

**Report to the Board of the
National Disability Insurance Agency**

**Issues Paper - Implementing the NDIS for people
with disabilities related to mental health issues**

December 2014

By the Independent Advisory Council to the National Disability Insurance Agency

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EXECUTIVE SUMMARY

Purpose

In late 2013, the Independent Advisory Council (IAC) for the National Disability Insurance Scheme (NDIS) identified the issue of improving the Scheme's responsiveness to people with psychiatric conditions as a priority for its work in 2014. Over the past 12 months, the IAC has undertaken considerable work in listening to the views of consumers and family/ carer advocates and the mental health sector, building an understanding of how the trial sites are responding to applicants and participants with disability arising from mental health issues. Conclusions and directions outlined in this Report were also informed by the findings of a concurrent Literature Review "Mental Health and the NDIS" (August 2014). On this basis, the IAC has been considering the conclusions and directions outlined in this report and the operational and definitional issues in delivering the NDIS objectives and deliberating on possible options for improving the Scheme's responsiveness to people with disabilities associated with mental illness.

The IAC has considered these issues throughout its meetings in 2014. This report represents the outcome of those deliberations and was approved by the IAC at its December 2014 meeting.

Background

The inclusion into the NDIS of people with disabilities related to mental health issues occurred after the initial Scheme design. The mental health sector has been supportive of the inclusion of people living with a severe and persistent mental illness into the Scheme but has also advocated for further refinements to improve its responsiveness and strengthen participation. The National Disability Insurance Agency (the Agency) has been aware from its commencement, of the need to address some specific requirements and issues in relation to people with primary and secondary disabilities related to mental illness.

There have been a number of forums and discussions between the Agency and Mental Health Australia (MHA) and mental health service providers interested in the Scheme at national and trial site levels. The Board asked the IAC to give consideration to this issue, and subsequently the IAC has focused in its work plan on developing a better understanding the particular needs of participants who are eligible for the NDIS due to disability associated with mental illness. A range of initiatives have been commenced within the Agency to identify areas for improvement and build engagement with the mental health sector. In May 2014, the Agency appointed Eddie

Bartnik as a mental health adviser to the Scheme. In addition, Mental Health Australia (MHA) was given a sector development grant to address policy and practice development issues.

There is now sufficient trend data and information emerging from the trial sites to give some indications as to how the Scheme is responding to people with a mental illness. In its first 15 months of operation, 1,114 people with a disability related to mental illness have been found eligible for support. Of these, 752 participants recorded a mental illness as their primary disability and 362 with mental illness as their secondary disability. Most of these participants come from NSW and Victoria and are aged from 35 to 64 years of age.

Data from the trial sites indicates that ineligibility rates from access requests from people with primary mental illness that are significantly higher than other disability types with 1:4 applications requesting access due to primary mental illness being determined as ineligible compared to 1:9 for applicants across the rest of the Scheme.

The number of participants with disabilities related to mental illness in the Scheme to date is lower than projected by the Productivity Commission, and there is a need to understand the reasons for these trends. The data from the first 15 months of operation highlights the centrality of the issues raised in this report for the future of the Scheme.

While it is still early in the Scheme's implementation, and more detailed analysis is required, this report has found that those who are eligible are receiving additional levels of support and there appears to be reasonable levels of satisfaction with the operation of the Scheme. The fundamentals of the Scheme appear to be sound for people with disability associated with a mental illness but some refinement is required to maximise the Scheme's potential and minimise some risks that the Scheme is exposed to at this point. A major risk identified by the Council is that lack of national consistency across the trial sites in the assessment of severe and permanent disability due to mental illness and the determination of reasonable and necessary resources. The operating guidelines, funding items and Agency practices need to be tweaked and adjusted to improve NDIS responsiveness to the needs of people with disabilities associated with mental illness.

This report identifies a number of emerging issues that require more concerted attention by the Agency. It proposes that the adoption of an 'NDIS Mental Health Implementation Plan' would facilitate the Scheme reaching its full potential for people with disability associated with mental illness. This report offers ways forward for the Board and the Agency to address these issues and mitigate the risks associated with lack of attention to these matters.

There is enormous good will at Board, Agency, State and Territory Government levels, at Mental Health Australia and within the mental health sector to make the Scheme work as well as it can for people with disability arising from mental illness. Changes required are achievable within the current legislative and financial settings for the Scheme but will require concerted action and investment over the next five years. The changes required address definitional and operational issues and be readily addressed with clear and timely actions.

Proposed Way Forward

The IAC recommends that the Board considers the development of a five-year ‘NDIS Mental Health Implementation Plan’ as a statement of its directions and priorities in improving the Scheme’s responsiveness to people with disabilities related to mental illness.

It also recommends that the Board and the IAC are provided with an annual report card in October each year, concerning progress towards achieving the goals as set out in the implementation plan.

Committing to such a plan would assist the Agency to address these issues in a strategic focused and timely manner over the next five years.

The report identifies a number of key issues that the IAC recommends need consideration in the ‘NDIS Mental Health Implementation Plan’ and the proposed strategies to address these issues. This Executive Summary highlights five of these, which are outlined in the table below. These and other key issues are discussed in detail later in the report.

ISSUES AND PROPOSED RESPONSES

ISSUE	PROPOSED RESPONSES
<p>Definitions and guidelines on what constitutes severe and permanent disability related to mental illness</p> <p>Ineligibility rates for applicants with a mental illness are significantly higher than those resulting from applications from people with physical, intellectual and sensory disabilities. The reasons for this are unclear and need further investigation.</p>	<p>NDIA should build on-going capacity within the Agency to develop its own evidence-based working definition and guidelines on severity, permanency and episodic nature of disabilities related to mental health issues.</p>

ISSUE	PROPOSED RESPONSES
<p>Within the trial sites there is no consistent evidence base behind determinations or around the current definitions of severe, persistent and episodic disabilities for people with disabilities related to mental illness, and application appears to vary across state jurisdictions. This forecasts significant risk and predicts that the Agency may be subject to higher rates of appeal unless a consistent and evidence-informed approach is applied to the determination of severe and persistent impairment. The Agency must develop a position on determining permanency that encompasses ‘episodic’ and functional impairment as well as indicating ‘reasonable and necessary’ supports as a matter of urgency.</p>	<p>NDIA to establish a specialist mental health/ psychosocial disability team at the NDIS Head Office with deep understanding of disability and expertise in assessment of eligibility, reasonable and necessary supports and support planning and review for people with disabilities related to mental illness as well as mental illness and other disabilities, in particular intellectual disability and autism.</p> <p>This team to be led by a person with significant experience in both disability and community-based mental health service delivery. It is envisaged that a team of three to four people would be required to oversee and undertake the scope of activity.</p> <p>This work would be in addition to the work of the specialist adviser on mental health, Eddie Bartnik.</p> <p>This team to lead the work focusing on policy, guidelines, quality and practice development in regard to the Agency’s definition of permanence of disability related to mental health issues and provision of training, tools development and support, and advice on assessment of eligibility .</p>
<p>Building a nationally consistent approach to reasonable and necessary supports</p> <p>The available evidence suggests that judgements by Agency staff about what constitutes a ‘reasonable and necessary support’ required by people with disabilities associated with mental illness vary markedly between</p>	<p>That the Agency build the knowledge, evidence base, organisational practice and tools through its support and development of a specialist mental</p>

