Brisbane North PHN

North Brisbane Partners in Recovery

SUPPORTING THE TRANSITION TO NDIS

FINAL REPORT

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1. EXECUTIVE SUMMARY

This report makes recommendations about the entry into the National Disability Insurance Scheme (NDIS) of participants with psychosocial disability arising from severe and persistent mental illness. The report's purpose is to help inform and guide those who will be working with this group under the NDIS, including participants themselves, planners, local area coordinators, and those delivering services.

The report was commissioned by Brisbane North PHN, North Brisbane Partners in Recovery (PiR) and the transition to the NDIS working group.

The report recommendations are drawn from a process of collecting the stories of successful outcomes for six participants in the North Brisbane PiR program. The stories were analysed to find out how and why PiR supports enabled the successful outcomes. The most recent NDIS price guide was then used to identify which supports are available to NDIS participants, and which are not available.

The process used was a participatory process called Collective Story Harvest - a method of using narrative to understand the what, why, how, when and who of a story, as well as uncover themes, critical elements for success and other, richer detail.

The Collective Story Harvest Process

A person is invited by a story circle host to tell a story of their experience. A group of listeners hear the story through 'listening arcs' - a particular lens or focus and note aspects of the story they hear related to that arc. The host and listeners ask clarifying questions at the end of each story. Listeners then reflect back to the storyteller what they heard and the storyteller has an opportunity to reflect on the experience and what they heard reflected back to them. Listeners are also invited to choose two or three key insights they had for their listening arc and these are collected and displayed (see Appendix 1). A framing and check in process before the stories and a check out process afterwards helps frame the process and support people to be in a space of feeling supported, willingness to share and deep listening.

The listening arcs chosen by the working group for this process, and the supporting prompts supplied to listeners included:

- narrative arc
- breakthroughs
- supports
- systems reform
- recovery
- personal strengths
- NDIS principles.

One participant and their Support Facilitator (SF) from each of the eight PiR teams were invited to tell their stories, from their perspective, of the participant's experience of PiR. Ultimately, only 12 of the 16 potential stories were collected due to either participant's mental health, availability or time constraints.

PiR teams chose the participant storyteller based on the following criteria:

1. Presumed eligibility for NDIS.
2. Active PiR participant.

3. Positive outcome over their time engaged with PiR.
4. Perceived capacity to articulate their story and to benefit from being heard.

The story harvests were collected in three separate sessions involving two or three teams at a time. Listeners had an opportunity to hear stories they were not familiar with and storytellers were listened to by supportive and unfamiliar listeners.

This report recognises that many support services provided to PiR participants are available to NDIS participants with several important exceptions. It also identifies the type and quality of support provided to PiR participants is paramount for this potentially vulnerable group and makes recommendations to the National Disability Insurance Agency (NDIA), policy makers, service providers, potential participants and their families and carers. These recommendations are summarised below and the indicators for success can be found on page 9.

Recommendations for National Disability Insurance Agency (NDIA)

1. Communication: ensure that all relevant service providers have the appropriate skill set to meet the needs of this population group.
2. Pre-planning: a comprehensive well-resourced pre-planning phase to ensure the participant receives a plan that meets their needs.

Recommendations for policy makers

1. Ensure adequate resourcing throughout the planning process.

Recommendations for service providers

1. Engage in transition and planning activities from a recovery oriented framework.
2. Provide adequate support and training for staff.
3. Be thorough in documentation and evidence gathering process.

Recommendations for participants, families, carers

1. Seek knowledge, skills and support in preparing for the NDIS.
2. Engage in training or activities to enhance skills in communication and self-advocacy.

2. INTRODUCTION

This project was commissioned by Brisbane North PHN on behalf of the North Brisbane Partners in Recovery (PiR) Transition to the NDIS Working Group.

The work was undertaken to gain a depth of insight into what works well to support people with severe and persistent mental illness. The primary purpose is to help inform and guide those who will be working with participants under the NDIS, including planners, local area coordinators and those delivering services.

The North Brisbane PiR Consortium includes: Brisbane North PHN, Aftercare, Open Minds, Institute for Urban Indigenous Health, Neami National, Footprints, Mental Illness Fellowship Qld, Richmond Fellowship Qld and Communify.

This final report includes the project's phase 1 report, which covered the findings of the data collection process.

This report investigates the collected data through the NDIS lens. It identifies if North Brisbane PiR support services align with the NDIS, the implications of any lack of alignment and recommendations which may be useful to participants, their families and carers, PiR teams, case workers local area coordinators, planners and policy makers within government.

Additional data that was collected for or referred to in this report are included in appendices.

This report is made up of an executive summary, three parts and appendices.

- **Executive summary and introduction:** brief outline of the project and recommendations.
- **Part 1: Collecting stories:** The process used to collect stories and analysis of the stories.
- **Part 2: Recommendations and indicators**: Recommendations and Indicators for several audiences: NDIA, policy makers, service providers, participants and carers/family members.
- **Part 3: Alignment of supports:** Shows where supports provided under PiR align with the NDIS price guide and where they do not.
- **Appendix 1:** Visual harvests for participants and PiR teams.
- **Appendix 2:** Stories and raw data from Collective Story Harvest listening arcs.
- **Appendix 3:** Brisbane North PHN workforce survey results.
- **Appendix 4:** Details of the WRAP® (Wellness Recovery Action Planning (WRAP®)) and Wise Choices programs.
- **Appendix 5:** Tells the stories (based on the experiences of storytellers) of two hypothetical people receiving support from PiR transitioning to NDIS.
- **Appendix 6:** Hunter Valley PiR webinar transcript.
- **Appendix 7:** Full table of PiR supports matched with NDIS funded supports including item numbers and descriptions.

3. COLLECTING STORIES

As noted in the executive summary, the Collective Story Harvest process was used. This method uses narrative to understand the what, why, how, when and who of a story, as well as uncover

themes, critical elements for success and other richer detail.

The listening arcs chosen by the working group for this process and the supporting prompts supplied to listeners included:

Narrative arc

Details of the story: people, events, stages, facts, emotions, values.

Breakthroughs

What were the breakthrough moments in this story? What were the tipping points where the person felt they were getting what they needed or were supporting that to happen? When was a wicked problem solved? What did they look like? What was important?

Supports

What were the direct and indirect supports/interventions offered by the SF in this story? What interventions, processes, applications, discoveries happened? Were they successful or not? Why - what made these successful or not? Where did barriers and challenges show up, what were they and why?

Systems reform

Where did local systems reform opportunities/examples show up? What did this look like? Were they successful or not? Why - what made them successful or not? Where did system barriers and challenges show up, what were they and why?

Recovery

Where did the principles of recovery show up in this story? Increase in people's capacity and resilience? Working towards a life of their choice? Hope and optimism? Person first and holistic? Organisational commitment and workforce development? Upholding of human rights and social inclusion? Did original recovery goals shift? Where did barriers and challenges show up, what were they and why?

Personal strengths

What values, knowledge, behaviour and skills of the story teller contributed to the positive outcomes in the story? Where did barriers and challenges show up, what were they and why?

