Hunter Partners in Recovery

Hunter PIR and the NDIS

Building a Stronger Partnership

February 2015

NSW Health Hunter New England Local Health District

medicare local HUNTER Connecting health to meet local needs

integrated living

Samaritans

aftercare

Care Social Services Hunter-Manning

TAFE NSW HUNTER INSTITUTE

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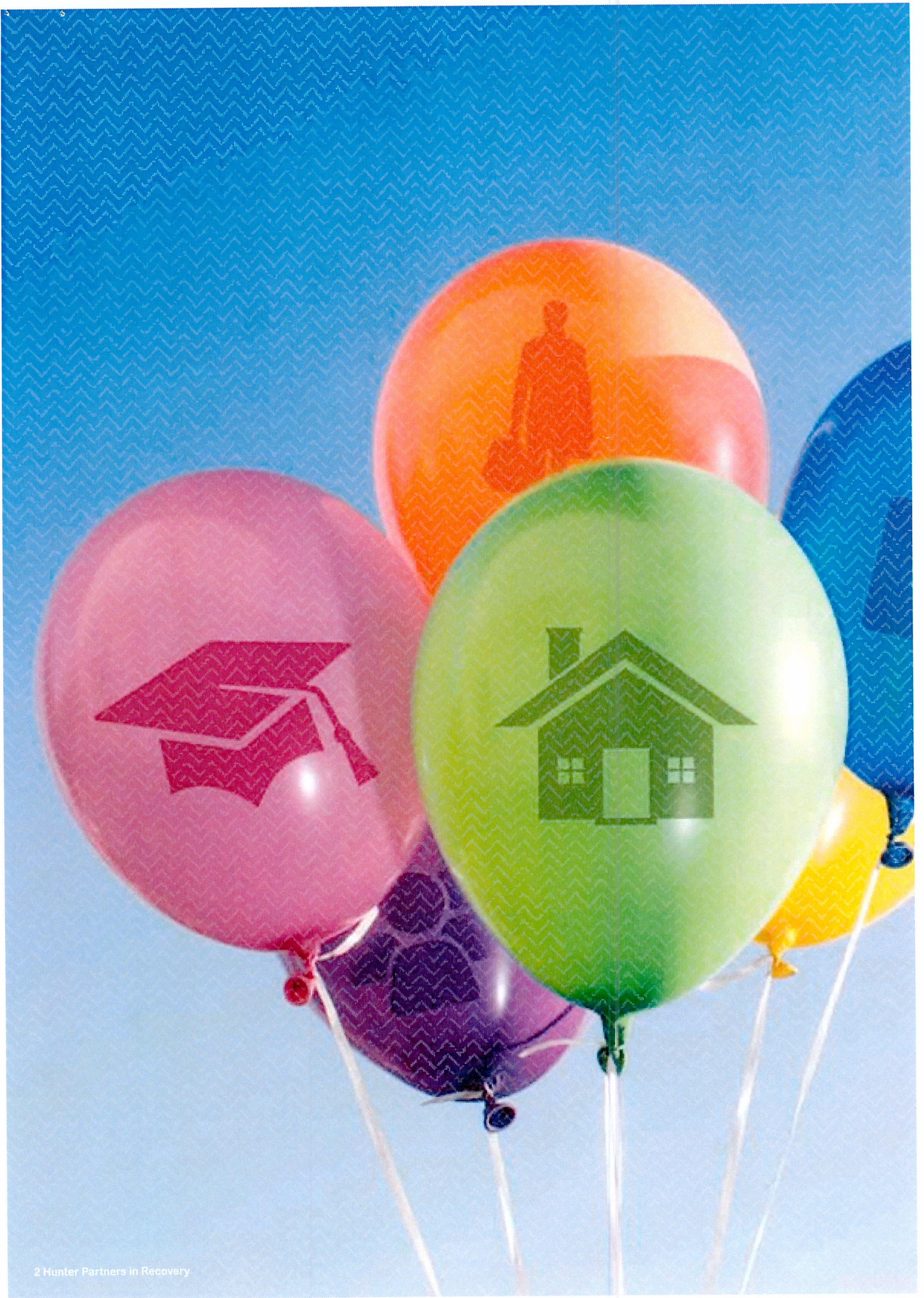

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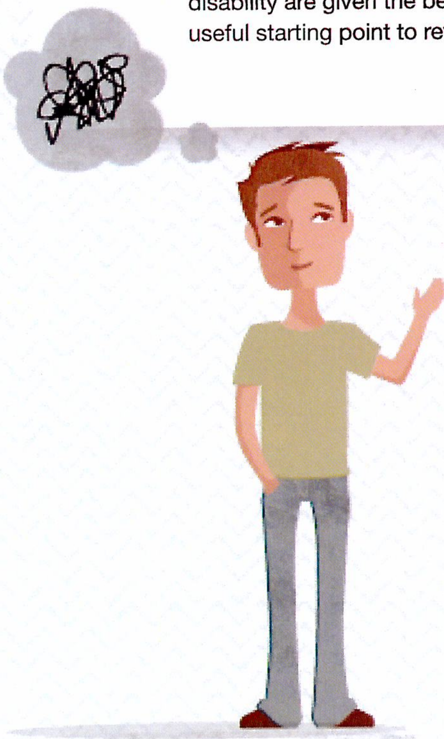
1.0 Executive Summary

The Partners in Recovery (PIR) Initiative provides coordinated support for people with severe and persistent mental illness and complex needs. As well as improving health outcomes for consumers, Hunter Partners in Recovery (PIR) is striving to improve the mental health system for all those affected by severe and persistent mental illness by encouraging collaboration and the development of innovative and collective responses to the challenges presented.

Hunter PIR commenced receiving referrals in November 2013, several months after the commencement of the National Disability Insurance Scheme (NDIS) in the Hunter trial site on 1st July. The concurrent operation of both programs provides a significant opportunity to learn from their combined experience. The Hunter Region is unique in that it is the only Year 1 2013/14 adult NDIS launch site which also has a Partners in Recovery (PIR) Program.