ISSUE	PROPOSED RESPONSES
<p>the Hunter and Barwon trial sites. In NSW, average committed supports for 25 – 64 year olds with primary mental health disabilities was around \$33,000 compared to \$20,000 in Victoria. Assessments of reasonable and necessary supports appear to vary markedly based on geographical location.</p> <p>In addition, significantly differing patterns of types of support committed have been found in NSW and Victoria. In NSW, a large amount of funding has been committed to supports for daily tasks / shared living and assistance with personal activities. In Victoria, a larger amount of funding has been committed to support for life skills, development and assistance with a life stage transition.</p>	<p>health/ psychosocial disability team as mentioned above.</p> <p>Monitoring the patterns of resource allocation between States/ trial sites and encouraging stronger peer review by Agency staff across States.</p> <p>Stricter use of better defined reference packages in the allocations of resources for support plans</p> <p>That the Agency explore the development of a validated Australian instrument for determining the severity and permanence of functional impairments and support needs for the NDIS target population.</p>
<p>Predicting future demand from people with disabilities related to mental illness and influencing future demand</p> <p>Young People: Future demand for NDIS funded supports from people with disabilities related to mental illness will be significantly impacted by the supply and effectiveness of clinical services to young people presenting with mental health issues. International evidence indicates that early intervention for young people with emerging patterns of psychotic behaviours can prevent or minimise long term functional impairments and disabilities.</p>	<p>That the Agency’s Scheme design staff, should develop a tool for the NDIA to track the level of services provided for this group by national programs such as Headspace and public and private youth and child mental health services.</p> <p>If services for young people with presenting psychotic symptoms are not adequate, the Agency should have an advocacy strategy to influence the Commonwealth, State and Territory governments for improved youth mental health services.</p> <p>Such advocacy could be an effective and low-cost early intervention strategy for the Agency.</p>

ISSUE	PROPOSED RESPONSES
<p>Funding of mental-health specific support items</p> <p>The NDIA support clusters and funded items provide the current basis for the funding of service packages. These clusters and items offer a broad range of support and equipment items for inclusion in support packages and the current list are appropriate for participants with disabilities associated with mental illness. However, there are several mental-health- specific support items that should be considered for approval on the support items list. These are funding for peer workers, life coaches and advanced independent living practitioners.</p>	<p>Additional support items for peer workers, life coaches and advanced independent living practitioners should be created for participants with disabilities associated with mental illness.</p> <p>That this issue be addressed by the Working Group already set by the Special Adviser, Eddie Bartnik.</p>
<p>Building participant capacity</p> <p>Many participants with disabilities related to mental illness, are able and should be expected to work towards building their skills and capacities in social and future economic participation. Support planning should focus on building skills and capacity amongst participants, consistent with insurance principles, even if they are not requesting such assistance to maximise their independence, employability and contribute to the financial sustainability of the Scheme.</p> <p>This ability to build skills and capabilities needs to be recognised and encouraged in participants' individual plans.</p>	<p>The recommended specialist mental health/ psychosocial disability team within NDIA Head Office should be given responsibility for building capacity development for participants with disabilities related to mental illness into operating guidelines and staff training for support planning staff.</p>

Impacts of funding and policy shifts in the mental health sector

The Council wishes to advise the Board of a significant policy and funding issue that is likely to become a major challenge and risk that will need to be carefully managed by the Agency next year (2015). The funding design for NDIA originally committed transition of funds from a range of Commonwealth-funded community mental health services. They include Personal Helpers and

Mentors (PHaMs), Partners in Recovery (PIR) and a range of other programs; some targeted at families and carers of people with mental health issues. It is difficult for the Council to identify exactly the level of funding involved, but our understanding is that it is in the order of \$800 million in forward estimates. Funding for these programs is scheduled to cease over the next 12 months with a significant number of contracts ending on June 30, 2015 unless there are further contract extensions. Many participants, staff and agencies will be affected. This is likely to become a public issue in the first half of 2015.

While this is an issue for Minister Fifield and the Department of Social Services to manage, we forecast that the Agency will be drawn into the debate for several reasons. First, some State and Territory Governments are assuming that (and advising consumers and agencies that) the NDIS will or should be inclusive of this group of participants who are currently receiving services. While this will generally be correct for users of the Partners in Recovery Program, current users of PHaMs and family mental health support services are unlikely to be eligible under the severe and persistent criteria in the NDIS guidelines. Significant numbers are likely to have access to these services withdrawn.

Second, the community mental health sector and some State and Territory Governments are concerned about the impacts of this change and the impacts on people who are currently receiving supports under these Schemes who will miss out. This may be an unintended consequence of the process of putting together the funding package for NDIS. Some in the sector consider that this funding problem requires the Agency to be flexible in responding to episodic functional impairments due to a mental health issue. This matter, will in our opinion, place pressure on the Agency in regards to its interpretation of severe and persistent impairments associated with mental illness. This report has identified a lack of national consistency and the need for the Agency to strengthen its eligibility criteria and practices in the determination of severe and persistent disabilities associated with mental illness. The IAC consider that this issue may emerge as a significant issue in 2015 that the Board needs to be aware of and carefully manage. It has the capacity to do reputational damage to the Agency if this does not happen. We understand that our Chief Executive, David Bowen has recommended that the Department extend the contracts for PHaMs and family mental health services, which would be a sensible resolution to this issue. The problem is compounded by states such as Victoria who are shifting all their current funding for mental health community support services into their contribution to the NDIA and leaving no recurrent funding to meet their obligations under the COAG 2012 agreement to deliver recovery and rehabilitation services to people with mental health issues. The community mental health sector is rightly arguing that funding arrangements for NDIS are resulting in a significant reduction in community mental health services. Our advice is that this is a

Commonwealth, State and Territory policy and funding issue, yet the Agency may be drawn into this it.

The Independent Advisory Council considers that the adoption of a “Mental Health Implementation Plan” that includes the elements recommended in this report, would allow the Agency to build its responsiveness to the specific needs of this participant group, build its technical capacities in eligibility assessment and planning support and manage participant and community expectations of the Scheme for people with disabilities associated with a mental illness.

We commend this report to the Board.

1. INTRODUCTION

The inclusion of people with disabilities due to mental illness into the National Disability Insurance Scheme is a significant step forward in social policy and heralds much needed support for a population group whose needs have been inadequately met in the past. This group was projected to constitute between 10% and 15% of the participants in the Scheme and is therefore a significant sub-population of the Scheme. The inclusion of people with disabilities arising from mental health issues into NDIS occurred after the initial scheme design and had strong support amongst all State and Territory governments and community groups during the NDIS Consultations in 2012. This report starts from the principle that the Federal Parliament and State and Territory Governments have defined the frameworks and the principles for the treatment of people with disabilities associated with mental illness (PDMI). It starts from the premise that there are some distinct needs and requirements of this group and that the task of the NDIA is to make the Scheme work as effectively and efficiently as possible for this participant sub-group. The purpose of the trial period of the Scheme is to learn, adapt and develop and this report is a significant contribution to this important phase of the Scheme.

The IAC has identified the need to give consideration to improving the responsiveness of the Scheme to people with disabilities related to mental illness. As part of its work plan, it commissioned two of its members with expertise on mental health and psychosocial disability related to mental health issues, Gerry Naughtin and Janet Meagher AM, to prepare a paper on the key issues for the Agency to consider in implementing NDIS for people with disabilities related to mental health issues. This work was undertaken through conversations and discussions with fellow Council members, critical reflections on presentations and discussions with staff from the Agency, selected experts and people in the mental health sector, and Mr Eddie Bartnik, the Strategic Advisor to the NDIA on mental health and psychosocial disability and Ms Sarah Johnson, the Scheme Actuary.

As part of this report's development, a literature review was commissioned by Mind Australia and the IAC and undertaken by the Centre for Mental Health, School of Population Health, and University of Melbourne with input from Mind staff.

The literature review addresses eight key topics:

1. The concept of 'permanent' impairment and its usage elsewhere, including existing rules set by other schemes and their application in practice in determining appropriate supports and whether impairment is considered permanent.