NDIS principles

Where did effective planning show up? Where was flexible funding useful in overcoming program/service limitations? Where did social and economic participation show up? What did this look like? What was important in these principles showing up? What barriers and challenges showed up, what were they and why?

One participant and their Support Facilitator (SF) from each of the eight PiR teams were invited to tell their stories, from their perspective, of the participant's experience of PiR. Ultimately, only 12 of the 16 potential stories were collected, due to either participant's mental health, availability or time constraints. These stories are recorded in Appendix 2.

PiR teams chose the participant storyteller based on the following criteria:

1. Presumed eligibility for NDIS.
2. Active PiR participant.
3. Positive outcome over their time engaged with PiR.
4. Perceived capacity to articulate their story and to benefit from being heard.

The participant's SF invited the chosen participant to take part in the process. The participant was offered remuneration of $30/hour for a maximum of 4 hours to honour their contribution to the project. It was interesting to note that every single participant, when being offered this remuneration at the end of the process, stated that they would have participated regardless of remuneration. They felt they were making a contribution to PiR and as a way of 'paying back' what they felt they had received from PiR, as well as benefiting others with mental illness.

The story harvests were collected in three separate sessions, involving two or three teams at a time. Listeners had an opportunity to hear stories with which they were not familiar and story tellers had an opportunity to be listened to by supportive and unfamiliar listeners.

Participants invariably enjoyed the process and felt they had both contributed and gained something from the process. One participant, when asked her experience of the storytelling and reflection back, said *'Awesome - I didn't know how good this would be. I feel fantastic, like I could do anything'.* Every participant expressed feelings of validation and enjoyment in contributing their lived experience for others' benefit. In being listened to so thoroughly and in having positive aspects of themselves and their stories reflected back to them. PiR team members also reported the same experience - enjoyment in hearing positive stories of transformation through PiR and validation that their work was useful to people. They also reported feeling *'inspired'* and *'uplifted'* by the astonishing resilience and courage of participant storytellers. They also appreciated the opportunity to reflect on different practices of PiR teams and to hear new ideas and approaches.

After the initial data was collected, the working group met to conduct a 'sense-making' session, analysing and sorting the data through an NDIS lens. This sense-making activity was used as a basis for the final report on alignment and non alignment of PiR supports with NDIS funded supports. Its purpose was also to identify gaps and opportunities for shaping the NDIS implementation for people with psychosocial disability.

It is evident that people with severe and persistent mental illness are an at-risk group under the NDIS framework. Potential vulnerabilities include:

- Needs that may not be clear or easily understood.
- Lack of trusting relationships with people who can translate their needs.
- Marginalisation and stigma which may affect participation in the scheme and in broader social and economic life.

The knowledge held within PiR can inform how the scheme works for people and shape the experience of accessing support to have a significant positive impact on people's lives. This experience is captured below.

Supporting people to meet their goals - a synthesised story of PiR

People who come to PiR for support have, without exception, suffered profound trauma in their lives.

Many have been physically and sexually abused, have experienced significant loss and grief are disconnected from their families and socially isolated. They have been given multiple diagnoses, had multiple hospital admissions, are highly stigmatised and have experienced many instances of discrimination.

Storytellers shared the effects of such a life history including dysfunctional relationships, interrupted or absent work history and housing issues. A couple of major commonalities in people's stories were the disabling effects of substance use and hoarding, and the multiple and repeated service and system failures.

North Brisbane PiR has created a taxonomy outlining the various components that support facilitators undertake to improve the system response to and recovery outcomes for people with severe and persistent mental illness with complex needs. The table below show the various components, which have been grouped into engagement, care coordination, service integration and systemic change. This table is a reproduction of an original table in the Brisbane North PiR framework manual. Whilst people can certainly move between the components easily, as a guide, Support Facilitators generally spend time in each phase, moving from left to right.

Engagement	**Care coordination**	**Service integration**	**Systemic change**
Development of a positive working relationship with potential PiR.	Improved operation of the service system for individual PiR consumers.	Identification of and response to service gaps for the PiR population group.	Systemic problems resolved and reform achieved for the PiR population group.

• Promote PiR services to individuals, services, networks and communities. • Outreach to places where there are potential customers. • Receive and respond to initial inquiries. • Receive and respond to referrals and initiate intake. • Build an open, trusting and productive working relationship with people referred.	• Undertake a comprehensive assessment to ascertain needs and goals. • Develop an Action Plan to meet needs and goals. • Source case management if needed, including flexible funding. • Facilitate access to services and supports consumers have used before. • Identify new and different services and supports for consumers. • Broker access to services and supports. • Communicate with and coordinate the range of services involved in the Action Plan. • Work with other agencies to remove service blockages. • Work to make existing services and supports more effective. • Regularly review assessment and Action Plan.	• Identify service gaps across the PiR population group. • Improve referral pathways that facilitate access to the range of services and supports needed by the PiR population group. • Identify and work on opportunities for extending, expanding or streamlining services and supports. • Identify and act on service integration opportunities that support better consumer outcomes. • Develop partnerships and protocols to facilitate and broker new policies, programs, services and supports. • Use flexible funding to respond to service/support gaps. • Support and/or participate in Innovation Fund projects. • Get identified service/support gaps on the agenda of relevant agencies and work collaboratively to respond to these gaps.	• Use partnerships and collaborative mechanisms to identify, discuss and resolve systemic problems. • Facilitate and broker new policies, programs and services. • Undertake systems advocacy.

NB: This table is a reproduction of an original table in the Brisbane North PiR framework manual.

North Brisbane PiR is also underpinned by four key guiding principles:

- recovery oriented and participant focussed
- flexible in its roll out
- complementary to existing service systems
- able to better coordinate systems.

The taxonomy and guiding principles provide the framework for how support facilitators engage and interact with participants. These structures will be used to guide the following section of the report.

Initial engagement - what does it take to build an open and trusting relationship?

In supporting people who present to PiR, we found the importance of initial engagement cannot be underestimated. It lays the foundation for the open and trusting relationship which is critical as people work together to achieve their goals.

Skills and strengths of support facilitators

Initial engagement with people was open, empathic and supportive. Some participants were referred, but others were encouraged to self-refer after PiR team members noticed their needs and engaged with them. Meetings took place where the person felt safe including: a park, a coffee shop or whilst working alongside one another at a Christmas hamper packing facility.

Joy told a story of being engaged with deep humanity, respect and kindness when she contacted PiR after being given a pamphlet by a pharmacist. She was suicidal at the time:

> *'I have faith in God, asked if the PiR people could help me, my son and my family. If it didn't work I could always go back to my plan to end my life. I called and spoke to a lady on the other end of the phone. She was so kind. She was genuinely listening to what I had to say. She had great empathy and knowledge. She said something that nobody had ever said to me before – 'It's okay to reach out for help' and said she was glad that I had called. I was bewildered at her kindness and that someone has understood what I was saying. Then Mila called, and she also seemed to understand and was very kind to me. She said she would help me no matter what it took. I decided to take this opportunity and make the greatest use of it.'*

Critical to this phase of engagement were SFs who were very skilled and demonstrated high emotional intelligence. Some of the aspects of emotional intelligence that shone through the stories were empathy, compassion, non-judgement, acceptance of difference, respect, patience, trustworthiness and overwhelmingly a belief in people's capacity and potential.