This paper describes a number of general findings that have emerged relating to access, the application process and the 'lifelong' versus 'recovery' concept in the NDIS. In addition, key issues have emerged relevant to Hunter PIR and the NDIS relating to the category 'coordination of supports', the recognition of Hunter PIR's contribution including 'Tier 2' ('Information, Linkages and Capacity Building') and the risk of Hunter PIR-eligible people being excluded from the NDIS due to a range of barriers.

In the long term PIR is described as 70% 'in-scope' for the NDIS. There is a significant risk that if a diminished version of PIR is absorbed into the NDIS, following the cessation of its funding in June 2016, a number of gains achieved from the investment of PIR may be lost. Given there is ongoing review of the NDIS, it is hoped that our findings and recommendations may be useful for the NDIS to consider going forward, especially in relation to psychosocial disability. It is imperative that people with psychosocial disability are given the best possible outcome under the NDIS. PIR may well be a useful starting point to review the NDIS design.



2.0 Introduction

Partners in Recovery (PIR) is a Commonwealth Government (Department of Health) Initiative aiming to better support people with severe and persistent mental illness and complex needs, and their carers and families, by connecting them more effectively with the services and supports they need in a collaborative, coordinated and integrated way. There are currently 48 PIR initiatives operating nationally, and these are aligned with Medicare Local regions. The Commonwealth has set a target of reaching 24,000 PIR consumers nationally by the end of the initiative.

The Hunter PIR Program is led by Hunter Medicare Local in partnership with a Consortium of eight (8) other government and community managed organisations including Aftercare, CatholicCare Social Services Hunter-Manning, Hunter TAFE, Integratedliving, Relationships Australia, Samaritans, Wesley Mission and Hunter New England Local Health District – Mental Health Services. Five (5) organisations have partnered with Hunter PIR to host Support Facilitator teams across the Hunter Region including Aftercare, Benevolent Society, Neami National, RichmondPRA and Wesley Mission. Since Hunter PIR became operational in November 2013 more than 800 referrals have been received to date and 359 consumers are registered in the program as of the end of December 2014. Estimates prepared for the Department of Health suggest that there are 1,706 consumers who meet the criteria for PIR in the Hunter region. Hunter PIR aims to assist 40% of this population (or 709 individuals) directly over the three year lifetime of the initiative.

For Australians with a permanent and significant disability, the National Disability Insurance Scheme (NDIS) provides an opportunity to receive the lifelong support they require to pursue their goals, participate in the community and to fulfil their potential. NSW was one of four states trialing the NDIS from July 2013. The NSW trial is located in the Hunter Region and involves a staged rollout across several Local Government Areas LGA's, from Newcastle in 2013-14, to Lake Macquarie in 2014-15 and finally Maitland in 2015-16. The Hunter currently has more than 2,000 NDIS registered participants. The Hunter Region is unique in that it is the only Year 1, 2013/14 adult NDIS launch site that also has a Partners in Recovery (PIR) Program. As the Hunter Region was the first NDIS launch site for NSW (commencing 1 July 2013), we believe we are in a unique position to present findings based on our experience with the NDIS.

3.0 Purpose of the paper

This paper has been developed to document findings based on the experience of Hunter PIR working alongside the NDIS, and to propose recommendations for future collaboration between the NDIS and PIR. We believe there is a significant opportunity to learn from Hunter PIR's experience with the NDIS. Hunter PIR is well placed to offer recommendations to ensure people with severe and persistent mental illness with complex needs are given the best opportunity under the NDIS. The support provided by the NDIS is already having a positive impact on the lives of many individuals with a disability, and their carers.

The paper brings together information on key operational issues identified by relevant stakeholders including Hunter PIR Support Facilitators and consumers during the first year of operation of Hunter PIR and the NDIS. It is hoped that sharing our experience may lead to adjustments of relevant aspects of the NDIS in order to achieve the best possible outcomes for individuals living with a psychosocial disability, and demonstrate the complementary and highly valuable role of PIR in the NDIS.

In this paper, we will:

- Outline the relationship between Hunter PIR and the NDIS *(see Section 4)*
- Report on some general findings regarding psychosocial disability and the NDIS *(see Section 5)*
- Propose recommendations for consideration *(see Section 6)*

4.0 Hunter PIR and the NDIS

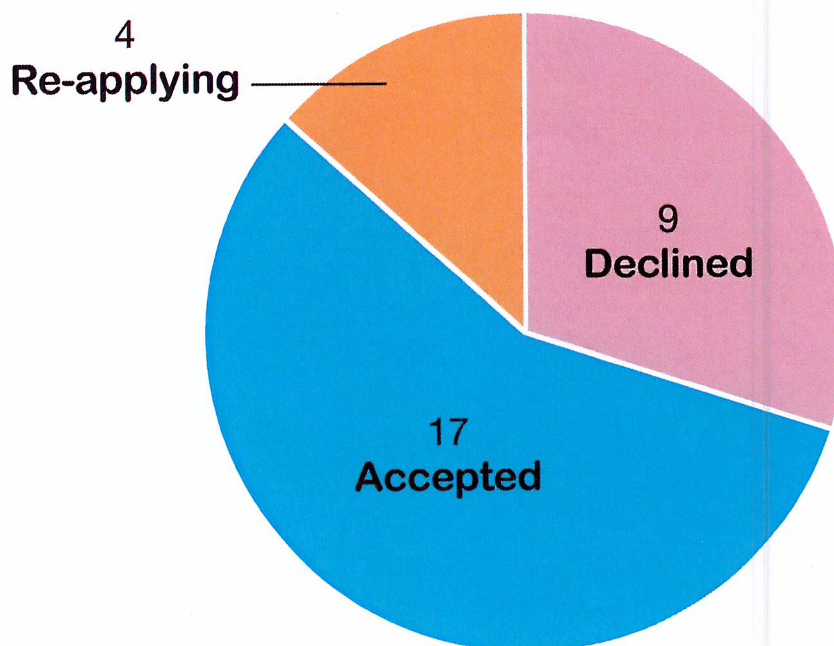
Hunter PIR is contracted to provide 'in-kind' support to the NDIS to an estimated value. No other detail was outlined at the outset of the contract, and the role of Hunter PIR has developed over time in consultation with the NDIA leadership in the Hunter. Hunter PIR is the preferred mental health provider for the NDIS for *'Assistance in coordinating or managing life stages, transitions and supports'* (Coordination of Supports) which may include assisting the consumer with budgeting, parenting training, developing capacity and resilience in the participant's network, coordinating complex supports, life planning and resolving crisis situations. Should an NDIS participant choose an alternative provider of *Coordination of Supports* they may do so to ensure 'choice and control'.

