

Phase 1 Workshops:

# Thoughts and Experiences About NDIS Psychosocial Support

Participant and Carer Feedback

National Codesign Workshop Series

December 2021

NDIS Recovery Oriented Psychosocial Delivery Support Project

Growing National Workforce Capability

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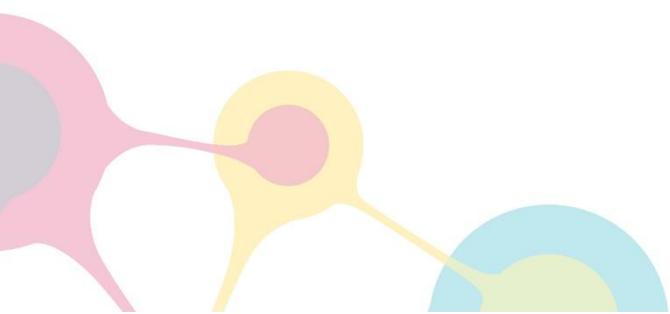
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A very special thank you to the host organisations and lived experience facilitators who ran these workshops across Australia, and to all NDIS participants and family/carers who attended the codesign workshops.

Thank you for sharing your experiences and contribution for making a positive difference in the NDIS environment.

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## Methodology

### Workshop program design

A combination of 19 face-to-face, online and hybrid workshops were designed and conducted for a three-hour duration across the nation.

### Workshop activities:

**Warm up activity:** Word association or Image interpretation

**Activity 1:** What makes a 'good' support person?

**Activity 2:** Enablers of recovery-oriented practice voting poll

**Activity 3:** Jamie case study – Part 1. Barriers and Part 2. Resolutions

### Out of scope:

Experiences of gaining access to the NDIS or the planning process is considered out of the scope of this project.

### What we wanted to know from NDIS participants and carers:

Activities were designed to engage attendees, and spark conversation with the following underlying questions:

1. How should good recovery-oriented psychosocial disability support be described and delivered?
2. What does the current workforce need to enable good recovery-oriented practice in the NDIS environment?

### Advantages of the tailored regional partnership approach:

- An opportunity to hear how the experience of receiving NDIS psychosocial supports is different across the country.
- Provided a better opportunity for those from less populated or smaller States and Territories, and for key population groups to be heard.
- Building on extensive stakeholder consultation undertaken by the Project.

### Key considerations

Communicating the intent of the project and the purpose of consultations is diluted or lost in translation, or in retelling. In other words, it is a challenge to contain and difficult to concentrate on one aspect without talking about the latest most controversial NDIS issues.

**Mitigation:** A Facilitator Guide was developed, and two train-the-facilitator sessions were run, and these were recorded for lived experience facilitators to watch. This ensured a well-articulated understandings of the project intent and purpose of those who facilitated sessions.

State peak bodies may not have reach into other communities or regions in their State or Territory, particularly remote and very remote areas.

**Mitigation:** We supported a mixture of online and face-to-face workshops and engaged further as needed, via surveys, targeted interviews with SMEs and focus groups. Adaptation to regional differences was considered by approaching existing networks, particularly in remote and very remote areas and in regards key population groups.

## Information gathering

Information gathered from the workshops will add to the projects' analysis of current participant and family experiences of receiving recovery-oriented supports within the NDIS and this will guide our efforts to improve the capacity of the Psychosocial workforce in the delivery of Recovery Oriented support. All sessions were recorded with consent using the zoom function, for analytic purposes and deleted once this report was finalised. Information for all activities was gathered through the following methods:

**Facilitator notes** captured high level key points and other high-level information during the workshop session. This was either on butcher's paper for face-face session or entered onto the PowerPoint presentation if via Zoom.

**Scribe notes** paraphrased quotes from attendees during the workshop to capture a complex level of qualitative data communicated through conversation. Scribes were predominantly MHV project team members dialling in via Zoom.

## Coproduction & Codesign approach

The Project's evidence-base to recovery-oriented practice (ROP) and workforce capability building approaches are informed by the direct input from primary stakeholders, there were two of this:

### 1. Lived Experience Coproduction:

The codesign approach for the stage 1 workshops comprised of three main stages:

#### I. Design of workshop content

The Project team worked closely with the LEAG to coproduce the workshop content for the Phase 1 workshops. Key outcomes produced included:

- A definition of codesign and coproduction in relation to this project.
- A Facilitator Guide to workshop content and presentation, template available upon request.
- Train-the-facilitator sessions.
- Slides and materials to be used in all codesign sessions, template available upon request.

#### II. Workshop facilitation and content delivery

Workshop content was delivered by 11 lived experience facilitators across the country. This included local lived experience facilitators for face-to-face sessions, or a member from the LEAG dialling in via Zoom if the session was conducted virtually. To ensure safety, a peer worker was available to workshop participants for debriefing and support. A full list of peak body lived experience organisations can be seen in Appendix 1.

#### III. Post workshop debriefing

The LEAG members were consulted after the workshops to ensure information was accurately captured, and appropriately represented in a meaningful way to inform the next phases of the codesign – Stage 2 Workshops with NDIS frontline worker and provider groups.

### 2. Codesign workshop feedback directly provided by NDIS participants and carers/family (primary stakeholders).

Current NDIS participants with psychosocial supports in their plans, and their carers/family.