SFs were seen as honest, sincere, transparent and organised, providing a point of stability and predictability in people's lives. SFs saw alternatives and possibilities, focused on strengths and saw the person as whole. They were hopeful, valued justice and were open to challenges. This sense transmitted itself to people, who began to be more hopeful and feel a sense of their own agency. A sense of humour and lightness in the midst of darkness was heard multiple times - storytellers related to their SFs many times through humour. All of these factors contributed to the creation of a sense of psychological safety for storytellers.

> *PiR – they don't chop and change their shift workers or carers. That is so vital for me. I'm an honest person. If I say something and feel I may have hurt one of them, they don't run away.*

> *I'm treated with dignity, respect, and professionalism – from a Department I didn't know existed! Joy*

Trust was further built through a focus on resolving immediate issues as quickly as possible and through person-first planning, where people always had choice and control. SFs were willing to try new approaches and always followed through on actions.

> *PiR has uplifted me, pointing out different perspectives, my achievements, how far I've come. If they can't see it working – nobody can! I was put in touch with another department, and there was an issue. I was able to freely and openly speak about it – my alarm bells were ringing. It was seen to and that was taken away. All of my stress went and I had room to breathe again. Joy*

Storytellers also spoke about SFs' creativity and flexibility and their broad range of life experience as helpful to them (participant storytellers) in moving forward. Knowledge was also important - storytellers talked about SFs' knowledge of services and systems, human behaviour, physical and mental health issues and medications. Important for an indigenous storyteller was the SF's indigeneity and her cultural knowledge and insight.

Skilfulness was needed, and noted and some areas of high skill for SFs were communication, mediation and most frequent and apparently most impactful, advocacy.

One storyteller summed all of these skills, knowledge, values and attributes of SFs by saying *'she just loves people'* and another spoke of the impact by saying *'there was no joy in my life before. Now there is'*

Appendix 3 is the results from a survey of the North Brisbane PiR Support Facilitators that demonstrates their skills and expertise.

Skills and strengths of participants

Participant storytellers also displayed key personal strengths that have kept them alive, open to being supported and willing to change themselves or their circumstances. This was seen as critical to successful outcomes as PiR has focused on people's strengths to support them to meet needs and goals.

The most common strengths observed by listeners were honesty, pride, self-reliance, hope and courage. They were remarkable in their resilience and willingness to trust and accept help, despite their experience. They showed a wonderful capacity and determination to learn and change, to think positively and to focus on the future.

'I am achieving so, so much progress and am able to report that I am living a quality of life I deserve' - Joy

Many storytellers were highly intelligent, well-educated and articulate, highly creative and artistic. Some had surviving connection to key informal supports in their lives. Some had a strong moral framework or religious faith which kept them moving forward. All cared deeply about their families and some were parents who were trying very hard to be the best they could be.

Many participants showed high levels of emotional intelligence a very appealing and developed sense of humour, were great communicators and self-advocates. They showed high levels of insight, were reflective, good problem solvers and had great capacity for functioning in stressful situations. Also

some participants showed self-compassion, compassion for others and a highly developed sense of social justice.

Routine and predictability was important for some, while others were more adaptable to change. Many were very hardworking and responsible in their daily lives. All had hobbies and interests. Some adored their pets and cared for them as a treasured family member.

Most striking of all for a group who have suffered so much trauma over their lifetimes, was the deep desire, expressed by every storyteller, to use their experience to help others.

Flexible, individualised support

In hearing the stories, it became apparent that supports that provide successful outcomes in PiR are flexible, creative and focused on or adapted to individual needs. One storyteller told of a work/small business history interrupted by involuntary hospitalisations and of his discomfort and troubled relationship with employment services. He had a specific desire to begin his own business again, so PiR supported him to carry out the necessary registrations, procure business cards and flyers and gain some sub-contracting work.

Another storyteller spoke of her ineligibility for many services and supports because of her WorkCover status. As a PiR participant she was able to access supports that suited her particular needs and importantly for her, were of her own choice, not because of a *'contractual obligation'.* After an initial period of trust building and goal setting, this storyteller was able to receive the services of a life coach, which suited her needs well.

A third storyteller felt unable to access culturally appropriate medical care. When a trusted PiR SF introduced her to a yarning circle, she was able to build enough trust to engage with the local indigenous medical service and her medical care and health has improved as a result. The same storyteller told of the SF speaking to her psychiatrist about the cultural meaning, for her, of hallucinations. This helped to improve the storyteller's relationship with her psychiatrist and her treatment.

Hoarding, as noted before, was a feature of several stories, as were the hoarding clean ups provided by PiR. One person felt unable to allow anyone she didn't know in her home, so the SF helped her to begin, with great results. The storyteller is now very house proud and the clean-up has meant that her granddaughter can safely and happily stay over.

Support to work with technology was often cited in stories, things as simple as using a smart phone or setting up a TV. The flexibility of PiR meant these supports were identified and offered with good results. For example, the storyteller who has begun his own gardening business, now knows how to use the GPS on his phone to find the address of jobs.

One storyteller spoke of the need for very specific individualised support. The participant had difficulty and experienced anxiety with setting boundaries around family, including her son who experienced mental illness. People would leave their dogs with her, frequently stay over and her home was very chaotic for her younger daughter and herself, with some hoarding occurring. The SF supported her to arrange the removal of the dogs and set rules around family staying over. They also arranged cleaners and a mini skip, a plan to obtain suitable housing, a plan for appropriate accommodation for her son and support to visit the school in regards to her daughter.

One SF storyteller spoke of arranging training for support workers from multiple agencies which was specific to the participant's needs. The participant requires consistency and has some significant

challenging behaviours and often had difficulties with different support workers coming into her home. Training specific to the participant and regular communication between support workers was arranged by PiR, with good results.

Other supports provided included referrals to psychologists, anger management group, a nutritionist, Personal Helpers and Mentors (PHaMS), and a frequent presenters program. Participants were linked into groups and peer support such as the Wellness Recovery Action Planning (WRAP®) group, bowls, art and craft groups and Wise Choices program (see Appendix 4).

One participant spoke of accessing these supports: *'I'm anxious now about meeting other people - at groups and in my home - and having those feelings shows I am no longer numb. Change is occurring'* and another said that meeting a peer worker *'gave me hope'*

Others received in home support and domestic assistance. One participant was supported to learn how to use public transport - a life changing skill for her. Another was supported to access free furniture and food from charities. Support was provided to another to find suitable housing and to prepare for a move.

Other individualised supports included asking for help, engaging with family, taking part in hobbies and volunteering. For some, a call to the GP or regular phone contact with the SF, was all that was required for some periods. One participant spoke joyfully of the results of support to access a mobility scooter - *'it's my freedom machine'.*

The stories highlighted that supports tailored to the unique needs of individuals are crucial to positive outcomes.