Currently, Hunter PIR and NDIS have 50 joint consumers and 32 NDIS applications are pending. Given there are approximately 229 registered Hunter PIR clients across the 3 Local Government Areas (LGAs) of Newcastle, Lake Macquarie and Maitland in the Hunter NDIS trial site, the potential of the NDIS to purchase individual support for Hunter PIR consumers has been limited due to a number of reasons:

- A significantly cumbersome application process limits the number of applications submitted by Support Facilitators, except for the most urgent or high needs people
- Long wait times for an NDIS plan to be developed
- Hunter PIR is already providing coordination of supports and no other funding support is required
- Ineligibility for the NDIS

In total, there have been nine (9) NDIS applications from existing Hunter PIR consumers from a total of 26 applications to date which have been declined, suggesting that a higher percentage of people with a severe mental illness than expected are excluded from the NDIS. As PIR is aimed at the people with the highest needs, it is expected a higher percentage of consumers would be accepted into the NDIS. Despite the overall number of joint consumers being very low, this indicates that approximately 35% of all Hunter PIR eligible applicants are deemed ineligible for the NDIS. Hunter PIR is currently assisting four (4) of these applicants to re-apply. See Figure 1 below.

Figure 1: Status of NDIS applications for Hunter PIR consumers



Total number of applications submitted = 26

4.1 'Coordination of supports'

The definition of 'Co-ordination of supports' by the NDIS is very broad. The expectations of this work have not been outlined by the NDIA. Locally, we have been advised to 'coordinate the plan' and ensure the person's needs are met. This can include identifying potential providers of NDIS funded supports and maintaining oversight of their work. There are two categories: 'Coordination of supports' (08 002) and 'Coordination of supports – higher intensity' (08 003), and it is unclear why the higher intensity category is applied in some plans and not in others. There are several NDIS Plans for Hunter PIR/NDIS consumers where both categories are included however it is unclear when to transition from one level of coordination of support to the other.

All the components of Hunter PIR including the Camberwell Assessment of Needs Short Appraisal Schedule (CANSAS) and action planning, are undertaken in addition to coordination of an NDIS Plan. PIR being 'recovery' focused has a broad scope of additional domains in which clients need to be connected to services. It is our experience that Hunter PIR, when providing Coordination of Supports, provides a highly holistic and enhanced version than what may otherwise occur. The standard of care is not explicit in the definition of 'Coordination of Supports'. The definition does not describe the highly specialised and skilled work of Hunter PIR Support Facilitators. It would seem more appropriate for there to be another category in order to aptly describe the highly specialised recovery oriented coordination that best meets the needs of consumers. Hunter PIR is also providing the necessary and important integration to health for our population of consumers with severe and persistent mental illness and complex needs. If the link to health is not explicit in the definition, then it may not be delivered by other providers of Coordination of Support which is a limiting benefit of the NDIS. Hunter PIR is concerned where a client has accepted Coordination of Supports from another provider, the quality of this service may not be comparable to that provided by Hunter PIR without adequate standards of accountability.

Hunter PIR Support Facilitators draw together a network of government, health and community partners to assist consumers to access the particular services and supports they require, and to help promote their optimal health and wellbeing. The Support Facilitators undertake a comprehensive assessment of the needs of consumers, identify existing service provision, and develop and implement individualised Action Plans in collaboration with the consumer. PIR acts as a centralised point of contact for consumers, their families and carers, and service providers, and develops appropriate relationships, communication and reporting networks. All Support Facilitators are appropriately skilled and experienced professionals who possess a comprehensive knowledge and understanding of the local service system (including health and welfare sectors) and both clinical and non-clinical support services. They also possess extensive experience working with the target group and a strong capacity to work with challenging issues, both at the level of the consumer and at the service delivery level. Support Facilitators have a dual role of not only coordinating the range of care and supports required by consumers but also developing and supporting the system-level reform required for better service integration across multiple service sectors.

Hunter PIR operates under a clinical governance framework with a high level of accountability. There are established quality assurance processes, and staff participate in ongoing training and development specific to the needs of the target population. Established governance mechanisms regularly bring together all partners and stakeholders in the Hunter PIR network to ensure collective responsibility, collaboration strategic oversight and effective implementation of Hunter PIR in the region. In addition, Hunter PIR has an interface with the Hunter New England Local Health District which is highly significant. Hunter PIR ensures there are smooth transitions between primary care, hospital/acute care and community based care.

Hunter PIR takes a holistic approach and addresses areas related to a person's:

- physical health
- housing/homelessness
- alcohol and other drug concerns
- employment
- education
- living skills
- income support
- social isolation

Hunter PIR makes sure there are no gaps and all needs are met, not needing to limit the focus of supports to social and economic participation.

Recommendation: The definition of Coordination of Supports needs to be improved in order to ensure consistency and standards are met and linkage to health.

4.2 Limits to claiming 'in-kind' support

Partners in Recovery is a provider of 'in-kind' support to the NDIS. We are 'claiming' this contribution via the NDIS Portal in terms of hours of support delivered each month per participant. The number of service hours claimed to date has been far below the estimate included in our contract with the Department of Health. Hunter PIR is only able to 'claim' from the start date of an NDIS plan. This excludes sometimes months of work in which time a CANSAS has been completed, PIR Action Plans developed and referrals made to services and supports, as well as the compilation of evidence towards an NDIS application. In addition, Hunter PIR is building strong relationships with services and undertaking assertive outreach work in order to reach the most disengaged. The total contribution is not demonstrated by the process of 'claiming' and may impede the recognition of the value of Hunter PIR.