## Engagement strategy

Partnerships with consumer and carer peak bodies and lived experience groups in each State and Territory were sought to strategically tailor a program of codesign workshops with NDIS consumers and carers/family across Australia.

**Jurisdictional face-to-face, online and hybrid workshops** coordinated by the State and Territory consumer and carer peaks in their local areas, using their connections and networks to promote.

National promotion via peak bodies of the jurisdictional workshops

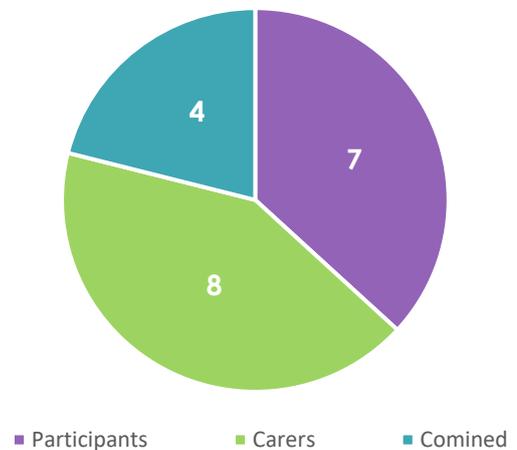
**NDIS Participant First Initiative:** Promotion of the jurisdictional workshops, and a national online workshop held via NDIS Participant First.

**NDIS participants or carers of complex support needs approach:** NDIS participants living with psychosocial disability and co-existing disabilities or health conditions, dual diagnosis, experience of homelessness, and/or complex support needs. Individual and group stakeholder consultations with key sector stakeholders as identified have been held.

## Reach to audience

The project approached current NDIS participants with psychosocial supports in their plans, and carers/family of current NDIS participants with psychosocial supports in their plans, to ensure information collected is relevant to the purpose of the project and specific to the NDIS environment.

Number of workshops across Australia:



Approximately 160 participants and carers in total.

19 workshops in total across Australia

A mix of virtual and face-to-face workshops were held across the country with at least one workshop in each State/Territory with:

- a lived experience facilitator, sometimes two, led the session.
- rural and remote engagement.

## Key population groups

MHV recognised there would be a small representation of members from key population groups in the workshops. Peak body organisations were consulted to gain a deeper understanding of the specific issues and challenges of these groups in the NDIS environment.

### **Aboriginal and Torres Strait Islander**

**approach:** Desktop review, individual consultations with ACCHOs and key stakeholders, and data from MHCC NSW Reimagine Today codesign workshops. Aboriginal and Torres Strait Islander NDIS participants and carers attended some workshops and provided specific information.

### **LGBTIQ+ approach:**

Consultation with [LGBTIQ+ Health Australia](#), a desktop review, and data from MHCC NSW Reimagine Today codesign workshops. NDIS participants and carers who identify as LGBTIQ+ attended the codesign workshops and provided specific information.

**CALD approach:** Desktop review, and data from MHCC NSW Reimagine Today codesign workshops. NDIS participants and carers from CALD backgrounds also attended the ROPDS workshops.

It is important to note that demographic data was not recorded in the scribe notes in any of the workshops as part of the deidentified process and therefore the exact numbers of participants who attended workshops are not known for each of the key population groups.

## What we heard from the workshop activities

The following discusses key points from each of the workshop activities.

### Activity 1: What makes a 'good' support worker?

**Activity description:** The question, 'What makes a 'Good' Support Worker?' was proposed to workshop participants under six domains. Attendees were then asked to list words that resonated with each domain accompanied by a brief explanation. This activity was an adaptation of *A 'Good' Support Person* (Brophy et al., 2014). Responses from all 19 workshops were recorded and collated into word clouds, to highlight a hierarchy of importance.

Quotes from the workshops have been pulled from the data set to accompany the word clouds and contextualise some of the responses.

What **Role** would you expect them to play?