Flexible funding

The use of flexible funding, a unique feature of PiR, was frequent and varied. Judicious use of small amounts of money was able to help achieve significant breakthroughs for many storytellers. For some, flexible funding was used to meet short term gaps in access to services e.g. a support worker and transport. On other occasions, flexible funding was used to support people to attend events which they could not otherwise have afforded e.g. a women's retreat and a church camp. Some items for the home were also funded. One storyteller purchased curtains to increase her sense of safety from neighbours and a vacuum cleaner to help her keep up her newly cleaned home. One received a mattress and sleeping bag as part of setting up a home. The small business owner storyteller had flyers and business cards paid for by flexible funding. The same storyteller has a treasured cat (Catus Quo!) whose boarding was paid for while the storyteller was in hospital. Another storyteller had emergency vet fees and transport to the vet for her cat paid for.

Care coordination and service integration

Care coordination

Several storytellers had multiple services involved, with multiple workers or case managers. The complexity of a person's needs was matched by complexity in service delivery, which lacked one central person who could advocate for the storyteller's needs. PiR provided this in a supportive, inclusive manner. Storytellers spoke of arrangement for case coordination meetings, plans across multiple services for crisis intervention and even mediation between case managers from different services. One storyteller is supported to have contact with other agencies by the SF sitting with him to make calls on speaker phone, where she is available if needed. Others have appropriate behaviour and language role modelled so they can learn to effectively self-advocate. Others have been connected to culturally appropriate services and to after-hours services. Several participants have been given letters of support for court or housing disputes and one was supported to find legal advice.

Several storytellers were persona non grata with government or non-government services. One storyteller's Department of Housing file was marked 'approach with caution' and she consequently never had maintenance or improvements done in her home. Visits by the Department were with a police escort. The PiR SF successfully advocated on her behalf for necessary repairs and for the Department to provide a fence to enhance her sense of safety from neighbours. The participant was able to have her story heard by the Department and they allowed her to keep her home, and now treat her respectfully.

The same participant was the victim of neighbourhood harassment, to which she responded by becoming abusive towards the neighbours. The police were frequently called and their response was to take her to a psychiatric ward for admission (up to three times per week). The SF worked with her to manage her own responses and with the neighbours and police to humanise the participant and disrupt the patterned interactions. This has been enormously successful, with the participant not having been taken to hospital by police at all in recent months, some neighbours becoming supporters and the participant herself feeling safer in her own home and neighbourhood.

Service integration

Service integration showed up in several stories. One participant spoke of the SF acting as a contact for agencies that the participant did not feel able to interact with. Another spoke of the use of flexible funding to cover the cost of a program until her individualised funding became available. One participant was given support to self-direct her individualised funding package. And when one PiR team noticed that there were no specific activities for promoting women's wellbeing, they funded a women's retreat to fill the gap.

A particularly innovative example of service integration was the development, with the services involved, of successful in-house training for consistency of support. The participant, who previously rejected support workers, hasn't needed to change support workers since.

Systemic reform

Systems reform, which grew out of working with individuals, showed up in several stories. What also made evidence included the difficulty of enacting systemic reform within the resource and capacity constraints of the PiR program. The stories highlighted many opportunities for reform across and within systems which PiR was unable to act on. Where opportunities arose for systems reform, many were grasped by SFs. These included setting up groups and programs to meet the needs of multiple people where they did not already exist, such as Wise Choices, WRAP, bowls, BBQ group and the women's retreat. Several stories also told of SFs raising issues of dysfunctional support with other providers in a positive and solutions focused way with good results. Other systems reform activities have been previously mentioned, including:

- training for a participant to self-advocate with other agencies
- case coordination mediation
- linkages to other services/programs
- advocacy with Department of Housing
- QPS
- courts
- the use of flexible funding to fill gaps while a funding package was moved from one organisation to another.

Other examples of support that can be seen as systems reform included:

- the use of peer workers, which gave sense of mutual understanding
- hope and recovery
- making a plan with emergency services to manage crises
- referral to the Frequent Presenters Program.

Potential systemic change opportunities

The lack of capacity, resources and influence within PiR to reform systems did not stop PiR teams and participants from identifying what is needed.

The invariable and strong presence of trauma in the stories highlighted the need for prevention and healing for people who have suffered trauma. In particular, one storyteller identified the need for more support for people reporting child sexual, physical or emotional abuse.

One storyteller had been completely isolated from support because many services are available only for people who are unemployed, not for people who are on leave from work. Fortunately, in the short term, PiR was able to respond to this gap.

Most storytellers highlighted the need for more employment opportunities. They were explicit that employment drives meaning in life. Work can help people feel *'valued, purposeful, useful, important, and part of something'.* One suggested that voluntary work could be incorporated into clinical practice as a tool for connection between people with lived experience and clinicians.

One storyteller identified that support to return to work should be in place for mothers - her experience was that she couldn't return to the same level job and that she had little support to return. She also spoke about the lack of rights for mothers with mental health issues, to maintain their relationship with caring for their children.

One storyteller suggested innovation in community and economic participation - activities such as time banking, volunteering, offering services that can be swapped and interchanged. Another suggested *'Hope'* services - including peer support, planning facilitation and support for a shifting consciousness. More cultural awareness training for government departments and agencies was also highlighted as a need. One storyteller noted the need for more access to Aboriginal and Torres Strait Islander services to connect with culture and support. She also suggested that art or jewellery making workshops could become an innovative program. She asked *'how can we bring people together to hold cultural arts and crafts and yarning - a place for people to go?'* A further suggestion was for camps and cultural gatherings for people to talk about mental health issues.

The issue of hoarding, having shown up in many stories, was also highlighted. One suggestion was for a hoarding task force that works with a person in a way that suits them. One storyteller spoke of her experience with domestic violence services that didn't build trust with her and didn't follow up with her. They simply provided numbers and she had to figure it out for herself. More resources to support people as they seek safety are needed.

The hospital system and its impact on people with mental illness came up several times in stories. There was a theme that more training for clinical staff in a holistic approach to supporting people was needed. Others felt they did not receive sufficient support in leaving hospital and suggested a step up, step down model for people exiting hospital. Another storyteller suggested that there should be access to more resources in the public system. The private hospitals provided gym and an anti-smoking group. This was helpful and contributed to recovery and should be available in the public system. The same storyteller suggested that the public hospital system is inflexible and tends to work against recovery. It requires self-advocacy training and a more recovery oriented approach. He also suggested that treatment in the home instead of a ward in a clinical environment should be available to people.

Within the stories heard, the treatment of people with mental illness by government departments was raised many times. They suggested that police needed better education and training around trauma and mental health issues and the idea of an education program led by people with lived experience would be valuable. One storyteller suggested a court support program would be helpful.

Most departmental issues noted concerned the Department of Housing. One storyteller said that departmental collaboration and understanding of mental illness was *'paramount in moving forward and not creating additional trauma'*. Others suggested that there is a need for housing options that meet people's individual needs. Another suggested that programs for transitioning to a new home were needed.

One storyteller summed up the issues saying that more respectful, individualised engagement was needed from the Department of Housing. She reported that housing made her apply again once she started with BRIC Housing (a community housing organisation) even though the dwelling wasn't suitable.