The contribution by Hunter PIR has not included use of flexible funding. Hunter PIR flexible funding can be used to purchase services and appropriate supports when a consumer's needs are identified but are not immediately able to be met through normal channels. Flexible funding provides support where there is a gap in service or significant barrier to meet the needs of the consumer. Based on flexible funding expenditure to date, there seems to be a strong overlap between the NDIS and Hunter PIR for Learning and Life Skills development, and Travel Assistance. Therefore, it is recommended that Hunter PIR is able to claim 'in-kind' support where flexible funding contributes to items in an NDIS plan. For example in October 2014, we were informed that the NDIS would no longer fund the cost of forensic cleans in hoarding and squalor situations, however the NDIS will fund post-clean support. Hunter PIR has purchased forensic cleaning at considerable expense, however, claiming this as 'in-kind' support has only been possible on one occasion to date. Other Hunter PIR flexible funding has been spent in the areas of private medical and mental health treatment, short-term accommodation, and household establishment and maintenance.

Partners in Recovery has been designed to deliver on a significant range of outcomes many of which are in the scope of the NDIS. A potential consideration for Hunter PIR in the future could be moving into the role of a *Registered Plan Management Provider.* This is not dissimilar to our current capacity to purchase services using flexible funding.

4.3 'Tier 2' ('Information, Linkages and Capacity Building') Services

The NDIS provides support at different levels or 'tiers' with Tier 1 being the lowest level and Tier 3 being the highest level of support. Tier 2, now known as 'Information, Linkages and Capacity Building' includes information and referral services about the most effective care and support options for anyone with or affected by a disability. Tier 2 aims to target about 800,000 people with a disability and their families and carers[1]. It is important that appropriate services and supports are in place for those individuals not eligible for 'Tier 3'.

We believe Hunter PIR is able to contribute significantly to 'Tier 2' within the NDIS particularly due to the 'no wrong door' approach we have adopted. A significant amount of time is provided by Hunter PIR for 'Tier 2' activities in order to link ineligible consumers to other services. This work may include exploring other appropriate services and supports, making referrals on the consumer's behalf, phone conversations with the initial referrer, consumer or carer and/or phone calls to potential services. Between November 2013 and August 2014, Hunter PIR assisted 74 consumers with 'Tier 2' support. On average, 1.7 hours per consumer has been spent on 'Tier 2' activities. We believe this should be able to be claimed as part of Hunter PIR's 'in-kind' support in the future. Until the 'Tier 2' approach is more clearly articulated by the NDIS, recognition of our work to date has not been achieved.

'Tier 2' design in the future may include capacity building at a service or system level. Partners in Recovery is responsible for system change strategies to influence the system to better support people with severe and persistent mental illness and complex needs. Hunter PIR is currently working on a number of system change activities such as:

- Enhancing support from General Practice
- Redesigning the service system response when someone is acutely unwell
- Improving pre-release planning in the Corrections setting
- Recruiting and training Aboriginal Cultural Mentors

Future planning of the NDIS and PIR relationship should incorporate this valuable work. By being embedded in the service system and able to step back and identify system change needs, PIR supports outcomes at an individual and system level which will also directly maximise the impact and effectiveness of the NDIS as is proposed in the *Disability Care and Support: Productivity Commission Inquiry Report*[2]. The goals, strategies and expectations of the NDIS are already underway with Partners in Recovery. This work drives innovation at the achievable local level. It is complementary to but outside the scope of Local Area Coordinators. Local Area Coordination (LAC) is provided in the Hunter trial site by the NDIA. The local arrangement has been that when a Hunter PIR Support Facilitator is involved an LAC is not, further emphasizing our complementary roles.

[1] *Rose, Valmae. 2013: Imagining and Planning for your Future; Workbook; Future by Design; Springhill.*
[2] *Australian Government: Productivity Commission, 2011, Disability Care and Support, No. 54; 31 July 2011.*

Recommendation: Hunter PIR's contribution to Tier 2 (Information, Linkages and Capacity Building) and systems change strategies is not isolated from the NDIS and instead is contributing to the Scheme. There should be greater recognition of this contribution to the Scheme.

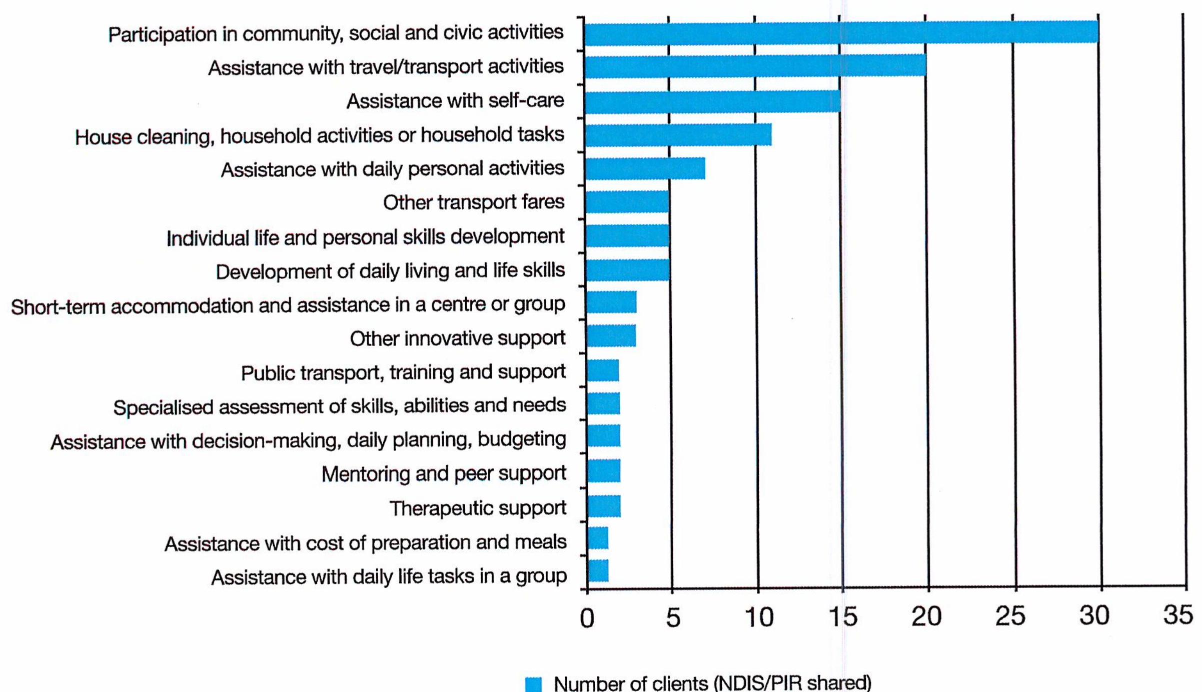
4.4 Resources associated with pre-planning