2. The likelihood of ‘permanence’ of certain forms of mental illness and the possibility of predicting the long-term course of a particular disorder for a particular individual.
3. The concept of ‘reasonable and necessary’ supports for people with psychosocial disability and how this is used and applied elsewhere.
4. The impact of psychosocial disability arising from mental illness on individuals and the evidence for the nature and extent of psychosocial impairment and its implications in terms of functional impairment.
5. Preferences for support of people with a psychosocial disability arising from mental illness, in relation to the categories of activity in which an individual may experience impaired psychosocial functioning.
6. Common supports used by people with a psychosocial disability arising from mental illness.
7. Gaps between the support preferences of people with a psychosocial disability arising from mental illness and existing services in Australia.
8. The evidence for the effectiveness of different supports, and limitations of that evidence in relation to people’s preferences.

The reviewers set out to consider the evidence on the nature of the disabilities that occur because of severe and persistent mental health issues. The literature review has helped form some of the judgements and perspectives presented in this report and will be made available as a separate resource for the Council, Board, Agency, and the mental health and disability sectors.

In this report we consider the issues and propose a set of actions to assist the NDIA/NDIS to be more informed and responsive to the specific requirements of the participant group in question. The IAC recognises the scale of change that the NDIS represents for people with mental health issues and mental health and primary care services. Notions of individualised funding, choice and control are new to many people with significant mental health issues, who have often had none or very limited choice let alone control in their history of seeking support with their mental illness or support needs. The state of readiness of this population group for NDIS is lower than in the community of people with physical, intellectual and sensory disabilities. There are some specific barriers to access for this population group that need to be addressed.

This report is structured around the issues that the IAC has identified in its analysis. Each of these themes has a brief description, followed by a discussion and suggestions of possible ways forward to address the issue for consideration by the NDIA Board. The IAC acknowledges that some of these recommendations may require further discussion and sector engagement in their implementation.

The IAC acknowledges that it is still early days in the Scheme and that the available data is still preliminary. Some of the judgements formed in this report will need to be refined and developed based on the data and feedback that will become available over the next few years.

This report provides advice to the Board of the National Disability Insurance Agency on strategies for improving the responsiveness of the NDIS to people with disabilities related to severe and persistent psychiatric conditions.

The final point that needs to be understood as part of the context for this paper is the use of the terms related to mental illness. The NDIS Act defines eligibility on the basis of one or more impairments attributable to a psychiatric condition that results in substantially reduced functional capacity in relation to communication, social interaction, learning, mobility, self-care and self-management. This language has been unfamiliar to many consumers and practitioners and resulted in some confusion about entitlement in the broader community from the outset. Current language used by many consumers and their families and carers, as well as service providers, includes terms such as “mental health”, “mental health issues”, “mental illness” “recovery”, “rehabilitation” and “mental ill-health”. Developing a shared understanding of the terms used and a shared language will become more important over time. One example is that the NDIS Act relates “disability” to “impairment in relation to psychosocial functioning”. For many people the term “psychosocial disability” is the preferred term as much time has been spent on developing a clear definition. For the purposes of this paper “psychosocial functioning” equates to “psychosocial disability” which is defined as:

“Psychosocial disability is a term to describe the disability experience of people with impairments and participation restrictions related to mental health conditions. These impairments and participation restrictions include loss of or reduced abilities to function, think clearly, experience full physical health and manage the social and emotional aspects of their lives.”

A psychosocial disability is one that arises from a chronic “mental health issue that affects people’s daily activities such as socialising or interacting with others in a social setting, learning or self-care, or their capacity to fully participate in society^j” and is present over an extended period of their life span.ⁱⁱ”

In this report we have tried to use the same terms that are used in the NDIS Act but at times, and in particular in relation to discussions about the sector and Tier 2 services, the preferred language

of the sector is used due to its more inclusive scope. The intent is that the terms are considered to be interchangeable throughout this report.

The authors wish to acknowledge the assistance, support and advice of Agency staff during the preparation of this report. In particular, we wish to thank Ms Liz Cairns, Chief Operating Officer, Mr Eddie Bartnik, Special Adviser to the NDIA, Ms Sarah Johnson, Scheme Actuary and Ms Alex Madsen from the NDIA Governance Section. We also acknowledge the significant contribution of Mr Ben Kite, a senior policy adviser working with Mind Australia on the preparation of this paper.

2. KEY ISSUES

This section considers twelve design and operational issues that need to be addressed and monitored in implementing the NDIS for people with disabilities related to a psychiatric condition. These are:

- Interpreting permanency
- Assessing of the degree of impairment
- Defining reasonable and necessary supports
- Responding to participants' fluctuating needs
- Developing, supporting and utilising individual support plans
- Preventing demand – monitoring of youth and child and adolescent mental health services
- Building participant capacity
- Less informal support
- State and Territory Governments' role in the provision of community rehabilitation and recovery-oriented services
- Development of Tier 2 services – to address dependence issues
- Requirement for information and knowledge
- Funding of mental health specific support items
- Sector engagement

For each of these issues, the paper outlines a brief description of the issue, followed with a discussion and suggestions of possible ways forward.

2.1 Interpreting permanency

What is the issue:

It is apparent that consistent determinations of ‘permanency’ of disability are hard to arrive at under the current assessment processes. One of the objectives of the NDIS Act is to ensure the provision of a nationally consistent approach to access, planning and funding of supports. Our observation is that there are significant variations across the pilot sites in the assessment of eligibility. This lack of consistency is compounded by definitional ambiguities in the NDIS. Anecdotal reports and preliminary data indicate a higher rate of ineligibility rulings on access requests from people with psychiatric conditions compared with other participant groups. One in four applications based on a disability associated with a psychiatric condition are being ruled ineligible by the Scheme as compared with one in nine across the Scheme. In addition, there are a significant number of access requests lodged in the system have not been followed through by applicants. The reasons for this variation require further examination and need to be considered in the broader context of interpreting the criteria of severe, persistent and episodic functional impairments for this population group.

Discussion:

The requirement of the NDIS Act that impairments be permanent or likely to be permanent in order for a person to be eligible for the scheme creates particular challenges in relation to disablement arising from psychiatric condition. The difficulty is that the NDIS Act provides no definition or clarification of the concept of permanence to assist in implementation and there are not Australian or internationally accepted benchmarks upon which to base determination of the permanence criteriaⁱⁱⁱ. To be eligible for the NDIS the disability impairment needs to be permanent, yet the Act does not define permanence and recognises the episodic nature of mental illness. This situation may result in unintended and inconsistent access to NDIS. The Agency needs to move towards its own working definition of permanency.

For people with an impairment related to a psychiatric condition the definition of permanence is made more difficult by the episodic nature of psychiatric condition^{iv}. The NDIS Act and the operating guidelines recognise the episodic nature of mental health issues. This is positive for participants but makes the assessment task more difficult. The complexity of the definitional task for this population is also being recognised in other areas of social policy. The McClure Report proposes a firmer distinction between ‘permanent’ and ‘episodic’ disability for the purposes of access to the Disability Support Pension (DSP) but does not offer any guidance about how this might be achieved. Developments emerging from this report will need to be closely monitored given the potential interaction between the DSP and NDIS. In addition it needs to be appreciated

that for people with mental health issues, functional impairments can be cumulative and on-going even when the symptoms of the psychiatric condition are not on-going or permanent. That is, the disability can continue even when the symptoms of the condition are not active or present. Greater weight must be given to functional impairment than diagnosis in the determination of disability permanence.

The National Disability Insurance Scheme has been designed around the principle of entitlement to support. Such entitlement will ensure that those Australians with a disability who meet the criteria for inclusion in the Scheme receive the supports they need so they can participate in the social and economic life of our community. This is a significant shift in emphasis from the previous arrangements which were predicated on the basis of provision of disability supports through a budgeted amount of funding unrelated to demand.