> *'Housing didn't respect my request to ring PiR or Red Cross only. It influenced my mental health. They threatened that if I didn't take the first property I would go to the bottom of the list. They had no respect and were rude on the phone. Workers from housing would just turn up unannounced.'*

One storyteller wondered *'Do services such as housing and police know how to engage with someone with complex needs? Do they know how to talk to them? Do they even want to understand?'*

North Brisbane PiR was able to achieve some systems reform for housing within the region - see below for details.

These stories showed multiple systems reform opportunities across housing, police, courts and other systems. Improvements in individual engagement with these systems were achieved in some cases, but no tangible, bigger picture reform was achieved.

Systems reform projects in housing that grew out of identified needs for PiR participants in North Brisbane

The North Brisbane PiR consortium instigated a range of local system reform projects to address housing needs amongst their participant group.

It was recognised that many of our participants live in supported (or level 3) boarding house accommodation, however the boarding house staff were often not sufficiently trained in mental health and in need of some extra skill development. Herston Lodge approached Footprints PiR team to see if they could assist. Footprints developed a self-paced training package, coupled with short face-to-face workshops for boarding house staff at Herston Lodge.

Support facilitators often work with participants who are homeless or at risk of homelessness. Since early on in the PiR journey, Support Facilitators across the North Brisbane region have been involved in regional multi- agency case coordination meetings, involving support and housing providers and the department of housing, to advocate for their participants getting access to, or maintaining their housing. They also worked to promote these meeting to the sector more broadly as a place to go to solve complex housing issues collaboratively.

Support facilitators from Neami and Aftercare, worked with the Moreton Bay housing and homelessness network to get their localised housing concerns voiced and to create solutions collectively. In the Redcliffe region, there was a gap identified regarding the lack of presence of the department of housing in the Redcliffe peninsular region. Aftercare PiR worked to get the department of housing to attend weekly outreach sessions at a local morning tea where many homeless people attended. This successfully enabled local people unable to travel to Chermside or Caboolture, to access the Department of Housing service.

Communify PiR saw that people who identify as transgender often found it difficult to obtain and maintain safe social housing. They pulled together local housing providers, LGBTI and mental health support agencies to create the transgender housing project, which resulted in one housing provider allocating a proportion of their units at one inner north Brisbane property, to specific transgender tenants.

In Caboolture, where public and social housing is scarce, but rental housing is available and reasonably affordable, Open Minds PiR developed a pilot system reform project in collaboration with a local community housing provider and support services to develop a peer partnered tenancy model.

Recovery principles

Recovery principles were mentioned in every story. Given that this is the model which SFs do their work, the large number of examples is unsurprising and encouraging for recovery practitioners. SFs know they can work with people with severe and persistent mental illness and complex needs, to assist them to move towards their goals and achieve great outcomes.

Supporting personal recovery

Many storytellers reported an increase in people's capacity and resilience. An example of this is when people received support to repair and maintain family relationships. One storyteller spoke of using 'wise information to assist with decisions for my son'. She reports a better relationship with her son now.

One storyteller said that he *'feels more fit in the community'* and *'I have a good understanding about how to keep me well. I take medications regularly. I have knowledge in how to manage my emotions and feelings. I know how to better manage anger. I have more routine in life. PiR helped me to have a more stable life.'*

Another spoke about her own increased capacity in *'recognising alcohol and what it was doing'* and *'discovering pride and respect; being proud, knowing the need to 'break the cycle'. I wanted to break the cycle of alcohol and abuse in my family'.*

Another storyteller talked about the positive coping strategies she had learned to employ in her time in PiR: *'I cleaned, I sang, I mowed the lawn'.*

People's capacity to take responsibility was enhanced by their connection to PiR. One said *'Housing came to my house and I wanted to throw rocks but I reflected and didn't'.* Another called police when her thoughts were becoming dangerous. Another said *'I seek support when I need it. For example, I call the hospital. Many years ago I would have avoided seeking support even if I needed it'.* Some reported that SF modelling had grown their skills and capacity – for example, showing the person how to make phone enquiries or to speak and behave appropriately.

One storyteller, with a long history of institutionalisation and challenging behaviours, now keeps a tidy home, living independently in New Farm. She has a loving relationship with her family. PiR helped her take care of her bird Frederick, who is the most important thing in her life. In 2015, the storyteller had 200 presentations to hospital. After her referral by PiR, the frequent presenter program set up an art space for her at home – a therapeutic space and a good distraction. This has helped to reduce her presentations. The storyteller has now had no hospital presentations in the past 4 months.

Empowerment and achievement was felt by many storytellers. One spoke of *'encouragement from SF around moving towards living and knowing I had the right to a good life' and how she 'Doesn't need 'stuff' like she used to when going through trauma'.* Yet another said, *'Now I don't like conflict and I feel like the mature adult that I am meant to be'.* This storyteller also spoke of going back and *'looking at previous goals to see how far I've come',* and that *'if I make a mistake, I don't see it as a failure but look at a different way of doing it'.* One spoke explicitly of empowerment, *'The empowerment. The feeling I don't need to be aided'* and *'Doing something that I never thought I could do'.*

A life of choice

A further recovery principle identified in these stories was that of working towards a life of choice. Every storyteller felt that they had choice from the beginning of their engagement with PiR. They had the choice to engage, set their goals and live the life they want. Given that choice and control is one of the pillars of the NDIS, this recovery principle is worthy of deep attention including:

- how to build relationship that supports people to make choices
- what does a life of choice look like
- how to support people to imagine it
- how to offer choice.

All from a Recovery mindset, are questions that can help people working in an NDIS context begin to answer.

PiR was a good source of information for people as they worked towards lives of their choice. They advocated for people's choices in housing, agency support and support from agencies within their homes. One storyteller reported that 'when something felt wrong about a referral from PiR, I felt free to talk about it and make changes'.

One storyteller spoke of *'personal choice – PiR worked with my strengths, insights and my choice of life'.* Another spoke about how he is *'still trying to find meaningful way of living and work towards the life I want. I currently have part time work. My goal is full time and I want to be a mental health worker'.* Another storyteller said *'I am working to keep up my tenancy, and remain independent' and that 'I am living an independent life now, previously I couldn't go out without someone else'*

Several storytellers spoke about how flexible funding allowed them to work towards lives of their choice by providing things they could not otherwise afford. One in particular spoke about the support she received for pet costs she could not fund independently. She and others spoke about PiR's focus on listening and tailoring interventions to what they, the participants, perceived as important.

Hope and optimism

SFs consistently demonstrated an attitude of hope and optimism towards participants. Participants began to feel hope and optimism as they achieved goals they had previously thought they could not.

One storyteller spoke of how PiR *'pointed out positives from a different perspective for me to see'* and *'talked about how far I've come when I couldn't see for myself'*. People's uniqueness was identified early by SFs and their belief in people's capacity for change was critical to participants developing hope and optimism.

