDIS services. The Hunter launch site provides an opportunity to learn from the experience of around 1,300 people living with psychosocial disability, including at least 454 new clients (the total number of transitioning clients with psychosocial disability is unknown). The very interesting intersect of this client group with the 700 people to be assisted through Hunter PIR over the next three years is also unknown.

To learn as much as possible from the launch sites we must strengthen approaches to data collection, including the monitoring of outcomes relating to the experiences of people with psychosocial disability and the organisations that support them. To build the capacity of the mental health sector to respond and work with the NDIS, it will be essential that moves to establish a community sector mental health minimum data set are progressed.

MHCC and the Mental Health Commission of NSW will continue to think and plan ahead about the potential impacts of the NDIS on the community managed mental health sector, which is the main provider of psychosocial rehabilitation and recovery/disability support services to people affected by mental illness.

**NDIS scenarios from the Hunter**

**Scenario 01:** A homeless man with mental health and drug and alcohol issues approaches a local emergency services program for housing assistance. He is deemed ineligible for transitional housing as his support needs are too high and is referred to the NDIA where he is assessed as eligible for Tier 3 funded services. He accesses the transitional housing program with four hours a day of additional support funded. Because the support chosen by the man is 7–9am and 7–9pm and the service is traditionally staffed 9am–5pm, they successfully explore options for expanding their operating hours.

**Scenario 02:** A man has been inappropriately residing in a psychiatric hospital for many months. He had been living in neglect with little food or furniture etc. and struggling to maintain his public housing tenancy due to very high levels of functional disability. The hospital was reluctant to discharge him without community support knowing that he would likely become acutely unwell again very quickly and he was referred to the NDIA. He was initially deemed ineligible for Tier 3 funded services but this decision was reviewed and a care plan has been developed for his return to the community.


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**References**

1. The title of this article acknowledges the very important foundational work undertaken by the National Mental Health Consumer and Carer Forum in its 2011 publication ‘Unravelling Psychosocial Disability’.
2. There is little Hunter discussion or activity as yet related to the operation of Tiers 1 and 2.
3. ‘In-scope’ means that a program has been wholly or in part included in the NDIS.
The introduction of the National Disability Insurance Scheme (NDIS) will transform the way the community managed mental health sector delivers services to people with a mental illness. These changes will challenge the capacity of agencies to deliver against their vision and mission, cause us to rethink our role in facilitating recovery, and threaten our alignment with evidence based practice.

At the same time, however, the NDIS will bring welcome change to an agency’s relationships with clients, delivering greater choice and control to the client, and greater agency accountability to clients and the community. The aim of this paper is to identify some the key issues that agencies will face in delivering rehabilitation and recovery oriented services in an NDIS environment, based on our early experiences in the current trial site in Barwon.

Defining disability under the NDIS

The NDIS is “a new way for people to get disability support that takes an individualised approach to providing care and support over a person’s lifetime.” To be eligible for the NDIS participants will need to demonstrate that their disability is the result of permanent impairment. These concepts are fundamental to the design of the NDIS.

Impairment refers to “problems in body function or structure such as significant deviation or loss”, and the concept of permanence, in the NDIS, applies when “there is no known clinical or medical treatment that would remedy it; and it does not require further medical treatment or review in order to demonstrate permanency.”

This implies the impairment would remain despite clinical intervention.

Disability is the impact of impairment on the person’s functional capacity to perform activities in one or more of the following activities – communications, social interaction, learning, mobility, self-care and self-management. These functional deficits impact on the person’s capacity for social and economic participation and are likely to require support for the person’s lifetime, despite variation.

These definitions underpin NDIS eligibility and design. While mostly applicable in many physical conditions, they lead to problems when applied to mental health and recovery.

Challenges for psychosocial approaches

Assessment of a disability arising from a physical health condition, for example the functional impact of a stroke on a young adult, is relatively clear. Health services provide immediate treatment and rehabilitation designed to remediate the condition and return the client to as near to pre-morbid functioning as possible. At some point in this process the health team determines that remediation is no longer possible and the focus shifts to compensatory or disability support that enables the person to function at home and in the community, despite what is now considered a permanent impairment. This somewhat simplistic example would see remediation approaches occurring in the health care system, whereas compensatory approaches would belong in the NDIS. In reality, of course, the shift from remediation to compensation is not dichotomous, but rather exists along a continuum.

Our current practice places the recovery plan as the roadmap for the services we deliver... This will no longer be the core work of our sector.
There is a risk that engaging different agencies to deliver different elements of the plan will result in ineffective, duplicative or competing approaches. Our early experiences of Disability Support Plans confirm this possibility.

Compensatory approaches could include assistance to shower, dress, and prepare meals, and to purchase mobility equipment and related training. NDIS supports, to date, are predominantly compensatory and funded at a level that reflects the staffing required to support clients, rather than applying psychosocial rehabilitative approaches that are designed to remediate impairment and build capacity.

Skills development approaches are also included in the NDIS and are defined as training participants or their carers to perform daily living and life skills. At first glance these approaches appear similar to some of the psychosocial rehabilitative approaches we use in the community managed mental health sector. In reality, however, these descriptors and their related funding reflect a pure training model that does not account for the work we do to address the underlying impairments that limit daily living and life skills. A simplistic but relevant example might be the way we work with people to manage obsessional compulsive behaviour that affects their self-care routine in the morning. Our approach here is not skills training, rather it is the development of strategies, based on cognitive behavioural techniques, to manage anxiety.