The principle of entitlement is fundamental to the Scheme's success. This principle of entitlement needs to be retained in the current debates on the size of the Tier 2 and Tier 3 population groups and in debates about language, terms and possible meanings. The experience of insurance schemes elsewhere suggests that effectiveness may be subject to escalating costs as more people draw on the scheme and/or it is required to fund greater levels of support. In some circumstances, tightening eligibility then becomes a mechanism for managing costs.

It is important to note that not all mental health consumers will develop a psychosocial disability and require support to participate in the community even if they have a diagnosis of a major mental illness. Despite their diagnosis many will achieve a quality of life that enables their social inclusion. Some people require supports intensively and continuously and others will require supports only episodically^v. Even amongst those who have severe and persistent mental health issues, there will be a number whose experiences leave them with mild impairments but remaining capable rather than disabled by their experiences. For this reason psychosocial disability can be a vastly differing experience, with diverse impacts, degrees of severity and varying outcomes even from within the same diagnostic groups and will fluctuate in its intensity over time^{vi}. The only valid process will assess functional impacts.

The practical challenge will be in making reliable assessments of the permanence and significance of a person's impairment. The current process for the determination of permanent or lifelong disabilities draws from a range of sources of information in making a determination. These include the expressed needs and preferences and information provided by the applicant, clinical assessments of diagnosis and judgements about functional impairment, historical service usage data, information from family members and service providers. A standardised assessment process and tool (SNAT) is used by the Agency to collate available sources of information and professional

judgements in their determination of permanence. This tool is not a tested or validated instrument and there is an inevitable level of subjectivity and variability to the judgements made by Agency staff and the external clinical and functional judgements upon which they rely. As the literature review has shown, there is no direct correlation between disease diagnosis and the level and permanence of functional impairments. The Agency guidelines put considerable weight on diagnosis of psychiatric condition in the determination of eligibility. Our report suggests that stronger weight needs to be given to the permanence and variations in functional impairments, to social factors and individual variability in dealing with functional limitations in the determination of eligibility.

Use of this type of assessment is also highly dependent on the skills of the assessor and in the case of people with a disability related to a psychiatric condition the assessors' knowledge of disability and of psychiatric conditions. As the method is subjective the assessors require exposure to and a strong knowledge of psychiatric conditions.

Such a person-centred approach to assessment of permanency and hence eligibility is a reasonable response that reflects a number of aspects of good assessment practice. However, the outcomes of this approach need to be carefully monitored over the next 2 years to assess the consistency of approach across the trial sites, the way in which assessments are responsive to episodic presentations of mental illness and how accurate the external assessments of permanence are. The judgements about permanency and hence eligibility for people with a disability related to mental health issues will be subject to appeal at the Administrative Appeals Tribunal. The Agency needs to have an evidence based rationale for its approach to the assessment of eligibility for this participant group to respond to such appeals.

Practice in relation to definition of severe and permanent and episodic have been developed and refined in each of the trial sites. Our observations, confirmed by some Agency staff is that the definitional issues are complex and Agency staff make their best endeavours to interpret the available assessment reports. Some staff undertaking such assessment either do not have experience in working with mental health clients and interpreting technical assessment data or have a purely clinical diagnostic approach. The Agency approaches rely heavily on external clinical reports/assessments of the disease rather than permanency of the disability for people with mental health issues. The difficulty with a reliance on such assessments is that many of these reports are based on an assessment of diagnostic characteristics rather than functional impairments.

The literature review undertaken as part of this report identified this as an issue experienced by a range of insurance schemes with no simple or obvious solutions. The matter has been addressed

in a number of ways including: clinical assessment requirements; duration of disability requirements; the degree of functional impairment caused by the disability and; the likelihood that the disability and functional impairment would continue into the future, which may be based on predictors of illness course and outcomes. This is a complex technical issue and an area of vulnerability for the Agency unless it develops its own working definitions and criteria of permanency of disability and development of tools to support people with mental health issues for use by both its own staff and staff in external agencies making judgements about the assessments upon which it relies.

Possible ways forward:

There is a need to work purposefully to address these issues. This work also requires the development of preferred changes in operational guidelines and language as well as the implementation of such changes over the next 2 years. The scheme needs to transition to a more nationally consistent approach and such consistency will require clearer guidelines in the interpretation of severe and permanent and take into account variations in intensity and support over the participant's lifetime. The Agency needs to build its technical capacity on this issue. The IAC recommends the following strategies to address this issue:

- The creation of a specialist mental health/ psychosocial disability team at the NDIS Head Office with expertise in assessment of eligibility, reasonable and necessary supports and support planning and review for people with disabilities related to mental illness as well as mental illness and other disabilities, in particular intellectual disability and autism.
- The development by the Agency of its own evidence-based working definition guidelines and tools to determine severity and, permanency and respond to the episodic nature of disabilities related to mental health issues.
- The promotion by the Agency of its working definition of permanence of disability related to mental health issues within the Agency and an undertaking to provide training on the determination of permanency to assessment and support planning staff.
- Publicise these working definitions and operational guidelines to staff and agencies in the mental health and primary health care sectors.

2.2 Assessment of the degree of functional impairment

What is the issue:

To be eligible for the NDIS, in particular, Tier 3, the disability impairment related to a psychiatric condition needs to result in substantially reduced functional capacity, in one or more of six areas. The determination of reduced functional capacity is a complex matter and there are no widely adopted guidelines to help frame consistency. Assessment reports are often based on diagnostic evaluations and criteria and not on functional assessments. The Agency has no validated and hence consistent way to determine substantially reduced functional capacity for people with a disability impairment related to a psychiatric condition which has potential to result in inequitable access to NDIS.

Discussion:

The literature review found that severe mental illness more often than not results in some level of disability and that functional impairment can occur in most facets of daily life including the ability to work or study, socialise and take care of a home. It found that social and occupational functioning seem to be particularly impaired and as a result, people with severe mental illness are often unemployed, single and socially isolated. The level of disability varies between people with a mental illness, but also within the individual with a mental illness over time, depending, in part, on fluctuations in the severity of symptoms at any particular time and the types of symptoms experienced. The findings from the literature suggest that resultant psychosocial disability can be persistent and enduring, lasting for decades. While functional impairment can decrease if symptoms remit, people with a mental illness most often continue to experience some level of functional impairment in a variety of areas, even if their symptoms are no longer seen at a 'clinical' level. One of the primary reasons that people with a mental illness experience an impaired ability to function in aspects of their everyday lives, even when symptoms of the mental illness have improved, is because they experience cognitive impairment, such as difficulties in processing and remembering information.

The disability requirements of the Act largely focus on functioning and participation. This approach is consistent with that of the World Health Organisation (WHO) International Classification of Functioning, Disability and Health (ICF). However, it does not offer an adequate tool for the assessment of functional impairments common with most mental health issues. The WHODAS v2 has come out of the WHO work on the international classification of functioning and does offer a practical instrument for the assessment of the level of difficulty for this group but does not point to the level or type of support assistance required. Reliable instruments exist in some disability areas (such as the Care and Needs Scale for ABI) to provide professionals with clear

guidelines for the determination of impairments and support requirements. However, there are currently no commonly accepted and used instruments for assessing functional impairments and indicating support needs related to disability due to a psychiatric condition. The provision of such an instrument would provide the NDIA and the mental health sector with clearer guidance and a validated tool for the assessment of functional impairment. Such an instrument may also contribute to the financial sustainability of the Scheme. Some of the leading world experts on ICS and WHODAS are based in Australia and have the knowledge and capacity to develop an appropriate instrument.