Connections to peers was also important in people developing hope and optimism. One storyteller spoke about a peer support worker saying *'you'll have your ups and downs, but you'll never lose hope.'*

Plans for the future speak of hope and optimism. Some examples include *'I hope to keep getting involved with community, do mental health work and do a course to help others. I want to keep involved in my gardening business'.* Another participant spoke of her plans to continue with her art and look towards selling it. Several spoke of plans to get work.

All participant storytellers spoke of a desire and plan to give back - a powerful expression of optimism. One said *'I want to give back from the best that I have become'.* Another said *'I am maturing in a social world and can adapt so the sky's the limit. Nothing will hold me back'.*

Finally, one participant spoke of her increased optimism thus: *'I like to wake up now'.*

Person first and holistic

Stories demonstrated the recovery principle of person-first and holistic support.

Firstly, several people spoke of the idea transmitted to them by SFs that *'it's okay not to be okay'*. This validated their experience. Others spoke of how their uniqueness and strengths were identified early, and that their own needs and goals were most important.

One spoke of the *'commitment of the SF when I was not forthcoming - when I didn't answer calls or come to the office, Dennise would visit and leave her card'.*

Another spoke of how the SF said to her *'we will do whatever it takes to help'*. For some this has meant an SF standing beside them in court, or being with them in mediation. For another, this meant helping her to clean her house when she didn't trust anyone else to be in the house with her. When a person had a particular need for consistency, SFs worked hard to provide it. They did what they could to ensure consistent support workers and were consistent themselves.

One story told of how the SF upheld the principle of *'nothing about me without me'* by advocating for the person to be involved in all meetings and decisions.

Another story told of SFs utilising support workers to support the person with practical issues. They had good knowledge of what was involved in the person achieving his goal and identified his strengths and assisted him to work towards it. At the same time, the SF provided support to facilitate the person to overcome possible barriers.

Upholding human rights and inclusion

The recovery principle of upholding human rights and social inclusion was mentioned in stories.

The right to feeling safe was respected and upheld in every story. One storyteller spoke of *'justice, integrity and feeling SAFE',* another that *'My recovery began when I joined PiR, engaging in your safe place'.*

Many stories spoke about how participants' human rights were upheld by the SFs engaging with the police, the courts and housing on their behalf.

All storytellers spoke about acceptance, belonging and inclusion. One said *'I had a good rapport with my SF, I never felt judged'.* Another said *'I always felt very supported with PiR SFs. They are supportive, they listen and respond to 98% of my phone messages.* One story told of the SF working with the person to regain their connection to their community and church. The SF ensured that their housing application had suburbs that would be close to their community and support services.

NDIS principles in PiR

How PiR aligns with the NDIS is a key question for PiR participants and workers. The stories told had much to offer in thinking about this alignment.

The NDIS is an insurance model, aiming to invest in early intervention and supports that will have good outcomes and drive down the cost of lifetime care and support.

Several stories highlighted how PiR is effective when viewed through this lens. Two participants in particular had multiple frequent ambulance and police involvement and hospital presentations over years prior to PiR. All of these have reduced significantly as a result of their involvement in PiR. Others reported a noticeable reduction in hospital admissions and decreased use of services as they received targeted support and increase in capacity and resilience across their life. PiR has been a very cost-effective model for this group is highly aligned with the insurance model of the NDIS.

NDIS is a legislated entitlement of all those whose functional impairment means that they require support to live a normal life. Some storytellers expressed concern that participants will require significant support to access the scheme and may potentially 'fall through the cracks'. Concerns were raised that the scheme may not have the capacity for planners and local area coordinators to engage with people in a way that meets individual needs, as PiR does.

Planning is an important part of NDIS - people develop goals that are then translated into funded supports if they are eligible for the scheme. Reports from the NDIS trial sites indicate that the planning process with participants may not be replicable in NDIS. Stories told of the importance of having the assessment in a safe place that planning in PiR felt constant, not one-off or ad hoc. Ensure there was no pressure and that planning was done at the participant's pace and that planning responded to changing needs and crises. Most importantly, PiR planning is based on deep and trusting relationship. There is reason to be concerned that the current NDIS planning processes do not look like this and that in particular, the 'My First Plan' initiative will be detrimental to PiR participants accessing the scheme.

Some alignment in the planning processes of PiR and NDIS showed up in many stories. PiR planning is based on needs, as is NDIS, qualified by the words 'reasonable and necessary'. PiR participants co-design their plans. their needs and goals which are all directed by the person. The same goes for NDIS. Planning in PiR can be augmented by information gathering from a number of services the person already receives, which, despite initial reluctance, the NDIA now includes if the participant allows it. And finally, PiR plans can change whenever a person requests it, which is also the case with NDIS, though the process may be considerably slower.

'My interactions with police used to be two-three times per week. Now I haven't seen them in six months.' Lisa

Social and economic participation is a key principle of the NDIS. This principle showed up in all of the stories of PiR participants. All wanted to connect to others, to be part of something, to belong and all were supported to do so. One storyteller said *'I have much more of a social life. I have a new partner, I have contact with my family. I have less problems with the police and housing. My SF helped me talk to them and now I even get praise from the police'*

Most participant storytellers wanted to engage in meaningful work, whether paid or volunteer work, and most have moved much closer to doing so, or have begun. One storyteller said *'I believe in myself*

now and think I can become more a part of the world than I was before. I already am. I want to work in the future in a women's shelter or with brain injured people'.

PiR is deeply aligned with the social and economic participation principle of the NDIS.

Choice and control, have been mentioned in many stories and is present in PiR support facilitation. It is also a key principle of NDIS. One PiR participant expressed her desire for choice and PiR's fulfilment of that desire, thus: *'It's important to me to have choice, this builds trust and lack of trust has been built over many years. People usually judge me and don't believe me, and make promises which they don't follow through on. I trust the PiR staff because they listen, believe me and don't judge me'.*

SF storytellers told of always supporting choice and control. For example, who the client wants working with her, what supports she receives, how she receives them, what she needed from flexible funding. This is, again, closely aligned with NDIS principles.

Finally, NDIS has a focus on individual needs and on innovation to meet those needs. The stories demonstrated that PiR has a similar focus. All stories told of people's unique needs being addressed in creative and flexible ways, as noted above. PiR-like services and supports will be well placed to continue to meet individual needs under an NDIS.

What has happened for people over their PiR journey?

Those who can best express the outcomes for participants of PiR are the participants themselves.