The NDIS does include therapeutic approaches carried out by defined allied health professionals, for example occupational therapy in a group. However the definition of these supports very clearly prescribes that they should assist the client to apply functional skills rather than improve their health.6

These concepts of health and disability, and the consequent differentiation between health services and disability support, present major difficulties to the community managed mental health sector, and more broadly to the delivery of evidence based psychosocial approaches that support recovery.

The risk to evidence based recovery

Victoria’s community managed mental health sector was established in the early 1990s and delivers a range of programs that support people with a mental illness to recover and build satisfying and contributing lives in the community. We work alongside, and increasingly integrate with, clinical services that deliver mental health treatment. We work with participants to explore and understand their recovery aspirations, and develop strategies to achieve them. Our specific intervention approaches are informed by the biopsychosocial model which provides foundation understanding of the factors that impact on mental illness and recovery.

This model holds that performance of activities, and hence disability, is impacted by a range of factors – biological, psychological and social in nature. These include the positive and negative symptoms of mental illness, and any cognitive impairment that is experienced as a result of long standing illness. Social factors, such as supportive relationships, are known to positively influence illness and recovery, while their absence has a negative impact.7

We, therefore, understand that difficulties in functioning, such as regularly caring for one’s self and one’s home, is rarely due to a skills deficit alone; rather it is due to an interplay of underlying deficits and the social factors. Our interventions, therefore, identify underlying deficits and, in partnership with the client, develop and practise strategies to overcome the deficit and build on strengths. These strategies are practised across the range of impacted tasks. Our intervention, thus, is directed at the impairment level rather than the performance itself (although an onlooker may not easily observe that difference).

Similarly, peer work is a specific example of an evidence based approach that is adopted by many community managed mental health agencies. It increases responsiveness to issues such as housing and employment and a person’s ability to bring about changes in their lives. Literature has suggested that instilling hope, the use of role modelling, and the nature of relationship between peer workers and participants are unique contributions from peer workers.8 Peer work, therefore, addresses some of the psychological impacts of mental illness, such as reduced self-efficacy and hope for the future. While peers often appear to be working at a functional level (that is, doing things with participants) their potency is best understood at a psychological level.

This places much of the work of the community managed mental health sector as a combination of health interventions and disability support, rather than disability support alone. Decisions by the Victorian Government, however, to cash out psychiatric disability rehabilitation and support services (PDRSS) and by the Federal Government to include Personal Helpers and Mentors service (PHaMS) and respite funding in the NDIS trials will challenge the capacity of organisations to deliver evidence based rehabilitative approaches.
The NDIS currently does not have a support item that enables agencies to engage with participants in a process of recovery planning and exploration. This process is exclusively conducted by the NDIA planner.

It is also doubtful that clinical services will be able to effectively take on this role and there is, therefore, a high risk that evidence based recovery services will be unavailable to people with a mental illness and their families.

**Changing the way we work**

The way we work with people in the NDIS context is also transformed. The intent of the scheme is to provide participants with maximum choice and control, enabling them to choose their support package and who will provide them. These features are closely aligned to the principles of delivering recovery oriented services. In practice:

1. A person or their carer will approach the NDIA, or be referred to the NDIA.
2. Their eligibility will be assessed.
3. If ineligible, clients will be linked to mainstream services.
4. If eligible, the client will become a participant of the NDIS and work with a planner to develop a Disability Support plan.
5. The plan will identify participant goals and the services that will be funded to deliver each element of the plan.
6. Services will only work on agreed support items for the approved number of hours.
7. Services will claim for payment after the hour(s) of support has been delivered. Payment will only be approved for services that have actually been delivered.
8. Plans will be reviewed by NDIS on a 12 month cycle, or if a significant change occurs.

These arrangements inherently fragment planning and service delivery. The planning process will be undertaken by NDIA planners who will explore each participant’s goals and aspirations and develop a related plan. This office-based process assumes that participants are able to articulate their goals and aspirations in a relatively short period of time and to a planner who they barely know. It will replace the current process employed by community managed mental health organisations to develop an individual recovery plan. Our current practice places the recovery plan as the roadmap for the services we deliver. It is developed in partnership with clients in the context of a relationship with a key worker who understands the individual’s barriers and enablers of recovery, and is able to coach and support them to imagine a better life. This will no longer be the core work of our sector.

What we do know is that some clients benefit from education, experiences and peer support to enable them to contemplate a life beyond their current experience of mental illness. MI Fellowship was funded to deliver peer led recovery education programs, known as MI Recovery, to prepare people for the NDIS. It was observed:

“All the individuals that participated in this group were stumped when I initially asked them to think about what they would want if they had the choice to choose the type of support they could receive and empower them to have a better life…. Not one of the participants knew what they wanted, not one of them could put a concrete want on paper... They had been so used to taking what they were given, and just accepting it whether they liked it or not, that they had actually become submissive in their own lives.”

(MI Recovery peer facilitator, MIF NDIS Practical Design Project)

The NDIS currently does not have a support item that enables agencies to engage with participants in a process of recovery planning and exploration. This process is exclusively conducted by the NDIA planner.