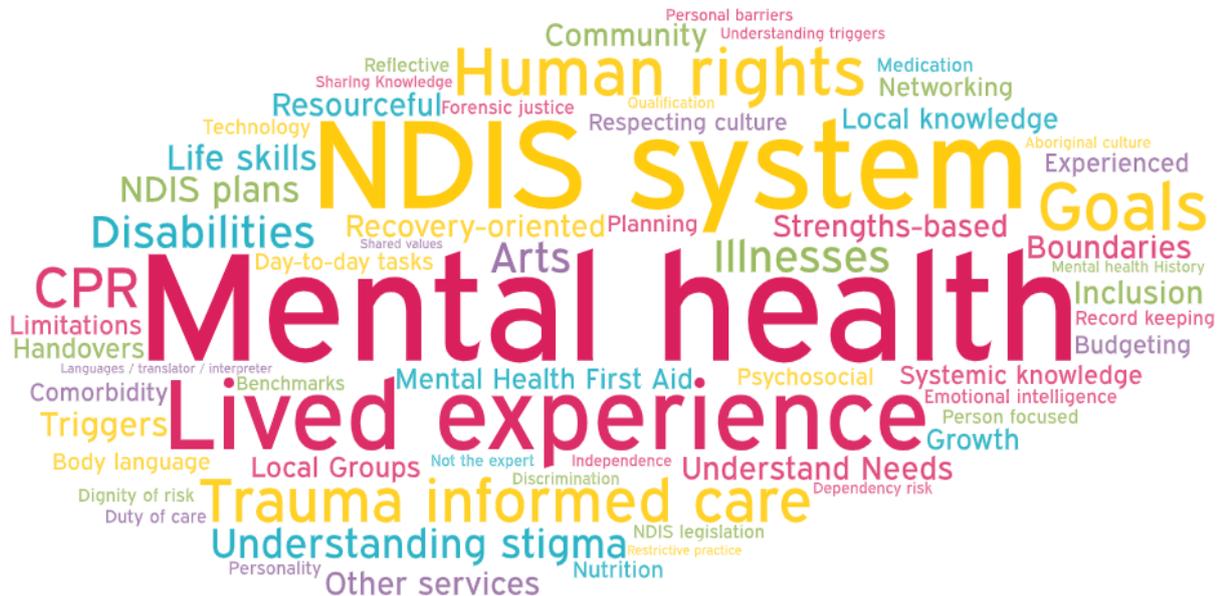


Word Cloud 1: N=19, Roles

*“A coaching model where the person is gently encouraged and builds life skills that are practical and realistic.”*

*“Advocate for me if I am unable to – alerting providers to crisis. Prompting, case coordination, etc. Be aware of the scope of advocacy.”*

What **Knowledge** would you expect them to have?



Word Cloud 2: N=19, Knowledge

*“Mandatory training in mental health: we are essentially saying we require a higher level of skills that must be underpinned by a higher level of education than is currently being funded and taught. A Cert III or IV qualification does not educate people enough in this space.”*

*“Self-responsibility and knowledge of disabilities – it’s not up to the client to teach and educate you about their disability. They should have an opportunity to if they wish, but it’s a lot of emotional labour, it would be great if workers did their own homework, and they should get that information from people with lived experiences”*

*“Different cultures understand mental illness in different ways, and this can be an issue with workers from different cultural backgrounds”*







What **Qualities** would you want your **NDIS provider** to have?



Word Cloud 6: N=19, Provider qualities

*“If you are going to have a good service you need to have a very stringent recruitment strategy, you have to recruit exactly the right people, not just hire people. Very particular personal qualities.”*

*“Good communication and consideration, today I had a support worker I had never met show up for a shift I had no idea was scheduled.”*

*“I know it’s a changing industry, but you feel a bit let down that you are not told one support worker is leaving, and you get someone new the next shift – some more honesty from the provider, more communication about staff changes.”*

## Activity 2: Enablers of Recovery Oriented Practice

**Activity description:** In the workshop pre-information pack, attendees were provided with a summary of the 14 enablers of ROP identified in the literature review report, *The Current Landscape: Good Practice in Recovery-Oriented Psychosocial Disability Support*. The attendees were then asked to pick five enablers that they felt were the most important to them, to prompt discussion about the enablers of ROP. They were also asked if they felt any enablers were missing, and why they thought the enablers that the group had picked as the ‘top five’ had been important. This generated a lot of discussion from the workshops around the design of the activity in general, and about the difficulty many participants had in ranking or picking ‘just five’, when ‘all are important’.

Results were collated from 16 workshops, results of the enablers that consistently scored high across all the workshops are highlighted Figure 1.

### Feedback about the activity:

NDIS participants and carers across the board in all workshops commented that it was difficult to pick just five enablers, feeling they are all important. Participants described all enablers as “*the basics*” for support service delivery, and that if practitioners are not aware of ‘Social Determinants’ or ‘Human Rights’, describing such elements as “*the bare minimum*” for support work they shouldn’t be working in the field. Further comments were made about why ranking the enablers was difficult, including “*it’s the integration of all the stuff put together*” that enables good recovery support.

There appeared to be a sense of conflict or tension about having to prioritize and rank the enablers, and participants made comments such as, “*it’s different between every single person what’s important to them*”.

For example, ‘cultural safety’ was discussed in one of the workshops with comments such as “*just because it is not in the top five for this group, it is still very important. We had to pick five that resonate with us. People from Aboriginal communities would put cultural safety as the top enabler. It is so important. In more diverse groups, this enabler would be in the top three.*”



Figure 1: Highest scoring enablers, n = 16 workshops

When asked why specific enablers had been chosen, participants responded, “We expect [these enablers] to be part of the system and service delivery, and we are saying they are not where we expect them to be right now”. These reflections on the current inadequacies of the NDIS as experienced by workshop participants lead to a question being raised by participants, “should the ‘enablers’ exercise be asking them to prioritize the areas that they believe are currently NOT being well delivered?” instead of what enablers are most important to the participants overall.

Enabler description	Total
<b>Lived Experience Workforce</b>	<b>17</b>
<b>Responsiveness to Trauma</b>	<b>16</b>
<b>Transparency and Communication</b>	<b>15</b>
<b>Human Rights</b>	<b>15</b>
<b>Collaborative Service Delivery</b>	<b>14</b>
<b>Carer and Family Inclusion</b>	<b>13</b>
Supporting Staff Through Training and Supervision	12
Interpersonal Skills	10
Sector Wide Recovery-oriented Practice Training	9
Cultural Safety	8
Recovery-oriented Practice Starts at the Top	8
Social Determinants	8
Staff Workload Management	7
Navigation of Service System	7

Table 1: Overall results from enablers activity

“Recovery is a lovely idea, but it very much should be the individual’s perception of ‘recovery’, it has been co-opted by funding bodies to mean what they want it to define, rather than individuals. Need to focus on recovery rather than assume that someone can never recover, there will be a percentage of people who can. In a way it wouldn’t matter how they phrased ‘recovery’ it is going to offend someone, but it is scary when it is based on your housing stuff. A lot of providers don’t use ‘recovery’, as it sounds like a measure/KPIs that gets used here.”