> *'I'd like to build a mould of you people – your love, compassion and respect. There's a lot of love in this environment for people, not positions. I'm in awe of you all. I imagine you must have had a lot of love in your lives to give it to others. The love has returned because I've been loved and respected. It's a privilege and honour to be invited to be here today. I'm valued. I'm not only valued, but useful!' Joy*

> *'I am achieving so, so much progress and am able to report that I am living a quality of life I deserve' Joy*

> *'Throughout my life I have always felt I don't matter – PiR has made me feel I do, given me a sense of acceptance, belonging, gentle encouragement, complete understanding. With my hoarding – Dennise didn't blink an eye. It was okay to be as sick as I was. My SF, the groups, other Support Facilitators – it was okay not to be okay, and to ask for help' Kate*

> *'I'm hopeful for the future, interested in working in space of mental illness, getting business started again. ..... I take every opportunity to tell people of injustice. Being upfront lets people know where they stand. Sick of bipolar, and being seen as aggressive. PiR has never felt like being in the system, not being held by rules and regulations. They listen to me, messages get passed on, they respond to my needs. .... PiR work with what you've got. It's hard to recall planning. I worked with support around goals. It's easy to deal with PiR..... I pretty much feel in control of the process..... Since PiR I'm more structured with my routine, getting support in areas I wouldn't otherwise, and haven't previously. It's nice to have one person who facilitates support... With the support of PiR, I'm able to function more freely in the community. I spend less time in hospital.' Mark*

> *'Supports have been set up that are appropriate to my needs. I feel I would be in a low care nursing home without Kim's intervention. The support workers I have now are good company. I am working to change behaviours but 40 years of the same neural pathways makes it difficult. Need to do a lot of work to stop self-harming. My goal is to have crockery and glassware including my mother's dinner set - I don't want to live in a world of plastic for the rest of my life.' Sally*

> *'I met Aunty Pepe. PiR - I didn't know it existed. I cried when I heard about it. I knew I needed help. Over the years I had too much pride. Pepe was there for me when I needed it. Shopping, cleaning. My daughter was missing school, she helped me. She would take me out away from my son. She helped with my health and got me into the medical centre. She helped me get a psychologist and helped me with my anxiety.' Elaine*

> *'Anne-Marie told me she was proud of me when I came off meds. I came up with my own coping mechanisms for dealing with my mental health issues. My interactions with police used to be two-three times per week. Now I haven't seen them in six months. They used to take me to Prince Charles every time they had contact. They have a better relationship with me now, I feel safe to call them when I need them' Lisa*

The collective story harvest process offered a rich set of data when examining what works for people with severe and persistent mental illness in being supported to live a good life of their choice. There is no doubt that PiR works with people who have some of the most complex needs in our nation and there is much to be learned from the approach.

Phase 1 conclusion

Based on the stories that were harvested, Appendix 5 is two hypothetical people receiving support from PiR as they transition to the NDIS.

Appendix 6 is a transcript from 17 June 2016 by staff at the Hunter Valley NDIS trial site. It provides insights into the opportunities and challenges of transitioning to the NDIS.

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4. RECOMMENDATIONS AND INDICATORS

Recommendations were developed by the North Brisbane PiR Transition to the NDIS working group, based on the stories told by PiR participants and support facilitators (see Appendix 1), about what supports were useful in achieving good outcomes for people, and why, and how they aligned with current experience of the NDIS. The recommendations have a series of indicators attached to them which were developed directly from the storytellers' experience.

Recommendations for NDIA

The stories told by PiR participants highlighted the potential vulnerabilities of people with severe and persistent mental illness in their entry into the NDIS. These potential vulnerabilities are generally related to participant experience of systems as disempowering, untrustworthy and lacking in skill when engaging with people with mental illness. The participant group frequently experiences social isolation, stigma, misunderstanding and disempowerment and requires education, clear communication, understanding, skill, and time to engage with the NDIS. In addition, this group can have very specific and changeable individual needs which require flexibility in any approach to support.

1. Communication: meaningful communication that reaches the target audience and is delivered in a timely manner

- Advertise NDIS broadly and with a specific mental health focus to reach people with psychosocial disability.

2. Pre-planning: a comprehensive well-resourced pre-planning phase to ensure the participant receives a plan that meets their needs

- Allocate more than one planning meeting for people who require time to feel enough trust to continue with entry into the NDIS.
- Fund well supported individualised pre-planning for people with psychosocial disability.
- Consult service providers about how to resource and train for pre-planning activities.
- Offer support (chosen support person/s to be present) to participants with mental health issues in the planning meeting.
- Recommend to participants that they seek pre-planning and implementation of the plan support from current service providers and/or independent planners and supports.
- Make existing pre-planning resources available to participants and service providers through an engagement strategy.
- Commit to regular communication with participants during the planning process, particularly if there are delays.
- Ensure planners honour pre-planning, regardless of format, by translating this work into 'NDIS plan' language themselves if necessary.
- Provide an automatic amount of funded Specialist Support Coordination (time limited) and ongoing coordination of supports for people with psychosocial disability arising from severe and persistent mental illness in every plan.
- Offer free and accessible advocacy and support for people with diagnosed mental illness to ensure successful engagement with and utilisation of plans.

3. Education, training and skill development: ensure that all relevant service providers have the appropriate skill set to meet the needs of this population group

- Ensure planners and Local Area Coordinators (LAC) have a mental health skill set, and understanding of the impacts of mental illness.
- Ensure planners and LACs are positive and compassionate and have experience in engaging with people who may have difficulty communicating their needs.
- Ensure planners and LACs take time to establish rapport and learn about the person's strengths, as an immediate focus on deficits or supports can be overwhelming and is not aligned with recovery oriented practice.
- Work with professional colleges to develop training packages for their members to increase awareness of and facilitate access to NDIS.
- Provide education for participants, carers and families to self-advocate.

Recommendations for policy makers

Recommendations for policy makers focus on resourcing flexibility and support in pre-planning, planning and review processes. The participant group often requires significant time to trust people working with them and frequently experiences changes in their circumstances due to the episodic nature of mental illness. In addition, high-impact, low cost supports purchased through flexible funding in PiR had good outcomes and should be considered by policy makers.

1. Ensure adequate resourcing throughout the planning process

- Preplanning: provide ongoing funding for preplanning activities, including after the completion of the rollout.
- Planning: allocate adequate time for face to face conversations to be had across a number of appointments to establish needs and build rapport.
- Post planning: provide a mechanism for entry back into the planning process when/if significant changes occur.
- Make flexible funding available for LACs to allocate for small sum/high impact interventions to target needs that may not be able to be addressed within the plan.

Recommendations for service providers

Service providers may enjoy high levels of trust from participants, work from a recovery oriented framework and often perform the valuable role of intermediary/support between participants and systems. In the case of intermediating between participants and the NDIS, a potential conflict of interest can arise between the needs and choices of participants and the business aims of the service provider. Recommendations focus on the intermediary/support role and directly address this potential conflict.

1. Engage in transition and planning activities from a recovery oriented framework

- Adapt/translate language in planning to the audience (NDIA and participants) to get the best outcome for participants.
- Provide culturally appropriate support in pre-planning for people from Aboriginal and Torres Strait Islander and Culturally and Linguistically Diverse population groups.
- Deliver NDIS information and pre-planning with optimism and over a period of time which suits the person's capacity.
- Support people to collect as much supporting information and start as early as possible.
- The planning process may engender discouragement - provide ongoing encouragement and support.
- Use available pre-planning resources that suit the person's needs.
- Ensure people have a mechanism to request a change in funded supports when / if changes occur.
- In pre-planning, start with dreams and aspirations, construct goals and then think about supports.
- Ensure the participant has thought about the informal supports available to them and about how they might like to manage their funding.
- Advocate for meetings to be held where the person feels comfortable. Ensure support is provided in the planning meeting if the person wants it.