Consequently, participants can receive a plan that engages a number of service providers to deliver different aspects of the support plan. While this arrangement provides for greater diversity of choice it can unintentionally disintegrate service delivery and may be inefficient. Typically, a person’s performance in more than one activity is affected by common underlying deficits and strengths and a range of social factors that can act as a barrier or enabler of recovery. Understanding these multiple factors and developing related strategies maximises the impact of intervention. There is a risk that engaging different agencies to deliver different elements of the plan will result in ineffective, duplicative or competing approaches. Our early experiences of Disability Support Plans confirm this possibility.
It is doubtful that the current design of the NDIS will enable organisations to effectively deliver against vision and mission. Not only will the types of services we are funded to deliver be affected, but also the people with whom we work.

NDIS impact on vision and mission

As organisations consider their responses to the NDIS they will undoubtedly turn to their vision and mission for direction. These statements are generally aspirational in nature and commit the organisation to a vision of a better life in the community for people with a mental illness and their families. They create a vision of recovery, and endorse best practice, a family inclusive approach and community capacity building. It is doubtful that the current design of the NDIS will enable organisations to effectively deliver against vision and mission. Not only will the types of services we are funded to deliver be affected, but also the people with whom we work.

It is likely that many clients currently served by PDRSS will not be eligible for the NDIS. The Productivity Commission has estimated that 60,000 people with a mental illness across Australia will be eligible for an individualised support package through the NDIS. Other participants will be redirected into mainstream services. Given an estimated 459,000 Australians have a mental illness, it looks likely that many will miss out on individualised support packages.

Services delivered to families and carers will also be affected by the introduction of the NDIS. There is currently no identified item to support and educate families and carers in their own right. Rather, reference to family is limited to support items that train the carer in parenting skills or managing behaviours of concern. The delivery of carers’ support, through evidence based programs such as Well Ways Family Education programs, respite or mutual support, and self-help groups will be limited under the NDIS, with only a proportion of carer support funding from the Department of Social Services remaining outside of the NDIS.

The NDIS presents major challenges to the community managed mental health sector. Changes in service delivery are being acutely felt by services operating in the trial site in Barwon. It is incumbent on the sector to understand the scheme and its impact and collectively work to influence the national roll out to ensure best outcomes for people with a mental illness and their families.

References

1 MI Fellowship is currently transitioning Youth Residential Rehabilitation and Mutual Self-help and Support programs in the Barwon region to the NDIS.
7 Anthony W A & Farkas M (2012), The essential guide to psychiatric rehabilitation practice, Boston University, Boston, USA.
8 Davidson, op. cit.
**Introduction**

The implications of psychosocial disability being included in the National Disability Insurance Scheme (NDIS) are not yet fully understood. It is anticipated that approximately 57,000 people with continuous and enduring psychosocial disability across Australia will be eligible for support under Tier 3 of the NDIS. They will be able to make choices about the supports that are “reasonable and necessary” to meet their needs. While there is some work currently being undertaken to prepare staff in the sector for the change, until now there have been few projects focused on the implications of the NDIS from the perspective of people with psychosocial disability.

In response Mind Australia has funded an innovative research project that has sought to:

- provide the CMMHSS and other stakeholders with an understanding of support needs and preferences of people with psychosocial disability and the types of changes needed to develop more responsive services in the transition to NDIS.
- give people with psychosocial disability the opportunity to have a voice in stating their preferences for support.

**Background**

People with psychosocial disability experience considerably poorer health and greater social isolation when compared to the general community in Australia. This is despite the efforts of both state and Commonwealth governments to provide rehabilitation and support services. Services are inconsistently provided and can be difficult to access due to factors such as lack of funding and location. Australia’s CMMHSS service delivery is likely to undergo substantial change in the context of proposed state-based reforms and the introduction of the NDIS. In addition, greater emphasis on individualised packages of support and increased client choice, as well as stronger links with primary care, are expected to enhance the current focus on improving social participation, physical health, employment and education outcomes.

This project presumes the NDIS has great potential to improve the well-being of people with psychosocial disability. The findings from this project will:

- contribute to improving health outcomes of people with psychosocial disability through identifying and communicating their service needs
- inform the CMMHSS about how the personal values and ethical stance of consumers influences their decision making and what support they need to make good decisions for themselves
- improve strategies to empower people to make these choices and inform the development of a more efficient CMMHSS as it prepares for the transition to individualised funding.

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**Consumer choices about mental health support services**

Annie Bruxner, Director of Research, Mind Australia  
Dr Lisa Brophy, Centre for Mental Health, Melbourne School of Population and Global Health, The University of Melbourne  
Dr Erin Wilson, School of Health and Social Development, Deakin University

This research provides compelling support for the introduction of a responsive and flexible system of personalised mental health care.
The Research Design

Participants

Under the project, 41 participants were recruited from the Barwon region who fit within current NDIS eligibility requirements, including that they were:

- experiencing psychosocial disability
- currently accessing or eligible to receive support from local community mental health services
- aged between 26 and 65 years.