Some participants generated discussion around the use of the word 'recovery' as it appeared in the Enablers of Good Practice activity. One participant commented,

*"Interesting that no-one selected the enablers around 'recovery'.  
E.g., What I was saying earlier about housing – on the form it states that if you 'recover' you have to move out of the house. On the paperwork. What do you mean 'recover'? It doesn't go away! It's my whole life. That's why they want our funding to get less and less, because they think we will get better.*

*Recovery oriented – I don't understand what that would look like for me. A certain proportion of people could reach that – but not most of us in the room. Someone needs to explain 'recover' more clearly when they give you the form. They can't define it because it's different from one person to another person – that's why I steered away from it – they need to clarify in the form what it means so it doesn't make people feel question whether they will recover. More open to interpretation, not set."*

The activity may have been more effective in a face-to-face environment where people can engage and interact with the Enablers pinned on the wall. Going through the list online was not perceived as the same experience. This was observed through comments such as:

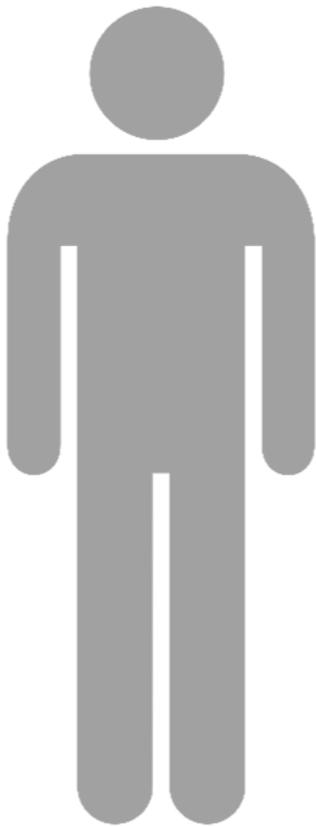


*I'm finding it hard because I don't feel the way the descriptors are written fit with what I value. Even if the 'title' feels like it's important. Honestly, one issue I have with practice is having to fit my answers into a box like this.*





## Activity 3: Jamie case study



**Activity description:** Workshop participants were asked to create a scenario for an NDIS participant who has psychosocial disability, Jamie. The purpose of this activity was to encourage individuals to speak openly about pressing issues with the intention to identify barriers for a person experiencing psychosocial service delivery without feelings of judgement.

**Scenario:** Jamie is an adult NDIS participant with psychosocial disability with psychosocial supports in their plan. Unfortunately, there are some barriers hindering Jamie's recovery journey and with their experience of the NDIS.

Participants were then asked to respond in two parts:

**Part 1 description:** Identify at least five barriers that may be impacting Jamie's recovery journey with the NDIS.

**Part 2 description:** Identify interventions, or suggestions to help improve Jamie's recovery journey.

There were consistent issues cited by participants as barriers for Jamie across the breadth of the workshops, such as an experience of homelessness/insecure housing, and financial instability.

Results from each workshop were compiled into one case study, pages 11-12:

**Tell us about yourself: How can we help you?**

**Application to access support:**

My name is Jamie.

I have psychosocial supports in my NDIS plan. I would like to talk to you about what supports I would like to access through the NDIS.

I have had a support coordinator who had to finish up last week. They have left me with a plan that I don't understand, and there is no-one providing psychosocial supports now.

I have just moved into the area, my dog Reco is my main companion. I don't see family and friends very often. Reco has gone missing yesterday, I'm very worried about him and the council said they'd let me know if he ends up being picked up. Some of my new neighbours said they'd keep an eye out for him too. I was evicted from my previous place by the Office of Housing, due to what they called 'unsafe hoarding'. My new place is a small unit and I'm not sure if I can afford to keep it.

I smoke and drink, maybe too much, wine most days, I can't afford the smokes either. I was getting diabetes treatment and I used to see a dietician a few years ago at the community health centre who was helping me think and plan my shopping. Changing GPs all the time doesn't help, we used to have diabetic nurses who were a great help.

I've been staying home most days, I'm very anxious about going out and what people think of me.

I've had a few doctors and case managers who have tried to help me with my issues, however they tend to come and go, and me moving hasn't helped as it means I have lost the connection with the local services. Lots of workers didn't want to come to my house and I don't like travelling to clinics.

It's been 15 years since I first received a diagnosis and that is in my file. People assume things because they read about a diagnosis made a long time ago by someone who didn't really understand me. I feel a lot of workers don't see me, they see my diagnosis. I feel that there is a stigma with having mental health issues that follows you everywhere. It means they are less likely to listen to me, what I need now. I'm very different from the person I was 15 years ago. I do get frustrated when I feel that the worker is telling me I am wrong about my own experiences and my understanding. This is where workers go wrong before they even get out of the starting gate.

I remember when I first heard about the NDIS I hoped that it was going to offer new ways of accessing the support I need. I liked that there was a long term offer of support and hoped if I had a really good support plan that my workers could get to know me and then stay connected with me. That I would not have to tell my story over and over. It's disappointing that this has not happened yet, losing my housing and having to move around doesn't help either.