In the absence of an instrument for accurately assessing functional impairment and support needs associated with a psychiatric condition, careful consideration needs to be given to the range of evidence available to determine functional capacity. Until a robust instrument can be developed, or adapted from existing instruments, careful and regular review is needed of the variety of ways in which eligibility and support needs are being determined and how consistency of approach is being achieved across the trial sites. Such an instrument could reduce review costs and provide more consistent assessments.

Possible ways forward:

- As per 2.1.
- That the Agency explores the development of a validated Australian instrument based on ICF/WHODAS for determining severity of functional impairments and support needs for the NDIS target population.

2.3 Defining reasonable and necessary supports

What is the issue:

The observations and discussion about assessments suggest that judgements by Agency staff about the reasonable and necessary supports required by people with disabilities associated with mental illness vary markedly between the Hunter and Barwon trial sites. In NSW, average committed supports for 25 – 64 year olds with primary mental health disabilities was around \$33,000 compared to \$20,000 in Victoria. Assessments of need appear to vary markedly based on geographical location.

In addition, significantly different patterns of types of support committed have been found in NSW and Victoria. In NSW, a large amount of supports have been committed for daily tasks / shared

living and assistance with personal activities. In the Victorian site, however a larger amount of support has been committed for life skills, development and assistance with a life stage transition.

The reasons for this are complex and needs to be further understood. We have observed that NSW and Victoria have had different approaches to community mental health support and this may be reflected in the assumptions and judgements of assessment and support planning staff. Each of the trial sites has been developed in response to the requirements of the pilot region and inter-sites comparisons are only commencing. These variations in the patterns of assessment of what constitutes reasonable and necessary supports is quite stark and suggests that the interpretation of operational guidelines by staff within the trial sites is also impacted by professional cultural influences and individual staff assessments of what might be reasonable and necessary. The financial and operational challenge over the next few years is to achieve stronger national consistency and a more consistent application of an evidence base to resource allocation judgements. Such practice development is essential if the “entitlement charter” of the Scheme is to be consistently applied for people with disabilities associated with mental illness.

An evidence base for the determination of “reasonable and necessary supports” will prove to be an important tool for fair and equitable resource allocation of a disability support scheme of the scale of the NDIS. However, there are no empirical markers of what are ‘reasonable and necessary’. The leading study on such markers in mental health, the National Mental Health Planning Framework has not been released publicly. The challenge is to develop some more objective markers of reasonable and necessary supports for people with disabilities related to a psychiatric condition and use these to ensure a more nationally consistent and cost-effective approach to NDIA allocation practices and to help frame participant expectations will be available based on groups of needs.

Discussion:

Decisions about what constitutes reasonable and necessary supports are central to the operation and financial sustainability of the Scheme. While there is considerable research on the supports used and required by people with disabilities related to psychiatric conditions in Australia^{vii} there are no empirical markers of what are reasonable and necessary supports for people with disabilities related to psychiatric conditions. The NDIS Act 2013 identifies the following criteria of what is reasonable and necessary: support to pursue goals and aspirations, social and economic participation, value for money, likely to be effective and beneficial for the participant, incorporates reasonable expectations of families and carers, supports appropriately funded through NDIS and supports that should not be funded because they should be funded through other service systems. These criteria are aspirational, provide a broad basis of what is reasonable

and necessary and individual elements may conflict with other elements. Assessors need to balance up each of these elements and the wishes and preferences of the participant in forming an opinion about what is reasonable and necessary.

For people with a psychiatric condition the level of functional impairment varies between individuals and also within an individual over time. Individual functioning will change due to the episodic nature of psychiatric conditions, severity of symptoms and the types of symptoms experienced. One of the primary reasons that people with a psychiatric condition experience an impaired ability to function in aspects of their everyday lives, even when symptoms of the psychiatric condition have improved, is that they can experience cognitive impairment, such as difficulties in processing and remembering information. There is also a range of symptoms and conditions that may complicate the assessment of functional impairment and the subsequent support requirements. These include conditions such as anosognosia (the vehement denial of the presence of psychiatric issues), demotivation and social presentations that are sometimes dysfunctional, bizarre or distressing and complicate the determination of need. In addition many participants with a disability related to a psychiatric condition will not have family members, carers, informal networks or community members who can reasonably be expected to assist in the provision of informal support.

Funding and provision of NDIS support needs to take account of what it is reasonable to expect families, carers, informal networks and the community to provide. Yet the nature of severe and persistent psychiatric conditions can create a heavy strain on relationships between people with mental health issues and their families and carers and other informal supports. Emotional burnout is common, and people who have had severe and persistent psychiatric conditions over a long period of time may lose contact with their families entirely, becoming highly isolated. People with similar 'starting points' can experience very different outcomes over a period of time because of differing levels of informal support.

This means that many participants with a disability related to a psychiatric condition will not have family members, carers, informal networks or community members who can reasonably be expected to assist in the provision of informal support. This group commonly experience social isolation with a large percentage living alone, having few or no friends, and experiencing high levels of unemployment^{viii}. The implication of this reality is that NDIS planners may not be able to expect the same level of informal support from families and carers than may be reasonable in other population groups. This factor needs to be recognised and factored into the funding of individual support plans and the assumptions underlying reference packages.

The literature review identified that relatively few Australian and international public insurance schemes use the terms 'reasonable' and 'necessary' support or any similar concepts in determining appropriate support services for intended beneficiaries. Where the terms 'reasonable and necessary' are used they tend to refer to the use of evidence-based treatments and supports with demonstrated efficacy in promoting recovery or rehabilitation for a particular disorder, the cost-effectiveness of that intervention, and the delivery of the intervention by an appropriate practitioner for only the duration that the intervention has an ongoing benefit. The needs of the individual and resulting payment of benefits are often determined using an assessment of the disorder and resulting impairment, and of the individual's personal needs. Such assessment focuses on the type and severity of the disorder(s) experienced, the complexity of the impairment and individual characteristics of the person such as their aspirations, goals and needs. In determining the level of benefit to be received to provide reasonable and necessary supports, a variety of approaches are used, including clustering of disorders that attract a particular level of payment, placing upper limits on payments made for particular types of services, and use of available historical service use patterns.

Support requirements are influenced by a range of factors including personal, structural and social circumstances. For people with a disability related to psychiatric conditions functional impairment can occur in most facets of daily life including the ability to work or study, socialise and take care of a home. There is a level of complexity of assessing functional impairment and the corresponding reasonable and necessary supports in activities such as social interaction and self-management for people with a disability related to psychiatric conditions.

NDIS is using reference packages to cluster support needs, expenditure and clusters of services required. This has been done because of the lack of validated and acceptable instruments, the focus on choice and control in the legislation and the need to build an adequate Australian data base to demonstrate a picture of what is reasonable and necessary. There is a diverse suite of issues in the interpretation of what is reasonable and necessary from a participant, family, Agency staff and service provider perspectives. For example, is it reasonable and necessary to provide taxi services for transportation rather than the costs of public transport usage? There is a trade-off between choice, cost and efficacy in the determination of reasonable and necessary.

The approach adopted by the Agency is consistent with the Act and the use of reference packages is a sensible and practical method for building a picture of assessed and preferred judgements of reasonable and necessary. The approach moving forward in the determination of reasonable and necessary for people with disabilities related to psychiatric conditions should build on a person centred approach and respond to individual needs and circumstances while recognising and adjusting for standardisation of need over time. The development and continued use of reference

packages should be encouraged and consideration should be given to publishing the outcomes of reference packages, when more reliable package data is available. The ICF and its domains provide a solid framework for defining the elements of reasonable and necessary. It is reasonable for the Agency to start to define what it considers is reasonable and necessary on need and cost grounds and to acknowledge that choice and control has limits. It is also reasonable for the Agency to publicise its guidelines about what is reasonable and necessary and such guidance can be helpful for participants and their advocates and Agency staff.