People with enduring and continuous (or elsewhere described as severe and persistent) psychosocial disability associated with mental illness will be eligible for the NDIS. Assessing eligibility has been a source of uncertainty in relation to the NDIS so this project included investigating the perspective of participants on eligibility. It also explored what people understand the terminology around “psychosocial disability” to mean and asked them to think about the impact psychosocial disability had on them in relation to a range of aspects of their life.

Methods

Current service users (Mind Australia consumer reference group and the Barwon Health consumer reference and advisory group) were consulted during the development of the interview schedule and methods. This proved to be very helpful in ensuring we got the correct language and tone of the interview. There was a focus on using accessible and meaningful methods so the interview did not rely heavily on the research participant’s literacy and numeracy skills.

In anticipation that many participants may not have been previously asked questions about their aspirations about having a “good life”, and may struggle to “think outside the box”, prompt cards (photographs and verbal prompts) were developed to help people think this through. We also used the 10 seed technique.

After participants nominated their good life goals (using prompt cards), they were given 10 seeds (which represent 100% of a funding package) and asked to spread them across these goals. In doing so, participants could indicate the amount of support funding they believed each goal needed in order for it to be achieved. Group consultations identified fluctuations in support needs as likely to be an important factor in people’s thinking as they answered interview questions. Therefore people were asked about how their support needs and preferences may have changed over time and to report on what types and qualities of supports and services may or may not have worked for them in the past.

Peer researchers were involved in conducting these interviews which led to opportunities for improved engagement in research and improved access to the voices of consumers.

These interviews went beyond asking people what their needs are (questions which most ‘clients’ are familiar with) and alternatively used the questions suggested by Rhodes (2012) including: What really matters to you? How do you want to live a good life? These questions enable people to identify what they want rather than what they know services offer.

This project asked people:

- what supports would help them achieve a “good life”
- what life goals would they prioritise
- how they would allocate their individualised funding package across these goals
- if they had the choices offered by the NDIS, what decisions would they make about the support services and how they would receive them
- who they would rely on to assist in making these decisions and choices.

Preliminary findings

We used quantitative data analysis, and inductive and emergent coding of the rich qualitative data to explore the data.

Participants were able to discuss the meaning of having a psychosocial disability and provided their perspective on how this impacted on their life. Whilst we were interested in understanding the current impact that a psychosocial disability had on participants’ lives, most participants identified long term and moderate to extreme impacts that were interdependent and changing over time. For example, many participants recognised that their psychosocial disability had a long term impact that precluded them from entering into either paid or full time employment and made it more difficult for them to gain education and training or actively engage in the community.
Further, there was some overlap between impact and the areas that participants considered important to having a good life. For example, where lifelong learning may have been impacted, some reported to have subsequently reduced ability to gain meaningful employment and therefore social connection through the workplace. Some participants reported that regaining social connection through sport or exercise would then lead to improved mental and physical health, and could lead to future education and employment opportunities.

We were also able to quantify the top five life goals that were most commonly reported as being important to having a good life for our participants. These included social connection, economic goals, health, housing, personal relationships and supports. Again, no life goal was independent of another. For example, gaining employment provides both economic benefits and opportunities for social connection. Indeed, preliminary investigation of participants’ economic goals found that people with psychosocial disability hope to overcome the difficulties of a low income (average weekly income was $429), regain financial security, and have sufficient funds to afford healthy and nutritious foods which then leads to improved health (both mental and physical). Also, within economic goals rests the concept of entering into meaningful and purposeful employment which participants reported as being essential to positive self-worth, mental health, and motivation to achieve other life goals.

Participants explored the kinds of services and supports they would choose that would enable them to live their good life, and how they would fund these ideas for supports. Where some goals may have been prioritised as most important, the allocation of funding and subsequent supports around those goals was sometimes relatively minimal. This can be explained by the fact that not all goals require direct assistance from supports and services. Self-esteem, for example, is essential to living a full and meaningful life but may not be supported through direct funding – it is the result of increased opportunities and acceptance from community through work, employment, social connection and reduced stigma.

**Discussion**

Preliminary findings identified that people value their health and wellbeing, connecting with friends, family and community, purpose and meaning in life as being important to having a good life. However, this research is unique in that it not only explores what is important to people with psychosocial disability but why these goals are important.

The interrelatedness (overlap) of goals and impacts across a range of domains was consistent across participants and preliminary analyses indicates that a “one size fits all” approach will not be enough to assist people with psychosocial disability to recover nor lead to a flourishing and good life. This research provides compelling support for the introduction of a responsive and flexible system of personalised mental health care.

Further, it is essential that supports, such as training and education, are relevant and meaningful to people with psychosocial disability. Services provided through the NDIS need to provide opportunities that are consistent with consumer needs if they are to help people achieve the lives they want for themselves.

Most participants nominated the importance of having a support person. A more detailed report will expand on the qualities and characteristics that people with psychosocial disability expect of services and supports.

**Conclusion**

Recognising the potential diversity and range of consumer preferences, despite common themes, has been a cornerstone of this research. The NDIS will equally need to respond to this broad range of needs and preferences as its efficiency and effectiveness for people with disability will depend on good decision making. This research has investigated how good decision making can be supported; it located people with disabilities as the experts on their needs. The research contributes to knowing about what decisions people with psychosocial disability are likely to make, the assistance they need and how they want to make these decisions.