There is significant cost associated with the extensive amount of time required to prepare and complete an application to the NDIS. It is our experience at Hunter PIR that substantial time and resources are committed in the pre-planning process, yet this is not included towards 'in-kind' support. It is important there is greater recognition of the work of Hunter PIR and other non-clinical services. On average, our Support Facilitators have spent 21 hours (per consumer) compiling evidence for an application to the NDIS. Furthermore, there has been the additional cost of purchasing Occupational Therapy (OT) assessments for some consumers which have been required as part of evidence and documentation for an NDIS application. Hunter PIR has used flexible funding to cover the cost of OT assessments which have ranged in price from $296 to $1008 per assessment. Recently, the NDIS advised that they would cover this cost in the future. This raises an important and significant issue about equitable access. Potential consumers may be excluded from the NDIS if unable to access the resources and advocacy to fulfil evidentiary requirements.

4.5 Complementary service provision

It has become increasingly evident that there is some duplication of effort from NDIS Support Planners and our Hunter PIR Support Facilitators. Duplication occurs both in the assessment of a consumer's needs and in planning. A sample of NDIS plans have been reviewed for joint NDIS/Hunter PIR consumers and the content of the plans is highly comparable. The goals most commonly identified by consumers in their NDIS plans were highly similar to the goals identified in the Hunter PIR recovery action plans. The most common goals identified by consumers were increasing social and/or community engagement, assistance with accommodation, assistance with addressing mental health issues with a health professional, and support to improve daily living skills. Engaging with support services, education/training and improving physical health were also common goals. Clearly, there is some cross-over between services provided by the NDIS and those coordinated by Hunter PIR for shared consumers. These services are addressing significant and often long term gaps of unmet needs. In particular, support directed towards greater social inclusion is a key benefit for consumers. See Figure 2 below.

Figure 2: Breakdown by NDIS category as stated in the NDIS plan (excluding coordination of support)



The following consumer experience highlights the complementary and valuable contribution of Hunter PIR and NDIS:

Consumer 1:

Hunter PIR received a referral for this consumer for Coordination of Supports. At the time, he was at risk of losing his tenancy with Housing NSW. In addition, he had outstanding matters with the court system, and both his physical and mental health had not been properly assessed or managed. He was not linked in with the local community mental health service or any counselling services. Both Hunter PIR and NDIS have provided the consumer with support and access to services which have contributed to a positive outcome.

The NDIS funded a forensic clean in order to prevent eviction and homelessness. As a consequence of the support, this consumer's tenancy is no longer at risk with no further complaints being made to Housing NSW or the Police. In addition, the NDIS have provided funding for individual counselling in relation to hoarding support and funding to assist the consumer to access community, social and recreational activities. Hunter PIR have provided support with outstanding legal matters and support assisting the consumer to access all necessary health services. He is well engaged with his GP, seeing a Psychiatrist and has been allocated a clinical nurse specialist at the local area mental health service. He and his partner are currently being assisted to have more access to their children.

Following discussions between Hunter PIR and the consumer regarding the consumer's NDIS plan, Hunter PIR met with the consumer's planner to negotiate further changes to enable the continuation of tailored support and the identification of further goals for the future related to participation in a course and some financial counselling regarding outstanding loans. As the consumer's partner also has an NDIS package, Hunter PIR has been involved with coordinating services that complement those in the consumer's partner's plan.

NDIS planners only have a small window of time to assess a consumer and it is feasible that the support needs of consumers could be underestimated. It is imperative that NDIS planners have a solid knowledge and understanding of the consumer's circumstances, current and future needs, and all aspects of the service system. Hunter PIR engagement can enhance the NDIS application process because we have capacity to take more time to build trust and rapport with consumers prior to submitting an application and are able to support them to prepare for a planning session.

From a time and resource perspective, it is important that duplication of effort is reviewed and addressed and where possible Hunter PIR staff contribute to the planning discussion prior to plan completion. The benefits of this approach include:

- Sharing of quality assessment information gathered by Hunter PIR Support Facilitators
- Accurate and timely assessment of the consumer's needs
- Implementation of a plan that requires less modification in the future
- Accelerated actioning of the NDIS plan
- Minimum repeated 'story-telling' from the consumer.

Our experience also gives weight to the benefit of one person undertaking assessment, planning and coordination as is being trialed in the My Way sites of Western Australia.

Recommendation: Consideration be given to joint planning by NDIS Planners and Hunter PIR Support Facilitators or other strategies to minimise duplication of effort and ensure continuity for the consumer. Hunter PIR action planning could be used to a greater degree by NDIS Planners.