Possible ways forward:

- As per 2.1 and 2.2.

2.4 Funding of mental-health specific support items

What is the issue:

The NDIA support clusters and funded items provide the current basis for the funding of service packages. These clusters and items offer a broad range of support and equipment items for inclusion in support packages and the current list are appropriate for participants with disabilities associated with mental illness. However, the IAC considers that there are several mental-health specific support items that should be considered for approval on the support items list. These are funding for peer workers, life coaches and advanced independent living practitioners.

Discussion:

In Australia, there is strong experience and evidence base for the effectiveness of three specific support roles that are not specifically covered in the NDIA support items list - peer workers, life coaches and advanced independent living practitioners.

The use of a key worker or support worker with a minimum Certificate IV in Mental Health qualifications and the skills to effectively engage and work with participants has been proven to be a successful approach to effective support. This approach has been based upon a key worker who has a competency set that reflects the ability to assist with meeting a broad range of individual support goals; work with individuals who have a high level of complexity; and work effectively and safely in the context of psychiatric conditions. The nature of the product or service stream that has been developed in mental health is different to attendant care and to professional services. The minimum qualification that is regulated by State and Territory Governments is generally Certificate IV and higher level qualifications. While there may be scope to include some of the functions of life coaches and advanced living practitioners into existing support clusters, the IAC

considers that a review of the current clusters and individualised support items for participants with psychiatric conditions should be undertaken and consideration given to the addition of support items for peer workers, life coaches and advanced independent living practitioners.

Possible ways forward:

- That additional support items for peer workers, life coaches and advanced independent living practitioners be created for participants with disabilities related to mental illness.

2.5 Responding to rapid and significant variations in support needs

What is the issue:

The support needs of participants with a disability related to a psychiatric condition support needs may change quickly due to the rapid, episodic onset of mental illness symptoms. Support plans and review processes need to be designed to be able to respond quickly and flexibly to these changing needs.

Discussion:

For people with a psychiatric condition the level of functional impairment varies within an individual over time. Individual functioning will change due to the episodic nature of psychiatric conditions, severity of symptoms and the types of symptoms experienced. The episodic nature of mental illness symptoms may mean that more intensive supports may be required during a period of significant illness and then be able to be reduced again when the illness symptoms have subsided.

This means that consideration needs to be given to ensuring there is flexibility in the provision of NDIS supports to meet the fluctuating needs of this participant group. There is a range of possible strategies that could be put in place to ensure timely responses to such fluctuating needs. These include:

1. Planning for variations in support plans in advance, with all parts of the service system, when the participant has capacity and insight, could ensure that the Agency and support providers can respond quickly to changing needs and ensure that accountability and approval requirements are in place. Providing support plan staff with the flexibility to vary support levels quickly on a temporary basis based until a formal review is undertaken.

2. Streamlining variation approval processes to ensure they do not impede rapid responses to changing needs.

Possible ways forward:

- That the Agency reviews Operating Guidelines to ensure that policies and procedures are flexible enough to respond to rapid and significant changes in support needs.

2.6 Developing, supporting and utilising individual support plans

What is the issue?

Feedback is indicating that some applicants with mental illness are finding the process and timelines of the Scheme difficult to engage with. The notions of choice and control are new for many people and while engaging, some participants need more assistance in understanding the opportunities that NDIS can offer in their lives and the processes and stages in support plans.

Tracking and analysing the experience of participants with mental illness in relation to support planning and review would assist improving and refining these processes.

Discussion:

Developing an individual support plan with participants requires the ability to build a trusting working relationship with the NDIS participant that will facilitate an open discussion on goals and aspirations, strengths, abilities and opportunities for development, along with daily support needs. The development of a responsive support plan is an iterative process that is developmental in nature and needs to be able to adapt to fluctuating needs. Cognitive impairments, understanding of the Scheme and motivation to engage are all individual participant factors that can result in longer periods of time and more meetings and contacts in the development of a support plan. Our consultations are indicating that the staff of the Agency are working very constructively to build trust with participants allocating significant time to discussions on goals and how to achieve them. These realities for people with psychiatric conditions also mean that timing for assessment and support planning will take longer than originally scoped in the bi-lateral agreements. Investment of time in building planner-participant relationships, support planning and thorough review will result in better outcomes for the participant and reduced costs for the Scheme. It is important to recognise that the investment in good assessment and support planning is critical to meeting the financial sustainability of the Scheme and that hurrying or truncating these functions may lead to a lack of discipline on cost containment.

Our consultations have indicated that in the first 12 months of the Scheme, considerable developmental effort has gone into working closely with mental health and other services to build an understanding of the Scheme and the information requirements of the Agency in determining eligibility and negotiating consent issues. The Scheme is reliant upon good access to diagnostic and support needs information from clinical mental health agencies and rehabilitation and recovery oriented services. All of this work is resulting in the building of a solid base for support planning and comprehensive understandings of short and medium term needs.

A trend that we have noticed is the higher use of support plan coordination particularly in the setting up of support plans for participants with complex needs; some individual support plans may require support coordination to implement the plan. The feedback we have received indicates that Agency staff are using support coordination to negotiate complex and new service arrangements particularly in regard to accommodation. This level of support coordination appears to be higher than originally envisaged for the Scheme.

The experience of the Scheme so far appears to indicate that many people with mental health issues require not only a longer period of time in establishing a meaningful plan and in assistance in the initial stages of plan implementation, but also a longer period of time in fully utilising the resources in the agreed plan. For many participants their NDIS plan is resulting in a significant increase in supports than have been available through NSW and Victorian Government schemes. Understanding the scale of additional support funding available and the flexibility with which such funding can be used are new challenges for participants with disabilities associated with mental illness. This scale of opportunity and the time participants and families and carers may take to understand the new opportunities available may take more time and needs to be understood. This reality ought to be factored into bi-lateral agreements and operational guidelines.

Possible ways forward:

- Greater use could be made of interim or temporary packages on outcome and logistical grounds.

2.7 Predicting future demand from people with disabilities related to mental illness and influencing future demand

What is the issue:

Future demand for NDIS services from people with disabilities related to mental illness will be significantly impacted by the supply and effectiveness of clinical services to young people with

presenting mental health issues. International evidence indicates that early intervention with young people with emerging patterns of psychotic behaviours can prevent or minimise long term functional impairments and disabilities. Hence, an effective tool for the NDIA to track potential future demand is to track the level of services provided for this group by national programs such as Headspace and public and private youth and child mental health services. Stronger investment in such services will reduce demand for NDIA services over the medium and longer and will be a factor in Scheme financial sustainability.

Discussion:

Contemporary practice in mental health services shies away from using labels of permanent diagnosis and disability and focuses on effective clinical interventions and supports to help young people to deal with their mental health. Although the NDIS is formally open to everyone under the age of 65, in practice it will be difficult for young people with a disability related to a psychiatric condition to enter the Scheme because most young people will not receive a diagnosis of permanent disability due to a psychiatric condition until after a period of clinical treatment. In addition, young people will be reluctant to engage with the NDIS because they are unlikely to see their conditions and the impacts as permanent.

Young people with a disability related to a psychiatric condition will therefore largely be supported by mainstream services, particularly clinically based mental health services, during the early years of their condition. Young people's engagement with mental health services is often poor - it was estimated that in 2007 only 31 per cent of young women and 13 per cent of young men with a mental health problem had sought professional help^{ix}. Some levels of the disabilities associated with psychiatric conditions in adulthood are preventable if effective mental health interventions with young people are available and accessed.