**References**

9. Rhodes 2012 above
10. Jayakaran 2002 above
The NDIS: What can Australia learn from other countries?

Theresa Williams, Director, Western Australian Centre for Mental Health Policy Research; Adjunct Associate Professor, School of Psychiatry and Clinical Neurosciences, University of Western Australia

Although the overall goals of citizenship, choice and independence drive both sectors, the critical questions in mental health are: how well do these disability support schemes work for people with a psychosocial disability and are there specific accommodations required to meet their needs?

**Introduction**

Despite a number of countries implementing national disability support programs with individualised funding over the past two decades, there has been little reflection in Australia on this international experience – both the pitfalls to be avoided and the ways to build success. Similarly, in the mental health sector there has been limited discussion on the features of other disability support schemes which have either helped or hindered people with a psychosocial disability on their recovery journey.

The good news is that it isn’t too late. The National Disability Insurance Scheme (NDIS) trial sites provide an ideal opportunity to translate this experience into an Australian context to make sure that the scheme works for mental health consumers, their families and carers.

**International trends in disability support**

The NDIS is embedded within a major international change in the way that support services for people with disability are provided; moving from a traditional welfare model which can create dependency to one which is enabling and based on active citizenship, choice and independence.¹

This current approach to disability support is underpinned by the United Nations Convention on the Rights of Persons with Disabilities. Signatory countries to the Convention, which include Australia, “recognize the equal right of all persons with disabilities to live in the community, with choices equal to others” and commit to taking “effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community”.²

The concept of ‘choice and control’ has become a core tenet of disability support programs. In practical terms this has translated into reforms in a number of jurisdictions driven by two key policy directions:

1. **Personalised support services** which are consumer-directed and designed to support each individual’s life goals and aspirations.

2. **Individualised funding** with a personal budget based on each person’s assessed needs to enable them to control the purchase of agreed supports.

Since the 1990s several countries, including the United States, United Kingdom, France, Germany, Belgium, Austria and the Netherlands have introduced programs for people requiring
long term support to increase the choice and control each individual has over the services they receive. These schemes are all designed to enable disability support to be consumer directed, with a key feature being the provision of an individual budget to purchase services. The NDIS, in line with this international direction, provides for each eligible participant to have an individual budget, based on assessed need, with the option of receiving funds directly or having the budget managed by a third party.

**Challenges in mental health**

National disability support systems aim to meet the needs of people with a wide range of different disabilities. Their design is, not unexpectedly, highly influenced by the disability sector and driven by that sector’s philosophy, values and language. However, historically mental health has been somewhat separate from the disability sector; more connected to health services and underpinned by the philosophy and language of recovery.

**Access**

One of the key challenges has been the low uptake of individual budgets for support services in mental health when compared with other disability groups. For example, in England during 2010–11 only 9 per cent of eligible adults with a mental health problem received an individual budget compared with 41 per cent of adults with a learning disability.5

The experience has been similar in Scotland. An evaluation of the self directed support test sites in three local authorities reported that mental health accounted for only 3 per cent of individual support budgets. A follow up evaluation found that while the absolute number had increased, the overall percentage remained low at just 2 per cent for people with mental health issues compared with 59 per cent for people with learning disabilities and 19 per cent for those with physical disabilities.6

**Assessment and information**

A number of other challenges specific to mental health were also noted in the Scottish test site evaluation, including difficulties in the assessment process with fluctuating support needs and the lack of promotion and information specifically designed for mental health consumers, their families and carers.7 There has also been a lack of awareness among consumers about self directed support and individual budgets, and where there is awareness, there is often confusion and misinformation.8

**Splitting health and disability**

In 2012 a series of workshops with mental health consumers, their families and service providers conducted by the Scottish Mental Health Cooperative and the Mental Health Foundation noted that health and disability (known as social care) are hard to split and most people’s route to support services is via their mental health services.

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The clear goals from the international experience of disability support schemes and mental health is that one size does not fit all.
This need for integration between health and disability support services was reinforced in a joint position paper on personal budgets by the Royal College of Psychiatrists and the Directors of Adult Social Services, which noted:

“The distinction between what is health care and what is social care is not clear and this creates duplication, fragmentation and waste at the boundary between the NHS (National Health Service) and social care. Many individuals with mental health problems receive services from both the NHS and social care and are frustrated by the lack of integration between the two systems.”

Despite the importance of clinical mental health services as a pathway to access disability support services, the report noted the lack of information on personal budgets among clinical staff. This can lead to fewer opportunities for people with mental health problems accessing the support needed as part of their recovery journey.

Rather than losing valuable time, the trial sites should be supported to take a proactive approach to mental health by identifying obstacles early and field testing innovative solutions.

Addressing the challenges

Scotland is leading the way in addressing the challenges which are specific to mental health within a national disability support scheme. The Social Care (Self-directed Support) (Scotland) Act 2013 goes live on April 1, 2014 following a long period of preparation and learning from the pilot sites. A hallmark of the Scottish approach to implementation has been a significant, long term investment in capacity building which follows from the launch of their 10 year national self directed support strategy in 2010.

The Scottish Government has funded several capacity building projects in mental health to address the identified barriers. Some examples include:

- **Getting There**: A learning network of mental health user-led NGOs funded for four years to prepare for the implementation of self directed support.