4.6 Lack of recognition of work from non-clinical services

Hunter PIR is increasingly working with people for some time prior to a plan being developed by the NDIA due to a delay from application to allocation to a Planner. Therefore, Hunter PIR has in most cases already established a Hunter PIR Action Plan and gained a thorough understanding of the person's needs and aspirations. The NDIA has responded to this circumstance by liaising more closely with Support Facilitators. However, there has also been a lack of recognition of the expertise of Support Facilitators and other non-clinical services, and an over reliance on clinical evidence. It is important that the NDIS values and recognises the work of non-clinical services who have specialist knowledge, experience and understanding of severe and persistent mental illness and psychosocial disability.

5.0 General findings

For people with psychosocial disability, there are a range of access barriers impacting on the application process and the likelihood of an application being approved. These include the use of *My Access Checker*, time and resources to complete an application, and attribution of deficit to disability.

As one consumer stated *"Being unable to make eye contact, persistent low self-esteem, fear of social encounters, isolation, depression – these are just some of the deficits I experienced as part of my psychosocial disability. The NDIS needs to take into consideration the complexity of this experience, and not just try to make all disabilities equivalent in one all-inclusive entry portal questionnaire."*

5.1 Access

5.1.1 My Access Checker

The *My Access Checker* is not a suitable tool for individuals with mental illness due to its strong deficit-focus. For example, a client is required to answer "*Yes*" to the question *"Is your disability likely to continue for the rest of your life?"* This approach contradicts the recovery-focus principle of PIR and the national mental health standards. Individuals with a mental illness may not be able to recognise the impact of their mental illness and/or accurately respond to questions relating to the level of help required to manage aspects of their life around mobility, self-care, domestic duties, communication, interpersonal relations and behaviour or learning and applying knowledge.

In addition, individuals with mental illness may internalise their feelings/symptoms or make huge efforts to minimise the impact of their illness. They may have difficulty trusting people and being willing to share personal information. Mental health consumers may require one-on-one guidance, support and coaching throughout this process and a high level of advocacy is required to enable a person to access systems and supports. Hunter PIR has been able to provide this support to consumers. However, in the absence of any support or assistance, there is the likelihood that these individuals may be excluded from the NDIS. This also raises the issue of equitable access to the NDIS.

5.1.2 Time and resources

It is an extensive and incredibly time-consuming process compiling evidence, often from multiple sources, to support an NDIS application. Although there are many variables which impact on the time it takes to submit an application to the NDIS, some applications may require up to five or more reports from difference sources, thus requiring a significant amount of time to request, gather and collate the information, and prepare a report. In addition, a significant amount of documentation required is clinical and this is frequently more difficult and time-consuming to collect compared to other information.

Obtaining the necessary information to support an NDIS application may involve multiple phone calls requesting information from various stakeholders, follow-up phone calls, organising appointments with the consumer's GP and/or Psychiatrist to complete documentation, requesting clinical notes and hospital discharge summaries, and following up on any incomplete documentation. The types of documentation required include but are not limited to the following:

- Clinical case notes or reports from the consumer's Care Coordinator
- Letters, reports and notes from the consumer's GP and/or Psychiatrist
- Medical history notes for the consumer
- Hospital discharge summaries for the consumer
- Letters from the consumer's Support Workers
- Reports from the Hunter PIR Support Facilitator for the consumer
- OT assessment reports for the consumer

As a result of the high level of documentation required in terms of letters and reports, significant coaching of allied health professionals and GPs is carried out by Support Facilitators on how and what to write to best support an NDIS application. Hunter PIR is currently developing a 'How to Apply' guide or tip sheet on how best to document and evidence needs and goals for the NDIS. It is our experience that the NDIS is continuing to request more and more information. In addition, there is inconsistency with the degree of evidence required. For example, some applications have only required a single supporting report from a GP or Psychiatrist as evidence of the consumer's disability, while others have required up to five or more reports from different services.

It is important that this process is streamlined as much as possible. There is the likelihood of consumers being excluded from the NDIS because they do not have the support and assistance required to access and complete the exhaustive documentation required by the NDIA Assessors and Planners.

Recommendation: There is greater consistency regarding the evidence required to support an NDIS application and that the amount of documentation is streamlined and/or greater weight is given to non-clinical evidence.

The following consumer stories highlight some of the challenges experienced in the NDIS application process.

Consumer 2:

There was very little available medical documentation as the consumer had only a nominal history with support services. However, a discharge summary was obtained from the only known hospitalisation and medical evidence was completed by a Psychiatrist.

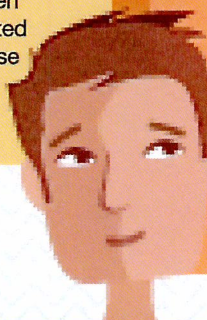
Although approval was eventually granted for this consumer, the NDIS requested an interview with the consumer for a SNAT (Support Needs Assessment Tool) assessment, Hunter PIR also completed a report, and the application took an additional 6 weeks to complete as a result of these additional processes.

Consumer 3:

Discharge summaries were requested back to 1982, in addition to a Psychiatry report, OT assessment report, and reports from both the consumer's Care Coordinator and Hunter PIR Support Facilitator.

Consumer 4:

This consumer's first application was rejected. As a result, it took some weeks to organise a conference with the consumer's current stakeholders in order for the Hunter PIR Support Facilitator to ascertain why the first application was rejected and what actions could be taken to ensure that a re-submitted application addressed these issues.

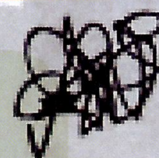


Consumer 5:

This consumer has a developmental delay and multiple diagnoses of mental illness. Evidencing the consumer's diagnoses and daily living skills was very difficult. There had been multiple services involved previously although some services had withdrawn due to either the complexity of the consumer's needs or the consumer withdrawing consent.

The consumer has not had consistent contact with mental health community services for some years and the consumer's hospital admissions were through the Emergency Department and, as a result, the consumer was not always seen by a consistent staff member.

The Hunter PIR Support Facilitator has spent on average 8 hours a week for 6 weeks communicating with various stakeholders, visiting the consumer and trying to build a rapport, gathering information, and is now preparing a report to submit an application to the NDIS hoping there is sufficient evidence to support the application.