2. Provide adequate support and training for staff

- Train staff in the planning process so they are well equipped to support people through it.
- Genuinely engage in pre-planning work with current clients without expectation of post-plan service provision to the client (being aware of conflict of interest).
- Provide people providing NDIS assessments with assistance to access relevant information about the NDIS.
- At implementation stage, clear and transparent communication, information and agreements will reduce confusion over changed roles.

3. Be thorough in documentation and evidence gathering process

- Supporting information should focus on how the person's disability impacts on daily functioning.
- Make the link to underlying mental health issues in pre-planning and do not focus purely on the presenting problem (e.g. substance use in and of itself is not covered by the NDIS, but there may be a mental health issue underlying the substance use behaviour).
- Ensure pre-planning is documented and the person takes the documents with them to the planning meeting.

Recommendations for participants, families, carers

Choice and control is a key pillar of the NDIS and is a principle that participants, families and carers may have had little experience with in their lives. Recommendations for this group are strengths based and focus on building capacity for choice and control.

1. Seek knowledge, skills and support in preparing for the NDIS

- Advocate for funded pre-planning opportunities.
- Seek pre-planning and planning support from trusted current service providers or independent pre-planners.
- Seek training in the planning process so you know what to expect and what can be contested.
- Collect as much supporting information and start as early as possible.
- Supporting information should focus on how the person's disability impacts on daily functioning.
- Make the link to underlying mental health issues in pre-planning and do not focus purely on the presenting problem (e.g. Substance use in and of itself is not covered by the NDIS, but there may be a mental health issue underlying the substance use behaviour).
- In pre-planning, start with dreams and aspirations, construct goals and then consider supports.
- Ensure you have thought about the informal supports available to you, and about how you might choose to manage your funding.
- Request planning meetings to be held where you feel comfortable.
- Ensure pre-planning is documented and you take the documents with you to the planning meeting.
- Include contingency funding for crises in plans, based on past two-year history e.g. hospitalisations.

2. Engage in training or activities to enhance skills in communication and self-advocacy

- Research and access opportunities for communication and self-advocacy training.

5. ALIGNMENT OF SUPPORTS

This part examines in detail where supports currently provided by PiR may fit into NDIA funded supports. The specific PiR supports categorised are identified by participant and support facilitator storytellers during the Collective Story Harvest phase of this project (see Appendix 1 for the raw data).

A finding that surprised the report writers in this alignment exercise was that most of the supports provided by PiR could reasonably be expected to be funded by the NDIA, depending on how goals were constructed in pre-planning and planning sessions. The stand out exceptions were flexible funding, pet care costs and advocacy.

NDIA funded supports

PiR provided supports that align with the most recent National Disability Insurance Agency (NDIA) price guide and can reasonably be expected to be provided in the plans of eligible participants under an NDIS. The supports are categorised using the NDIA support purpose categories and support Items. (A more detailed table, including descriptions and item numbers, can be found in Appendix 7).

Support purpose category: Core supports

A support that enables a participant to complete activities of daily living and enables them to work towards their goals and meet their objectives.

NDIS support category	PiR supports (as identified by storytellers)	NDIS support item
1.01	● support to volunteer	Assistance to access community, social and recreational activities - individual - per weekdays
1.01	● peer social connection ● acceptance and belonging with groups – “I matter to someone’ ● connections to art and craft ● connections to groups – social interaction ● assist social connection ● increase connections	Group based community, social and recreational activities - weekdays
1.01	● domestic assistance ● house cleaning	House cleaning and other household activities
1.01	● home maintenance – safety	House and/or yard maintenance

Support purpose category: Capital supports

An investment, such as assistive technologies, equipment and home or vehicle modifications, funding for capital costs (e.g. to pay for specialist disability accommodation).

NDIS support category	PiR supports (as identified by storytellers)	NDIS support item
2.05	● mobile scooter	Assistive Technology

Support purpose category: Capacity building supports

A support that enables a participant to build their independence and skills.

NDIS support category	PiR supports (as identified by storytellers)	NDIS support item
3.07	• case coordination • communication of mental health and behavioural triggers to relevant agencies with whom the person is working • developing a ‘shared’ crisis plan • working across the clinical and community services • access to specialised programs • access to the right clinical services • drug and alcohol support • coordinate care between clinical and non-clinical services • PiR – coordinate – other plans and mediate when services do not work • dind/ensure long term recovery supports found and provided (grief/loss) • human rights upheld with Police • self-advocacy training • support focussed on building capacity • developing understanding, rapport and relationships • built resilience and has new ways of managing difficulties	Specialist support coordination
3.07	• PiR helps keep me ‘on schedule’ • link to health practitioner • choice to access own identified support	Support connection

NDIS support category	PiR supports (as identified by storytellers)	NDIS support item
3.07	• co-ordinator of supports – helped with clarity • linking with other agencies • liaison with GP • linked to private hospital • medical links • access culturally appropriate support • had help with what she needed and choice • access to specialised services (coordinate) • control and life choices • always at the centre of all decisions • ability to self-determine • trust – barrier to accessing other services outside PIR - trusted support • flexibility to change plans • ability to work across multiple agencies • supportive routine – 'someone's got my back' • maintain relationships with other supports • building extended networks • build in crisis response	Coordination of supports
3.08	• support to remedy housing breach, tenancy sustainment, support to access new housing options • mediation with neighbours • finding a house	Assistance with accommodation and tenancy obligations
3.09	• learn to use a smart phone for navigation • support to use technology	Individual skills development and training
3.09	• wellness camp • art group – social connection	Community participation activities
3.10	• business set-up • support to manage new business • wants to return to work (previously dismissed)	Individual employment support
3.11	• behavioural support • communication support	Individual social skills development
3.11	• support to decrease hospital presentations	Specialist behavioural intervention support

NDIS support category	PiR supports (as identified by storytellers)	NDIS support item
3.12	• looking after myself – diet, cooking	Dietician consultation and diet plan development
3.12	• looking after myself – exercise	Personal training
3.15	• learn to drive	Specialised driver training
3.15	• parenting skills training • relationship building and improvement • transport training for independence • transport • living independently	Individual skills development and training, includes public transport training and support
3.15	• allied health support for daily living	Individual assessment, therapy and/or training (includes assistive technology)
3.15	• developing personal goals • focus on goal setting • support to achieve goals • relationship support • anger management support • personal skill development – coping skills • coping skills -control • managing stressful situations • anger management • managing anger • alcohol support • therapy – childhood trauma • grief counselling	Individual counselling

Supports not funded by the NDIA

Some supports noted by participants and SFs do not align with the most recent National Disability Insurance Agency (NDIA) price guide and cannot reasonably be expected to be provided for in the plans of eligible individual participants under an NDIS. These supports did, however, have significant impact on positive outcomes for participants and are therefore worthy of consideration.

The following supports were identified as not covered by NDIS plans:

- Information provision for participants and service providers.
- Collaboration and interagency support.
- Funding for incidental low cost, high impact items:
    - creation of an art space at home
    - companion pets, pet costs.
- Support liaison:
    - writing of support letters e.g. for the Court
    - advocacy with other sectors where needed
    - liaison with other agencies e.g. housing.
- Legal assistance.

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