- **Capacity Building for Third Sector Providers**: A four year program undertaken by the Scottish Mental Health Cooperative and the Mental Health Foundation to assist NGOs prepare for and engage with self directed support in mental health.

- **Pilotlight**: This project demonstrates how to tailor services to groups which are seldom heard, with one of the four priority areas being people with a mental illness. Pathways to self directed support are researched and co-designed with teams including both service users and those who deliver services.

A number of these projects are already delivering results and could inform developments in Australia. However, the greatest promise lies in learning from the way in which the capacity building is done. The projects are characterised by:

- being funded for an extended period, recognising that system and practice change takes time
- having a strong consumer voice and partnerships with service providers
- developing local solutions and trialing innovation
- disseminating ‘on the ground’ experience through learning networks.

Where to for Australia?

The clear message from the international experience of disability support schemes and mental health is that one size does not fit all. It is highly likely that the NDIS will require specific strategies and flexible solutions to make it work well for people with a psychosocial disability.

Rather than losing valuable time, the trial sites should be supported to take a proactive approach to mental health by identifying obstacles early and field testing innovative solutions. This fits well with the role for the sites articulated by Senator Mitch Fifield, Assistant Minister for Social Services, when he stated that:

“The purpose of the launch sites is to learn. For design features to be tested and changed if needed. The launch provides an opportunity to check our assumptions and to revise implementation practices.”

By the end of 2014 it is anticipated that each state and territory will have a trial site in operation. Each site could be funded to set up an NDIS Mental Health Capacity Building Network with membership drawn from those participating at the local level.
The success of the NDIS for mental health consumers, carers and their families depends on effectively using the ‘pre-season’ to build capacity across Australia over the next five years.

At each trial site the network would:

• identify any barriers to access and full participation in the scheme
• develop and trial creative, innovative solutions
• share what has been learned with other test sites
• link together to form a national network to be a voice to inform the NDIS national evaluation and shape government policy.

This ‘learning by doing’ approach has been successfully used in a number of human service settings in the US and can strengthen collaboration, encourage partnership and lead to effective policy development. It challenges a command and control philosophy and the complex bureaucratic processes which can sometimes bedevil national schemes. Even more importantly in mental health, it provides a way of trying to accommodate and fit the NDIS into an existing service system which is already highly complex, with varying service arrangements across the country and with multiple agencies involved.

Conclusion

When he spoke to the National Press Club late last year, Senator Fifield used a football analogy to describe the current stage of development of the NDIS:

“...in AFL parlance we’re still very much pre-season.”

To continue the analogy, the season proper is set to begin in 2019. The success of the NDIS for mental health consumers, carers and their families depends on effectively using the pre-season to build capacity across Australia over the next five years.

Acknowledgements

This paper was informed by my visits to a number of European countries in 2012 undertaken with a Churchill Fellowship from the Winston Churchill Memorial Trust of Australia and with support from the Western Australian Department of Health.
The challenges of implementing the NDIS

Frank Quinlan, CEO of the Mental Health Council of Australia

Most people with psychosocial disability have needs (and impairments) that fluctuate in severity and in nature over their lifetimes, and it is often difficult or impossible to predict which people will need long-term support and who will exit the ‘system’ and when.

Introduction
The National Disability Insurance Scheme (NDIS) represents one of the most fundamental and welcome changes to Australia’s health system since Medicare. More than this, the NDIS represents an historic opportunity to provide services to a group of people who have traditionally missed out on getting the support they need to lead a contributing life: people who experience psychosocial disability.

Psychosocial disability is not a commonly understood concept, although many mental health service providers see such people on a daily basis. This kind of disability can be experienced by people with a mental illness, but also by people with a cognitive impairment or with an acquired brain injury. It is characterised by, among other things, difficulties interacting with other people (especially unfamiliar people) and an inability to regulate daily activities and look after basic day to day personal needs like cooking, cleaning, dressing, or catching the bus.

Many people who experience psychosocial disability require intensive support. Unfortunately, at the moment, many have to rely solely on a carer within their family (if such a person is around and willing to fill a carer role). This is partly because there are not enough of the right services in the community. It is also due to a resistance by some people with psychosocial disability to anyone trying to help them, and the challenges faced helping them to understand their disability.

There are compelling reasons why people experiencing psychosocial disability should receive support through a scheme like the NDIS. Not least of these is cost: if the right services are available today, then we can prevent someone’s physical and mental health deteriorating in the future, representing considerable savings to government. A defining feature of a compassionate society is how we deal with those least able to help themselves but, at least in the current political context, economic arguments tend to hold stronger weight than moral imperatives.

For these and other reasons, it is absolutely appropriate that the scheme includes people who experience a psychosocial disability related to mental illness. However, the Mental Health Council of Australia (MHCA) has strong concerns about the implications of the scheme for mental health consumers, carers and service providers. These concerns relate to the design of the NDIS, the status of existing services, and the likely impact on future mental health programs.

This article outlines the current challenges for the scheme’s designers and provides some suggestions on how to resolve them.
Eligibility

Under the NDIS legislation, in order to qualify for an individualised package of support, a person must have a ‘permanent impairment’. While permanency may be a meaningful concept for some kinds of disability, in the context of mental illness it is less clear. Most people with psychosocial disability have needs (and impairments) that fluctuate in severity and in nature over their lifetimes, and it is often difficult or impossible to predict which people will need long-term support and who will exit the ‘system’ and when.