Consumer 6:

This consumer's NDIS application commenced in May 2014. The consumer was not living in the launch site as of 1st July 2013, therefore the application needed to be made under Exceptional Circumstances. The Support Facilitator was required to collect a large amount of information detailing why the consumer left the Sydney area, what services the consumer was connected to in Sydney ie. ADHC (Ageing Disability and Home Care) and where the consumer resided before arriving in Newcastle.

Findings were reported back to the NDIS and the Support Facilitator was informed that the consumer was not with ADHC and therefore could not simply transition to NDIS. The NDIS subsequently requested evidence from a Psychiatrist, proof that the disability is permanent, evidence the consumer has been in and out of the mental health system, an OT assessment report and proof of guardianship.

All of these requirements were met. This information was forwarded to the NDIS in October 2014 and after not receiving a response, it was followed up in November by the Support Facilitator. Subsequently all of this information was asked to be supplied again. The Support Facilitator was also advised that the consumer would need their GP to complete the Evidence of Disability form despite previous advice that this would not be necessary due to the OT assessment report and evidence from the Psychiatrist and clinical staff at NCMHS (Newcastle Community Mental Health Services) being sufficient. This additional documentation was submitted to the NDIS in December 2014 and the NDIS application was subsequently accepted in January 2015.

5.1.3 Attribution of deficit to disability

Attribution of deficit to disability is a difficult and complex process especially when an individual may have both physical illness and mental illness. The potential for exclusion or inadequately addressing the person's needs is very high. And this again highlights the necessity for Coordination of Supports to integrate with health services to ensure the interrelated issues are addressed.

The following example illustrates this issue.

Consumer 7:

A Hunter PIR Support Facilitator was advised that a consumer's NDIS application did not contain sufficient evidence to support approval for an NDIS plan. The consumer had a history of schizophrenia.

The NDIS worker stated that the consumer's problems were related to the consumer's 'physical health' commenting that the consumer's diabetes was 'out of control' and the consumer's obesity was causing the consumer's mobility issues.

The Support Facilitator explained that a common negative symptom of schizophrenia is a lack of motivation, and that the consumer is currently medicated on Clozapine which is known to cause an increase in appetite and weight gain, even for those on a strict diet. Initial advice from the NDIS was that this consumer's application for funding would be denied on the basis that the consumer's problems are resulting from the consumer being 'extremely obese'.

Hunter PIR staff explained that from the information which has been provided, and from professional observations and assessments, the consumer would not have the skills to care for themselves if the consumer's mother was not available.

Furthermore, Hunter PIR staff explained the extent of the consumer's physical and mental health-related disabilities that prevented the consumer from living a meaningful and productive life, including the impact on the consumer's ability to function in the community due to poor socialisation skills, paranoia and social isolation.

After considerable time and effort and ongoing discussions with the NDIS, this consumer's NDIS application was eventually approved.

Recommendation: The methodology by which the NDIS attributes disability and health related problems is unclear. Hunter PIR would support the development of greater transparency, such as an expert panel, and evidence-based approaches in cases where physical health issues are highly interrelated to the individual's mental health condition.

5.2 The application process

A unique and specialised assessment process is required for psychosocial disability, and it cannot be assumed that the same approach for physical illness will apply for mental illness. The current NDIS assessment methodology was not designed for psychosocial disability and may inappropriately exclude people from the NDIS. In addition, psychosocial disability is often episodic in nature and as a result, the needs of an individual can fluctuate over time and may not be particularly evident at a certain point in time.

Where an application to the NDIS has not been approved for Hunter PIR consumers, no information has been provided as to why the individual was considered ineligible for entry into the NDIS. It is important there is clarity around eligibility and ineligibility in the assessment process and that reasons for ineligibility are provided. Our experience indicates a variability in outcome depending on assessors and planners skills and expertise.

Recommendation: Clear information is provided detailing the reasons why an NDIS application has been deemed ineligible.

The following consumer experiences highlight barriers in the application process for individuals with severe and persistent mental illness:

Consumer 8:

A Hunter PIR consumer was assisted with her NDIS application. Hunter PIR funded a private OT assessment which provided detailed evidence of the consumer's disability and subsequent challenges.

A planning meeting was held with an NDIA Planner. Hunter PIR prepared a comprehensive planning document using NDIS criteria to summarise what supports the consumer needed and this was provided at the meeting. During the planning meeting, the consumer became very distressed as the NDIA Planner repeatedly asked the consumer direct questions about the consumer's illness and why the consumer was not able to perform certain tasks.

The Support Facilitator referred the planner to the OT report which outlined the consumer's struggles, however the NDIA Planner insisted on hearing it from the consumer's 'own words' and refused to take consideration of the OT report.

Subsequently, the consumer became distressed and left the room and cancelled the follow-up meeting with the NDIA because the consumer felt too anxious to participate. The consumer reported to the Support Facilitator that she felt "interrogated".

Another NDIA planning meeting has been scheduled and it is hoped at this time, the OT report can be utilised as evidence of the consumer's needs.

Consumer 9:

A Hunter PIR consumer with a high degree of paranoia especially regarding mental health services also refused to engage in assessments necessary to obtain evidence for the NDIS.

For consumers such as this, it is currently impossible to provide the necessary evidence to make a submission to the NDIS and therefore they are excluded from services.

Currently, Hunter PIR is the only form of support for this consumer, and flexible funding is being used to access other services to support this consumer in living an improved quality of life.

The development of psychosocial assessment tools is highly important as there is evidence to suggest that tailored support for people with psychosocial disability can improve functioning and enable individuals to live in the community with a reduced reliance on acute mental health services. It is essential that the needs of people with psychosocial disability are better recognised and supported by the NDIS. There is the need for the NDIS to use effective psychosocial assessment tools with a greater emphasis on psychosocial factors.