While I have a lot of issues and struggle with control of my life, I still have hope that my life will be smooth again, things will stabilise if good supports are in place. There have been some good periods in my life before and I often think back to these times and think about what good back was then. Having the right support, a stable place to live, seeing family and friends, a happy dog, feeling able to get out and do things, and being involved.

**I hope that you will be able to consider these things when coordinating my supports. This is what I think I need:**

- **Coordination and collaboration** – I want people involved in my care to know what's going on, including other workers, support coordinator, psychologists, GP, etc. They also have information about what's happening for me with my physical and mental health conditions.
- **Sometimes I have felt like I don't know who to trust** – if the different workers aren't talking to each other, I don't know which worker I can trust, who has what information. Having a '**one stop shop**' where there is good communication between workers. This will give me more confidence in my team.
- **A good networker** at coming up with resources, **someone who knows about quality options, and has knowledge of the NDIS plan and processes.** Someone who knows what I can access, even outside of the NDIS, including financial, housing, accommodation etc. Someone who can support me with navigation of other service systems.
- **Help me become my own organiser** – help me put things in diary/wall planner and remember what's coming up, develop this practical skill. **Once I get better and more confident at this, I should be able to organise things myself,** down the track. **I need workers to be patient, and persevere with me,** this will be ongoing and take a long time.
- I need workers to practice what I call "**ALOHA**", that is "**Ask, Listen, Observe, Help and Ask again**".
- Hoarding - **Have an understanding of what hoarding is** (don't just assume), and don't judge me. I'm up for support that will help me with the big picture issues, and this will help me work on how to cope better with the way I live in my place.
- **Financial support** – I will feel much better if I feel that **my costs of living are under control** and that **my housing is affordable and stable.** Having this is crucial to achieving my other goals.

- **Working towards achieving my goals and aspirations** – the worker needs training in supporting this to move things along where they can (while still being patient and responsive to me). **Acknowledging that I might not be feeling like I can do xyz today, but am still moving towards a goal**, helping me make some positive steps.
- **Finding some free activities for me, or activities within my budget**, helping me organise a Companion Card so that some activities can come for free.

I know this is a lot to ask, maybe it's too much for one person, it might take a team approach. If these things could happen then I'm sure I would be on the right path and that things could improve for me.

*Maybe this is a good sign, a neighbour just brought Reco back, found him at the park, happy to be home...*

## What we heard from NDIS Participants and Carers

The following discusses key themes highlighted from all the workshop activities.

### Recovery-oriented systems and processes at provider level

#### Having recovery-oriented HR Systems, Policies, Processes, and Rostering Systems

We heard that there are experiences where services and workers are less flexible because their workplace databases and software can't capture the range of needs of participants. Other examples of inconsistent organisational procedures are highlighted through the way they collect and store information. Participants and carers from the workshops mentioned that important forms weren't easily accessible and often are experienced as a barrier to inclusive practice. In some examples the requirements of providers to complete additional paperwork led people to feel they were duplicating information to the NDIS and the provider.

*“Can you have good support without a good support worker, I don't think you can. But you also need a good provider and system to get that good support worker.”*

*“You get your plan accepted, but then the provider says, ‘these are the reports we need done in our way’. Then more reports need to be done. But they've never even been in your house, don't know what the triggers are in your household, and have never spent time with us.”*

#### Integrating a sound complaints system

Workshop participants emphasised the importance of having their rights upheld through an effective complaints and compliments system that is clear and accessible. Complaint's systems were often found inaccessible for workshop participants, with concern expressed over the lack of transparency and effective complaint management systems. Receiving support to navigate issues or being provided the right information to give feedback was raised as an issue, impacting the likelihood of the complaint being made or addressed.

*“Those of us taking part in this workshop are reasonably educated around NDIS and able to advocate for our needs. What SHOULD be the minimum often is not and people with disability don't always know what their rights are, what rights are being violated or how to address it if they are violated which provides a perfect storm for providers to be able to NOT address the minimum. Where is the open disclosure process? So many NDIS providers don't even have a complaints policy for participants to put forward their complaints/issues in a positive way and have them addressed.”*

## Having quality recruitment systems and processes

The workshop participants raised a lot of frustration about recruitment – the transient nature of the workforce, the lack of choice and diversity particularly in regional areas, and the difficulties providers are experiencing in recruiting, retaining and attracting the right workers who can be matched with the participants' needs.

*“Good strong onboarding process to manage support worker understandings of what is expected of them during a shift – they are there to pay attention to the participant, not be on their phones, and doing personal stuff during shift time. Some of them couldn't care less.”*

## Endorsing commitment within consistency of care with workers to service users

The inconsistent nature of the workforce is having a significant impact on the quality of support received, this is evidenced below by the workshop participants' frustration over the lack of commitment and reliability in workers. They also highlighted the casualisation of some workforces. Participants recognised that providers also felt the pressures of workforce shortages, however the experience of having to repeat and rebuild relationships with a worker is discomfoting and not supportive of their recovery needs. A lack of communication surrounding scheduled supports is also leaving participants to feel let down by 'no-shows'. The need for better support to ensure a smooth transition of workers is emphasized.