With this in mind, the MHCA is very concerned about the implications for the very large numbers of people who experience mental illness who will not be eligible for the NDIS because they are not deemed to have a permanent impairment, or because their disabilities are not deemed sufficiently debilitating.

The MHCA doubts that the permanency principle currently embedded in the scheme can be reconciled with these realities. Feedback from the launch sites indicates that these requirements are already causing confusion.

If someone with a serious mental illness does not qualify for an individualised package of support, it is not yet clear how the NDIS will benefit them. On the contrary, current indications are that people who fall into what the NDIS calls Tier 2 participants (those who don’t have a confirmed ‘permanent’ impairment) will need to rely on existing systems of referral and support, the very systems that are currently under-resourced and frequently ineffective.

In our current economic climate, many of these existing programs also appear to have uncertain futures as they are being absorbed into the NDIS through the current funding arrangements (see below for more on this).

Assessment

While the NDIS legislation stipulates that someone must have a permanent impairment to be eligible for an individualised package of support, the mental health sector has little information about what this means in practice. Almost uniquely among many kinds of disability, psychosocial disability associated with mental illness is often episodic in nature and can result in fluctuating needs not only over a lifetime but over the course of weeks and months.

One person’s support needs may not be immediately obvious at any point in time, but may nevertheless be ongoing, while someone else’s needs might be quite apparent while not necessarily being ‘permanent’ (depending on how permanent is defined). For these and other reasons, the outcomes of assessment may be different depending on when and how it occurs and who is able to contribute to it.

With these challenges in mind, it is crucial that the assessment process incorporates three features if it is to adequately cater to people with psychosocial disability.

First, the process must involve carers, families, service providers and other support people to the maximum extent possible. Relying solely on conversations between consumers and NDIA assessors to determine the nature and extent of consumers’ long-term needs is not sufficient.

Second, any tools used to conduct assessments must be designed specifically for people with psychosocial disability related to mental illness, rather than being adapted from tools used for other kinds of disability. The launch sites will tell us quickly whether or not the tool currently being used by appointed National Disability Insurance Agency (NDIA) assessors is appropriate in this regard.
Understanding the needs of someone with psychosocial disability requires specialist skills and the ability to develop trust with consumers, carers and service providers. We must ensure the expertise of the mental health workforce is not lost or dumbed down.

Third, assessors conducting assessments must be trained and experienced in mental health issues. Understanding the needs of someone with psychosocial disability requires specialist skills and the ability to develop trust with consumers, carers and service providers. We must ensure the expertise of the mental health workforce is not lost or dumbed down.

Programs in scope for the NDIS

Agreements have been reached between the Commonwealth and state and territory governments about which existing mental health programs – and what proportions of their funding – are ‘in-scope’ for the NDIS. These decisions were made without any consultation with the mental health sector.

If replicated nationally, decisions about in-scope programs are likely to lead to reduced services for large numbers of people with serious mental illness who are ineligible for the NDIS. Given the high levels of unmet need and well-established under-investment in mental health in all jurisdictions, the MHCA is deeply concerned that the introduction of the NDIS could exacerbate rather than ameliorate the problems that people with mental illness currently have in accessing timely and effective services in the community.

The mental health sector and the broader Australian community need assurance that future mental health consumers and carers will not miss out on services, leaving them worse off, as an unintended consequence of a major initiative originally intended to deliver more support. If this were to come to pass, much of the mental health system would resemble an oasis in the desert, with the majority never reaching the safety of the watering hole.

Early intervention

Many of the mental health programs that are currently in-scope for the NDIS appear to deliver services that provide ‘early intervention’ rather than ongoing or life-long support. While these programs fund services for people with permanent illness/disability, they are usually not life-long solutions. Rather, they are often temporary (and even crisis) interventions to help people manage or overcome negative emergency circumstances that could rapidly escalate.

The fact that a person needs to have a permanent impairment before receiving early intervention (which will in turn reduce that person’s reliance on the service system in the future) is profoundly counterintuitive. Indeed, if early intervention services are reduced from existing levels, we will certainly see a greater burden on the service system, including additional presentations at emergency departments, increased reliance on crisis accommodation services and a greater risk of people with mental health issues encountering the criminal justice system. In the context of an insurance scheme which ought to reduce future risks, these arrangements appear misguided.

We need to see the development of a definition of early intervention from the perspective of psychosocial disability. Such a definition can only be developed in close consultation with stakeholders in the mental health sector who have an intimate understanding of the nature of effective non-clinical early intervention services.

Possible solutions

These issues are manageable if governments and the sector remain committed to finding solutions. Below are some thoughts on how we can begin the process, but many more ideas will be needed to reach a final destination that meets the needs of people with psychosocial disability and those of their carers.
Scheme design
The highest priority for governments right now is to formally commit to maintaining or increasing existing funding and levels of service for current and future consumers of mental health services, regardless of whether those consumers are deemed eligible for the NDIS or are accessing existing mental health services.