Recommendation: Greater recognition and understanding of the needs of individuals with psychosocial disability and the development and implementation of appropriate psychosocial assessment tools. It is important that the needs of people with psychosocial disability are better recognised and supported by the NDIS. Processes need to ensure there is equitable access for all people with a disability accessing the NDIS.

5.3 'Psychosocial disability' versus 'psychiatric disability'

Although 'psychosocial disability' and 'psychiatric disability' are defined by the NDIS, there perhaps needs to be more clarification when these terms are used in documents. At times, it appears these terms have been used interchangeably.

Recommendation: Further explanation and clarification of the terms 'psychosocial disability' and 'psychiatric disability' is needed to avoid any confusion.

5.4 Consumer/Carer/Community participation

There appears to be no substantial evidence of strategies in place for Consumer/Carer/Community participation within the development and design of the NDIS. It is important for the NDIS to determine how to ensure consumers and carers are active participants, and to adopt strategies for involving consumers and carers in service and planning, implementation and evaluation, as well as education and research.

It is important to involve consumers not just at the planning stage, but at every level of planning and delivery. Mechanisms need to be developed to enable both consumers and carers to have a 'voice'.

Recommendation: The development of local Consumer Reference Groups to ensure the views and needs of consumers are addressed and that consumers are actively involved in planning, implementation and evaluation.

Currently, there appears to be inadequate support for carers of people with a disability with high and complex needs. The NDIS is currently not explicitly designed to meet the needs of carers although the provision of services would assist indirectly. Supporting carers needs to be a priority in any NDIS related policies and procedures as carers are expected to provide ongoing informal support for many participants and the NDIS is designed to complement, rather than substitute informal supports.

In addition, carers may be involved in assisting consumers with their NDIS application as well as supporting participants to prepare and implement their plan. It is therefore imperative that carers understand the NDIS plans and are adequately supported by the NDIS. It is important that carers' support needs are not left out and are suitably addressed in the future.

Hunter Partners in Recovery (PIR) recognizes the importance of consumer and carer participation and has established a Consumer and Carer Advisory Group. Feedback provided by the group has demonstrated how extraordinarily valuable it is to involve both consumers and carers, and to gain insights from their lived experience of mental illness.

5.5 'Lifelong' versus 'Recovery'

Eligibility for the NDIS is based upon a requirement of a 'permanent impairment' ('lifelong') which contradicts the concept of 'recovery'. The idea of a permanent impairment does not build hope and is contrary to evidence. It is potentially devastating for mental health consumers to hear they will never recover. The principles of PIR are recovery-focused and consumer-centered.

The central concepts of recovery are person-centredness, self-determination and hope for a meaningful and contributing life beyond the constraints of a diagnosis. Recovery-oriented practice is currently the best practice in mental health. In the Hunter, PIR provides a community based recovery model aimed at supporting each consumer on an individual basis to make informed decisions about their care and to achieve improved mental health and wellbeing, and recovery focuses on strengths not deficits. Hunter PIR assesses a consumer's perceptions of progress in their recovery journey through the RAS-DS (Recovery Assessment Scale – Domains and Stages).

In My Access Checker, a consumer is required to answer "*Yes*" to the question "*Is the person's disability likely to continue for the rest of their life?"* This question contradicts the central concepts of recovery, even though a person may require services and supports for the foreseeable future.

In addition, the episodic nature of severe and persistent mental illness means that the needs and impairments of an individual with a psychosocial disability can change over time, both in terms of severity and nature. It is likely the nature of supports and services will vary over a person's lifetime.

The reliance on 'permanence' is highly problematic. PIR instead relies on evidence of severe and persistent mental illness which is historical and while likely to be present for the duration of someone's life it doesn't presume the impact and outcome of the person's future life. A disability insurance scheme does not have to rely on permanence. It is not obvious why the NDIS cannot be provided in the same way as health insurance, which caters for episodic interventions.

Recommendation: It is important that the NDIS supports rather than contradicts recovery-oriented practice and that the assessments used and the questions asked by the NDIS are designed for individuals with psychosocial disability to maximise wellness and recovery.

6.0 Summary of recommendations

Based on our experience with the NDIS to date, Hunter PIR is proposing the following recommendations:

Recommendation 1

The definition of Coordination of Supports needs to be improved in order to ensure consistency and standards are met and linkage to health.

Recommendation 2

Hunter PIR's contribution to Tier 2 (Information, Linkages and Capacity Building) and systems change strategies is not isolated from the NDIS and instead is contributing to the Scheme. There should be greater recognition of this contribution to the Scheme.

Recommendation 3
Consideration be given to joint planning by NDIS planners and Hunter PIR Support Facilitators or other strategies to minimise duplication of effort and ensure continuity for the consumer. Hunter PIR action planning could be used to a greater degree by NDIS planners.

Recommendation 4
There is greater consistency regarding the evidence required to support an NDIS application and that the amount of documentation is streamlined and/or greater weight is given to non-clinical evidence.

Recommendation 5
The methodology by which the NDIS attributes disability and health related problems is unclear. Hunter PIR would support the development of greater transparency, such as an expert panel, and evidence-based approaches in cases where physical health issues are highly interrelated to the individual's mental health condition.

Recommendation 6
Clear information is provided detailing the reasons why an NDIS application has been deemed ineligible.

Recommendation 7
Greater recognition and understanding of the needs of individuals with psychosocial disability and the development and implementation of appropriate psychosocial assessment tools. It is important that the needs of people with psychosocial disability are better recognised and supported by the NDIS. Processes need to ensure there is equitable access for all people with a disability accessing the NDIS.

Recommendation 8
Further explanation and clarification of the terms 'psychosocial disability' and 'psychiatric disability' is needed to avoid any confusion.

Recommendation 9
The development of local Consumer Reference Groups to ensure the views and needs of consumers are addressed and that consumers are actively involved in planning, implementation and evaluation.

Recommendation 10
It is important that the NDIS supports rather than contradicts recovery-oriented practice and that the assessments used and the procedures are designed for individuals with psychosocial disability to maximise wellness and recovery.

7.0 The future