*“Organisations being committed to recovery principles, this is reflected in how they treat people, who they train staff, the way they recruit people, vision and mission of the organisation.”*

*“Workers not turning up – even though the participant has called, the worker hasn't informed the provider, leaving the participant with no one. This is a big issue, workers not being reliable. Provider needs to check in on workers, so they can find someone else if a worker isn't available”*

*“Workforce shortages – consistency is more important than flexibility. Have to repeat the story to every new person, go through inner discomfort and bond building time.”*

## Profile matching the worker to fit in with participants and their carer

There was strong feeling that a 'one size fits all' approach is not appropriate when considering individual interests, needs and life experience is vital. Being able to choose the right worker to provide supports has been expressed as important to participants and to better respond to their choice and control. Ideas included the opportunity for the participant and families to meet and greet the worker with the intention of improving and encouraging compatibility.

*"Providers and the NDIS need to invest more in employing older people who have life experience."*

*"I want a balance – some younger ones who are tech savvy, some who can physically move, and some who have the same interests, depends on what you want to do on those days/each day."*

## More flexibility in weekday, weekend, evening, and overnight support

Inflexibility in shifts and unavailability of workers are impacting the access to suitable supports for participants. This theme details the limitations experienced due to the lack of flexible shift times. Workshop participants are also feeling unsure about the professionalism of texting their worker to confirm a scheduled support, as there is no standardised process or policy for how best to contact a worker communicated to participants.

*"Need the ability to contact a person outside of the shift hours because at the end of the shift that's it – to contact them to organise things to do on the shift, etc. I haven't had people in the past with phone contacts. I feel like I am crossing the boundary by texting them. Different providers have different rules. Email system or instant chat – forget about that. But an email vs a text message. A mechanism to email providers or workers about upcoming shifts. Texting a worker feels like it is crossing a boundary. Need to make sure it is respectful on both sides."*

## Strong values in organisations, and culture to match

### **Project notes on Key Populations and cultural competency:**

It should be noted that these participant and carer workshops were planned on hearing from people all over the country; they were not designed with a cultural or other key population group focus. Participants and carers from key population groups attended these workshops and provided specific information, which is highlighted below. Some participants made the point that in mainstream settings people with cultural issues and concerns are less likely to raise these. The project has conducted other consultations with key population organisations and SMEs and has interrogated the academic and grey literature as part of the Project evidence base to understand the context of recovery-oriented practice and cultural competencies in the NDIS environment. More detail will be released as part of the project findings.

### **Practice being culturally safe, including training a culturally competent workforce**

A lot of people hold different identities, it's important for NDIS agencies to acknowledge these. If this is not done well then people will feel marginalised, and this put recovery-oriented support at risk. In regards stigma there were conversations about the need for the NDIS to not just advocate for disability, but for social acceptance and equality as well. Workers/ providers need to understand that people from CALD backgrounds might have different understandings of mental distress, different faith explanations, different ways of using mental health language. The legacy and possible intergenerational trauma of colonisation and racism should also be part of the workforce training/ understanding and inform organisational policy. We need workers who understand social inequality, it is complex and often not seen by those who don't experience it. Employment of culturally diverse workers assists; however, their numbers are too limited.

*“Different cultures understand mental illness in different ways, and this can be an issue with workers from different cultural backgrounds”*

### **Value lived experience and peer work and utilise it well**

While peer work and lived experience is highly valued, we also heard a theme of making sure that the right connection is made between the participant's needs and the worker's experience. NDIS participants and carers expressed a concern that the peer workers are also well supported in their work and suitably trained to enhance their capacity to use their lived experience in their work.

*“I want to have a lived experience worker, who is also matched with my needs.”*

## Be a trauma-informed organisation and support trauma-informed care

Trauma-informed care brought up some problematic issues for participants and carers. In some cases, the workshop participants expressed a great deal of difficulty after experiencing workers and organisations that they felt exacerbated their difficulties. This is an area of significant importance to recovery-oriented practice and this feedback indicates that there is a clear lack of understanding among elements of the workforce.

*“Workers not trained in trauma-informed care are at risk of making participants feel worse than when they arrived for their shift, the comments they make can feel like criticisms, accusations, labelling etc., causing distress to participants and doing great harm”*

## Have honesty and transparency from end-to-end service delivery

Participants were concerned agencies have promoted their services and competency and their availability and then failed to deliver in these commitments in a timely way. People are seeking providers who are upfront and communicate in an open way with.

*“So many new organisations come in, unless people know what they’re getting, it’s hard. Organisation says they can do it, but they don’t actually have the workers or the trained staff, or they’re not registered to do that support and then it’s another 18 months before they can even offer that support.”*

## Adopt flexible service models

People are seeking services that can supply the kind of flexibility that can provide person-centred support. They seek persistent approaches and request that providers don’t develop low expectations of the participant. Services need to expand what they offer to the participants and not be too limited in the range of activities they offer. An enabling environment where the worker is confident that they and the participant can make decisions together is important.

## Help workers understand my needs

There was consistent feedback advising that the worker should be aware of the needs of each individual participant and that services are tailored to individual needs. They ask organisations to prioritise the person up front and not to weight the workers down with organisational policies that impede the flexibility of the support relationship. They advise that workers be given time and information that helps them understand the needs of individuals and this will help to build trusting, effective and transparent support relationships.

*“Different participants have different needs/expectations, so when you meet the worker, you should go through expectations together.”*

## Providers should value and care for workers' wellbeing

Supporting workers and considering the impacts of fatigue and vicarious trauma from the workplace was viewed by participants as essential in preventing worker burnout. The impact of staff leaving and workers appearing stressed was felt by the participants, leaving participants concerned about the level of support provided. Looking after the workforce mental wellbeing, through adequate time allowance for admin and travel, encouragement of self-care for workers, and opportunities for upskilling was expressed as an important part of holistic service provision.