Policy development
Adequately addressing the issues will require significant work on the part of governments, with close and meaningful engagement and consultation with all relevant stakeholders. A formal process is needed to advise governments on how to best meet the needs of people with psychosocial disability. Whatever structures are established, they must involve a range of stakeholders including the non-government mental health sector, as well as carers and consumers, if the eventual solutions are to be meaningful and credible.

Evaluation and monitoring
Governments need to involve mental health stakeholders to a much greater degree in monitoring and evaluating how well the NDIS meets the needs of people who experience psychosocial disability. This engagement should include, at a minimum, an early warning system to identify and act on problems well before the formal evaluation of launch sites is complete, and a robust process to identify the extent and nature of unmet need and the barriers to those needs being addressed.

Conclusion
The mental health sector stands ready to assist governments to realise the possibilities that the NDIS represents. The scheme has the potential to correct historic injustices and to meet Australia’s obligations under the United Nations Convention on the Rights of Persons with Disabilities. Mental health consumers, carers, along with service providers and non-government organisations, must be at the centre of the scheme’s development if it is to meet community expectations.

We must all acknowledge that implementing such a major initiative will take many years, and that all stakeholders are working hard to make the NDIS a reality. However, implementing a scheme without first getting the fundamental design features right may lock in a set of practices and principles that will not benefit the majority of people with serious psychosocial disability relating to mental illness.

By offering governments our assistance in good faith, we hope to work with them and the sector to ensure that people receive care and support appropriate to their needs, regardless of their path through the many systems (NDIS or otherwise) that someone with a mental illness may encounter over a lifetime. Together, we can help build a scheme that meets this worthy goal.

...the MHCA is deeply concerned that the introduction of the NDIS could exacerbate rather than ameliorate the problems that people with mental illness currently have in accessing timely and effective services in the community.
new paradigm
VOX POP
Our *vox pop* further explores the benefits and risks of the NDIS with key people in Victoria’s community managed mental health service sector, representing organisations working inside and outside the Barwon launch site.

What do you see as the main benefit the NDIS will hold for people with psychosocial disability?

**Arthur Papakotsias**: Choice, power and self-determination. Hopefully, people will get what they want and with whom, and can change when and if they are not happy with the service. Organisations will have to market and promote their services in a way which is understood and appreciated by consumers and carers.

**Peter Waters**: The NDIS builds consumer participation and rights into the system architecture, including individual funding that enables people with psychosocial disability to choose their service provider. Clients become empowered customers, and true person-centred supports become essential to service viability.

**Gerry Naughtin**: The NDIS will provide significant additional funding for people with psychosocial disability, greater choice in service provider and flexibility in how their funding can be spent.

**Elida Meadows**: Long term support, portable across Australia, life-long if required, and greater personal choice and control over the services people receive, to the benefit of the people directly affected and the people who care for them.

What is the greatest challenge in the implementation of NDIS, in relation to people with psychosocial disability?

**Arthur Papakotsias**: Ensuring that pricing structures and service design reflect recovery paradigms and the fluctuating needs of individuals: designing an insurance system that takes into account dual diagnosis, dual disability, complex needs and the needs of people who may have decision making impairments.

**Peter Waters**: Respecting how the life-changing supports delivered by Community Managed Mental Health (CMMH) services are informed by a sophisticated understanding of complexity. A whole-of-health approach is essential.

**Gerry Naughtin**: Bedding down the funding and administrative arrangements under the Abbott Government.

**Elida Meadows**: Dealing with impairments and support needs that fluctuate in severity and in nature over a person’s lifetime. Some of these needs are predictable; others are not and may not be identified through a single assessment. Lifetime assessment and care must include the input of consumers, carers and families and reflect the critical importance of recovery as the basis for working with mental health consumers.
“The NDIS will result in broader access to the economy and society for many Australians living with a disability, representing the fulfilment of their basic human rights and self-empowerment.” – Elida Meadows

What is the biggest challenge that Community Managed Mental Health (CMMH) services face under the NDIS?

Arthur Papakotsias:
The unknown! The current system is very different to the NDIS: organisations with a history and capacity to change and evolve are likely to fare better, as are those whose organisational culture is built to demonstrate the effectiveness of services.

Peter Waters:
The workforce challenges are significant, particularly preserving the current highly skilled workforce and recruiting and developing new quality staff in a competitive, market-based environment. Ensuring ongoing professional development occurs, including regular supervision, is vital to good services.

Gerry Naughtin:
Developing and delivering services and products that meet the preferences of participants.

Elida Meadows:
The biggest challenges so far are organisational and workforce readiness, including understanding that small organisations inevitably will need to partner with others or be pushed out of the spectrum of support.

What do you think will be the most significant result of the implementation of the NDIS?

Arthur Papakotsias:
I hope and trust it will be better outcomes for consumers and carers, a more responsive service system for consumers and a more efficient and integrated mental health service system.

Peter Waters:
The NDIS has the potential to provide people with access to, and choice of, the supports they require to achieve their goals. Progressive and innovative services will discover more and better ways to provide this support.

Gerry Naughtin:
More diverse service responses and the decline of the community mental health support service sector as a discrete service provider entity.

Elida Meadows:
Broader access to the economy and society for many Australians living with a disability, representing the fulfilment of their basic human rights and self-empowerment.