The NDIS costs and liabilities will be impacted by the strengths, weaknesses and responsiveness of schools, tertiary facilities and youth services as well as clinical mental health services and rehabilitation and recovery oriented services. Service access, service effectiveness, service gaps and funding in the youth and child and adolescent mental health space all have the potential to impact on the future demand and the financial sustainability of the NDIS. Close collaboration between the Agency and clinical youth and child and adolescent mental health services in State and Territory jurisdictions and the effectiveness of youth and child and adolescent programs in mainstream services (e.g. headspace) will be crucial to reducing the level and cost of disability support that these young people may require later in life.

Possible ways forward:

- That the Scheme Actuary monitors patterns of expenditure and service trends in the provision and effectiveness youth and child and adolescent mental health services in all states and territories in Australia and contrast these with emerging patterns of demand from participants aged 20 years and above with disabilities associated with mental illness.
- That the Board recognises the early intervention opportunity to impact demand on the Scheme from people with mental illness by supporting and encouraging expansion of youth mental health services.

2.8 Building participant capacity

What is the issue:

Many participants with disabilities related to mental illness, are able and should be expected to work towards building their skills and capacities in social and future economic participation. Patterns of functional impairment may be different from those in other participant groups. Support planning needs to focus on building skills and capacity amongst participants, consistent with insurance principles, even if they are not requesting such assistance to maximise participants' independence, employability and contribute to the financial sustainability of the Scheme.

Discussion:

For most people with a disability related to a psychiatric condition, the nature of the disability has some differences from disabilities for intellectual, cognitive, neurological, sensory and physical disabilities. Psychiatric conditions are not necessarily progressive nor are they fixed or definitive in the nature of the permanent impairment and they can vary due to episodic and environmental factors. In addition there is the overlay of stigma which impacts on confidence and motivation which in turn impacts on skills and capabilities. This means that many people with a disability related to a psychiatric condition are able to build skills and capacity in social and economic participation while they are eligible participants of the Scheme.

This ability to build skills and capabilities needs to be recognised and encouraged in participants' individual plans. The building of skills and capacity is important to ensure that the NDIS principles of personal choice and control, independence and self-management and social and economic participation are able to be met. It will also assist with financial sustainability of the Scheme.

At the same time it needs to be recognised that not every participant will want to be building skills in every possible area of their life, at all times. As with all people, sometimes options such as someone doing or helping with the task is appropriate. Skill building is also not necessarily linear. All of this means that enhancing individual capacity needs to be undertaken in a systematic, flexible and effective way. This should include a bias towards access to mainstream services such as TAFE and University and mechanisms for ensuring that learning/skill development activities are achieving their stated goals.

Possible ways forward:

That the recommended specialist mental health/psychosocial disability team within NDIA Head Office be given responsibility for building capacity development options for participants with disabilities related to mental illness into operating guidelines and staff training for support planning staff.

2.9 State and Territory Government's role in the provision of community rehabilitation and recovery-oriented services

What is the issue:

The COAG Agreement (7.12.12) resulted in state and territory governments committing to ongoing responsibility for the provision of community based rehabilitation and recovery-oriented services for people with mental health issues. The adequacy of ongoing funding for rehabilitation and recovery-orientated services in the future and effective collaboration between mental health services and NDIS will be important factors in the ability of NDIS to achieve its charter.

Discussion:

The COAG Agreement in 2012 was important in that it defined the ongoing responsibilities of state and territory governments for rehabilitation and recovery oriented services for people with mental health issues. Many people are unaware of this agreement and its implications for state and territory mental health services. There was a perception in some sections of the mental health sector that NDIS would be responsible for recovery orientated services. This perception was reinforced in Victoria by the decision of the Victorian Government to transfer all of its Mental Health Community Support Services funding into its funding commitment towards NDIS. In addition, the previous Federal Minister for Mental Health, Mark Butler had stated that the Commonwealth were planning to transfer current funding for Commonwealth funded programs such as Personal Helpers and Mentors (PHaMs), Day to Day Living in the Community (D2D) and

Partners in Recovery (PIR) into the NDIS funding base. While the majority of participants of PIR and Day to Day Living are likely to be eligible for NDIS, a significant number of people using the popular and successful PHaMs program would not be eligible because they would not meet the permanency criteria.

These policy and funding changes have created concerns within the mental health sector for two reasons.

First, there is a concern that state and territory commitment of ongoing funding for people with episodic mental health issues will not be adequate. Compounding this, the loss of the PHaMs, D2D and PIR programs will exacerbate this funding create gaps and lead to service shortfall.

Second, there is a concern that NDIS will not maintain a 'recovery focus' in its work. 'Recovery' is an approach that has been widely adopted in the mental health sector and is a positive mindset that has a focus on notions of belief and hope in a future where the person will have a contributing life. It includes possibilities of being able to manage with activities of daily living, but also runs much more broadly to encompass a person's life goals, and resilience in the face of challenges. It is important to note that there are many similarities and synchronicities with the core NDIS principles and the concept of recovery. The language of disability is different from the language of recovery but there are no grounds to suggest that the approach of NDIS will not be recovery oriented. Rather the language of NDIS needs to be more inclusive of a recovery perspective for people with mental health issues. Recovery does not mean cure or cessation of all symptoms. It is about a person discovering their ability to live a meaningful, contributing life despite their symptoms. A person can be 'in recovery' even when they experience a permanent impact and functional impairments due to their condition. Recovery is about the individual's journey, maintaining personal hopes and dreams. Rehabilitation is the process and methods of intervention by service providers and funders to support the management of mental health issues. Clarity about these distinctions is very important in public discussions about NDIS and mental health.

Perceptions within the mental health sector about NDIS are important to manage and it is essential that the Agency engage with the sector. There are two responses that should be considered:

1. NDIA should be restating and publicizing state and territory governments' ongoing responsibility for rehabilitation and recovery-oriented services and rearticulate the separate and different responsibilities of NDIA and State and Territory Governments.

2. The language of NDIS for people with mental health issues should incorporate a recovery flavour and highlight the consistency between the NDIS principles and a recovery approach to mental health supports.

Possible ways forward:

- That the Agency restates and publicizes state and territory governments' ongoing commitment and responsibility for provision of mental health related rehabilitation and recovery-oriented services, the importance of collaboration and the agreed separate and different responsibilities of NDIA and State and Territory Governments.
- That the language of NDIS around mental health interests should incorporate a recovery flavour and highlight the consistency between the NDIS principles and the recovery approach to mental health supports.

2.10 Development of Tier 2 services

What is the issue:

The recent focus on the roll out of Tier 2 services is supported and there are some specific requirements of people with mental health issues and their families and carers that need to be taken into account in the design of Tier 2.

Discussion:

Tier 2 services, information and referral to mainstream services are crucial to the architecture of the NDIS and therefore have an important influence on its outcomes. KPMG, in its interim report on full scheme transition, identified Tier 2 as the key to Scheme sustainability "as it is the gateway to effective diversion from specialist supports"^x. The recent decision of the Board to move toward the development of Tier 2 is welcome.

There are a number of elements of Tier 2 services, accessed by people experiencing mental health issues, which are important to the NDIS. Firstly timely access to Tier 2 services is important in terms of reducing future need for NDIS support. For people who are deemed not eligible for the NDIS (at a particular point in time) and for young people this is important. Secondly, information for people with mental health issues about Tier 2 services needs to be provided in accessible formats and take account of the variation in literacy and numeracy abilities in the targeted population. Use of social media is important as well as the recognition that some people with

serious and permanent mental health issues do not have access to the web or have low computer literacy skills.

Our observation is that many people who may be eligible will have a weak understanding of the Scheme and how it may be able to assist them. Consideration should be given to the development of a marketing campaign for potential participants with mental health issues to inform them of eligibility and how the Scheme can assist. The design of such a campaign should factor in the commonalities and differences between this participant group and other disability groups.