*“Staff workload management is a high priority – Why? Work smarter not harder. We don’t want workers to burn out, change over every six months. As carers we are talking about management, we don’t sit in that stream, the fact that everybody has mentioned it means we can see what is going on higher up, you wouldn’t assume that we would be talking about workload and staff and management. It flows down. It is reflected in the turnover you face with support workers. You get used to one person and then they move on. We need consistency. What affects one affects everybody. They are doing it hard trying to keep the staff they have, offering a flexible service, workers are sick, we are aware of all these things too. Participants and carers have emotional intelligence and can pick up when someone you are working with is burning out.”*

## Services should Be well informed about the NDIS and the mental health system to help service users understand the systems better

Throughout the workshops as a general theme, participants expressed a lot of frustration and disempowerment with the complexity of the NDIS and the difficulty in navigating multiple, siloed, highly bureaucratic service systems, and expressed a strong desire for their workers to understand and to be able to help them navigate these systems.

*“Help the worker walk between the pressures of the medical model and the bureaucracy of the NDIS – agencies need to support workers to navigate these pressures to be effective.”*

## Recognise coexisting disability and/or health needs

Workers and the providers must provide competencies in supporting other co-existing disabilities that a person may present such as vision impairment, hearing loss, autism and to have wheelchairs access at their premises/ centres. Participants reported that often workers don’t know what other disabilities they have i.e., vision/hearing, and sometimes don’t know what else is in the NDIS plan.

## Be respectful, person-centred, and treat all parties equally

NDIS participants and carers are seeking supports that are inclusive and respectful. They seek flexibility in the way they are supported and reject approaches that are too rigid and not designed to match the needs of the person. There are some personal boundaries that workers should not cross with the people they are supporting.

*“Has to be all about the person. Sometimes it seems to be all about the worker or organization – If the recipient isn’t confident or able to speak up – their needs are overlooked or not heard”*

## Have an awareness of stigma

Some very important feedback was received about ways that staff can be conscious of not contributing to the possibility of stigma in the way they work with people in the community. Sometimes participants don’t want it to be known that they are with a NDIS worker. The participant should have a choice about whether a worker wears a uniform or a lanyard.

## Advocate for service users - to the NDIS and other services

The importance of the worker as an effective advocate, particularly when the participant is in crisis situations. This was an area where the groups spoke of the worker as a really strong support and agent of potential positive change.

## Workers need to know how to communicate with carers or family members

There is a great opportunity for the worker and provider to build effective relationship and communication with the family members/ carers. If workers consider families as partners in support, if they include the carer as a care team member, if issues of confidentiality, consent, boundaries and mutual respect are determined then the recovery outcomes will be greatly improved.

*“I have experienced patronising and patriarchal behaviour...not listening to me as an advocate, put down by staff, unsupportive. I’m the one that’s there all the time. Be respectful of that. I’m not trying to control [the participant], I’m there to support [the participant] to articulate their needs and exercise their choice and control.”*

## Utilise networks to reinforce a strong community

### Multidisciplinary care teams to work in collaborative ways

Workshop members recognised the importance of the multi-disciplinary approaches and carers spoke of the importance of being included in these teams. The most positive experiences of multi-rolled teams were when there were clear and collaborative communication between members and that the shared work was focussed on building the participants' capacity to exercise choice and control and lead the planning process. The workshops highlighted that workers and teams need to be adequately resourced to meet and plan together and develop the collaborative plans/actions required. The benefits of effective early intervention and crisis avoidance plans were underscored.

*“Need something where they can have team meetings to handover on participant. I want my support worker to have time to debrief, even by Zoom, once a fortnight or once a month to be able to say – has anyone followed up on this? Or this?”*

*“Team leader – not a team, they are five workers working with the same person. Accountability, shared responsibility.”*

### Providers to be able to support participants and carers to navigate the NDIS and access to other service systems

This was a strong theme in the workshop feedback. You can see from the word cloud information that navigator and coordinator are very common responses when describing the desired worker roles. Participants and carers while often holding high levels of system knowledge, are seeking to work with providers and workers who they can partner with to effectively navigate the emerging and forever reforming NDIS and broader mental health, health, housing and welfare systems. Access, mediation, liaison, advocacy, legislation translation, referral and negotiation are all key aspects of the skills sought in a successful navigator. A navigator also needs to be aware of what is coming next and helping the participant to steer in that direction.

*“I don't expect my cleaner to navigate the NDIS system. I don't even know how to.”*

*“I'm not engaging with the mainstream health system to get treatment because it gets 'too hard' because I don't have that informal support person so I'm putting it off. Day surgery – they'll just assume you've got someone to pick you up.”*

## Strong and timely communication methods

Some very practical feedback was received in regards good communication. People want regular updates from providers, they want their calls returned, their texts and emails responded to and the option for 'snail mail' for those who choose. Quick and appropriate responses go a long way to providing engaged care.