Families, carers and informal networks play important roles in the lives of people with mental health issues and section 2.3 highlighted the heavy strain on family and informal relationships created by mental health issues. Information and referral strategies developed in Tier 2 should also target the families and carers of people with mental health issues. They play roles as advisers and supporters to applicants and they need to be included in the targeting of information and referral strategies that are developed in Tier 2.

The effectiveness of Tier 2 services in terms of preventing, reducing or maintaining current levels of service demand will also impact on reducing future need for NDIS supports, contributing significantly to the Scheme's sustainability.

Possible ways forward:

- That the specific needs of people with mental issues be taken up by the Agency in its development of a strong and effective Tier 2/mainstream service system to support people who are deemed not eligible for the NDIS, young people, families and carers and the NDIS participants who have non-NDIS funded support needs.

2.11 Requirement for information and knowledge

What is the issue:

The NDIS is a new concept for people with a disability related to a psychiatric condition, their families and carers and the service system. The operation of the Scheme will be enhanced through the provision of information and knowledge.

Discussion:

There are three components to information and knowledge that need to be considered. They are: information on NDIS for participants and their families and carers; psycho-education for

participants and their families and carers; and information to service providers who work with people with a psychiatric condition.

Individualised funding and packages have been commonly used for service provision for a number of disability groups for many years. When initially introduced they required a significant shift in participants' thinking from being a more passive recipient of pre-determined services to being an active participant in choosing and purchasing services. For people with a disability related to a psychiatric condition individualised funding and packages are relatively new. The historic block funding of agencies who deliver services to people with a disability related to a psychiatric condition is only just starting to change. People with a disability related to a psychiatric condition, their families and carers have had limited choice in both the provider and the type of support offered.

The NDIS has principles of personal choice and control, independence and self-management. In order for these to be fully realised for the NDIS participants with a disability related to a psychiatric condition the provision of information, awareness, educational programs and pre-planning advice is required. Support with these tasks prior to an access request could be advantageous to the Scheme in preparing this group to exercise enhanced choice and control in the support planning and service purchase phases.^{xi}

Other specific disability population groups are being supported to prepare for the NDIS but currently people with a disability related to a psychiatric condition are not receiving any support in this area.

Along with the provision of information as to how the Scheme works, there is also a serious need for education on disability, social responses to disability and positive language and attitudes to disabilities related to mental health issues. This needs to occur at a variety of levels. For example the provision of psycho-education for individuals with mental health issues and their families has come to be viewed as an evidence-based practice for the treatment of schizophrenia^{xii}. As a result, family psycho-education is frequently recommended in treatment guidelines such as those of the Royal Australian and New Zealand College of Psychiatrists (RANZCP) for the treatment of schizophrenia^{xiii}. Based on recommendations regarding the length and conduct of family psycho-education issued by the Schizophrenia Patient Outcomes Research Team (PORT)^{xiv} the RANZCP state that:

“Family psycho-education is a program delivered for at least nine months, in which the person with schizophrenia and family members are helped by clinicians to learn communication and problem-solving skills to solve the many challenges that accompany schizophrenia”^{xv}.

Such psycho-education for people with a psychiatric condition and their families and carers is effective in building better understandings about mental health and helping to maintain or restore better family relationships and functioning. Given the likelihood of lower levels of informal support for this participant group, trying to maintain and re-establish and rebuild informal supports could improve rates of informal support. Such support could be offered on a group and community basis rather than tied to individual plans.

The third component of information and knowledge is related to Tier 2 services. Given the dependency of the NDIS on Tier 2 services it is important that Tier 2 service providers understand the NDIS, how it works and what it means for participants. Information and knowledge of the NDIS is required by all Tier 2 services that work with people with a psychiatric condition and their families and carers including: specialist clinical services, generic services such as primary care, housing, justice and Centrelink who work with people with a disability related to a psychiatric condition who may not be engaged with specialist mental health services. This will ensure appropriate access to the NDIS plus minimise people falling through the gaps and improve service system efficiency through the clarifying of roles and responsibilities.

Possible ways forward:

- That people with a disability related to a psychiatric condition and their families and carers are actively supported to prepare and orientate themselves to the NDIS and that DSOs are funded to undertake these functions for mental health consumers and their families and carers.
- That Tier 2 service providers who work with people with a psychiatric condition and their families and carers are actively supported to understand NDIS, how it works and what it means for potential participants.

2.12 Participant populations with specific support requirements

What is the issue:

In consultations and discussions, a range of individuals and organisations have raised the issue of needing to address the particular needs of specific population groups. Responding to the requirements of Aboriginal and Torres Strait Islander participants and their communities has been identified as a priority issue in a number of trial sites and the IAC has a strong focus of the needs of this participant group. The specific needs of other participant groups- people from culturally and linguistically diverse backgrounds and people in the LGBTIQ Communities and, in particular, those

exiting juvenile justice or corrections areas whose needs are quite specific, will all require consideration.

Discussion:

In the monitoring and implementation work proposed in this report, specific focus needs to be given to the particular access and support requirements of specific population groups within eligible participants based on their mental health issues. The connection between gender and sexuality identification and long term disability has been established for some time. The particular needs of this participant group are complex and many suffer from marginalisation and exclusion. Program re-design work should test out assumptions about the particular needs of this population group and whether any adjustments need to be made to operating guidelines for this group. A similar approach needs to be taken to engaging participants and potential participants from culturally and linguistically diverse backgrounds that have disabilities related to mental illness. Particular requirements in relation to marketing and engagement with the Scheme and in relation to support plans should be investigated and rolled out in a progressive manner as required.

The more specific issues confronting each of these participation groups require consideration, consultation and operating guidelines development. Work with these participant groups should be undertaken as part of the implementation and monitoring work proposed in this report.

Possible ways forward:

- That in support planning reviews, consideration is given to the specific individual and community support needs of Aboriginal and Torres Strait Islander participants, people who identify with people from culturally and linguistically diverse backgrounds, LGBTIQ Communities and those exiting juvenile justice or corrections areas.

2.13 Sector engagement

What is the issue:

There has been limited involvement of the mental health sector, including consumers and their families and carers as well as service providers in the design and implementation of the NDIS.

Discussion:

The active involvement of people with a disability related to mental health issues, their families and carers and mental health services providers is important for the success of the Scheme. Regular and appropriately timed consultation and engagement will lead to improvements in the

design and operation of the Scheme that will ensure that the Scheme is responsive to the particular requirements of people with disabilities related to mental health issues. Consultation and engagement will also improve the effectiveness of the Scheme in the longer term through improved operating processes in both Tier 3 and Tier 2.

Consultation and engagement needs to be targeted and inclusive, reflecting the awareness and connection of different parts of the sector to the NDIS. Consultation and engagement with the sector needs to become a standard way of working.

Possible ways forward:

- That the Agency actively engage with all parts of the mental health sector (consumers, their families and carers and service providers) on the continued development and implementation of the NDIS.

3. CONCLUSION

Some of the elements of the needed responses to people with disabilities related to a psychiatric condition are already in place. Further work is required on the key design, operational and implementation issues identified in this paper, along with the adoption of the possible solutions. This would further strengthen the NDIA strategies on inclusion of people with disabilities related to a psychiatric condition. Some of the matters raised will also prove useful and applicable to a broader range of health related conditions that result in people experiencing disability as a result of the condition.

There is a need to work collaboratively to address these identified issues, continue to identify additional and new issues as they arise, identify changes and modalities that can be trialled during the next 18 months, track actual performance over the few years, and ensure that required changes to operating guidelines are in place before the full Scheme roll-out.

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