*“At the moment there are heaps of issues with poor communication in services and that leaves participants having to chase up things multiple times and often not knowing till the last minute what’s happening.”*

*“Agency Communication: Have a focus from providers on communication and sharing information – be clear with workers about what the organisation’s expectations are. Clarity around GOOD communication. This has many positives if done well.”*

*“My plan expires in two days, I haven't heard from my support coordinator in about nine weeks, haven't heard from the NDIS either”*

## Providers should always strive for continuous improvement

### Regular service evaluation to ensure service user satisfaction

Processes for evaluating the service and taking on feedback for continuous improvement and measuring the satisfaction of their clients and families were seen as important and improved the confidence in the quality of the service being provided.

### Uphold legal, ethical, and moral obligations.

Workshop attendees identified examples of conflicts of interest that they found to be ethically questionable, when professionals made referrals to family members and examples where providers are seen to support their own business model, rather than led by the individual client needs.

*“Person might be steering towards a particular provider and there’s things being done without knowledge of the clients. Might never have spoken to or sat with and gotten to know the person.”*

## Prioritise quality and safeguarding within the services offered

Safety was identified as very important and a focus on providers having quality risk management systems in place. The feedback acknowledged that duty of care vs dignity of risk, it's a fine line and it's complicated and providers need to assist workers to navigate this in a constructive and client centred, client safe way.

*“What I've found is that the mental health workers that have all left the NGO space and opened independent businesses to support NDIS participants. They are definitely getting a higher hourly rate, and none of the policies and procedures that would have traditionally protected participants accessing services are in place.”*

## Offer adequate supervision to their workers

Participants and carers recognise that providers need to offer workers adequate supervision, mentoring, support and resources. They see that if the support worker is struggling, then this can cause disruption to a good support relationship. They are concerned at the risk of losing the engaged worker and having to work with a rotating team of strangers.

## Consistency across NDIS platform providers

There were mixed views on the use of platform providers. Concern that some workers have very little training and experience and others who are looking for convenience and control of the workforce

*“We use [platform providers] because you can pick and choose workers, but also comes with downside of not having an organizational framework behind them”*

*“There is a big concern for me ..... Going to an org such as that, where you don't feel your information is protected enough, and that person who is selected may not be safe. There are not enough checks and balances for people with MH. How do you ensure the consistency of standards?”*

## Workers to have access to affordable, quality courses that enable them to meet workforce requirements

There was a great concern that workers who are not adequately trained are not providing recovery focussed support. The groups identified that it is important that the workers have a foundational level of understanding what are the expectations of their role and at how they can most effectively support the participations and also when and how to liaise and work with other professionals. There was a strong consensus that the workforce should be resourced to gain a basic level of competency and several references to Cert IV levels as a minimum were made and a recognition that ongoing professional development was needed. There was some recognition that the Psychosocial workforce could include those who are starting their careers and building experience and for some of those a lower standard of qualification might be acceptable if there is adequate on the job training and support.

*“Mandatory training in mental health: we are essentially saying we require a higher level of skills that must be underpinned by a higher level of education than is currently being funded and taught. A Cert III or IV qualification does not educate people enough in this space.”*

*“I am worried about mandating qualifications for the workforce, as times the Cert I and Cert II workers can be ok for certain tasks on certain days, and I don’t want lose access to that workforce. But the rest of the workforce is transient and is and is just doing this work while they are studying and move on. They need opportunities for upskilling and career progression. Might have fewer hours with the more highly skilled workforce, but at least you would have workers available to you and career opportunities for the workforce while they are upskilling. Don’t want to exploit people who are trying out the disability sector – some of them are great people. All workers, even lower qualified workers, need basic training in ROP/foundational mental health/psychosocial skills. Even someone driving me somewhere can trigger anxiety in me.”*

## Person-centred, person-led and person-first recovery-oriented service

### Participants should be empowered by setting their own goals

Workshop participants want workers that provide choice, self-determination and dignity of risk. This was expressed as a need for workers to be encouraging and motivating, offering support but not making the decisions for the person. Understanding the individuals wants and enabling personal choice is key to upholding an empowering approach. Working together with the participant as a team and being ‘willing to give it a go’ was one example of how participants felt workers could be a ‘helper’ not a ‘hinderer’, building skills and confidence.

*“Gives you choices, not decide for you. Don’t expect the right choice the first time. My choice might change, nothing is set in stone.”*

### Promoting individuality of each participant

Seeing the individuality of the person and respecting their own ‘self-care’ strategies and personal needs was viewed by participants as a fundamental behaviour for workers to possess. This was expressed as an essential component to understanding the whole person, including their ‘quirks’, goals and life experience without judgement or bias. Showing curiosity and trusting in the individual to be the expert in their own care and life was one way in which participants felt their uniqueness and individuality could be reflected.

*“Workers have an assumption that ‘I’ve worked with someone like that before, so I know how to do it’, but everyone is different. Not everyone is the same and no one visit is the same.”*

*“Have curiosity about the person, showing interest and seeking new ideas. Be non-judgmental – bias and stigma need to be contained.”*

### Workers to present and engage when providing support

The theme of being present and engaging was repeated throughout every workshop. Workshop participants expressed feelings of frustration with seeing workers on their mobile phones during a shift with a participant. Participants and carers felt let down by workers do not understand the need to be present and engage with the person they are working with, or the nature of their role. A common complaint is that support work is ‘not babysitting’, it is work of a highly complex nature that requires proactivity and for workers to ‘show up’ fully.

*“Wish some of them would throw their mobile phone or leave it in the car. Do not access your mobile phone during the session. I see workers ignoring the person they’re supporting. Their phone is more important than the person they’re supporting. Should be there for emergencies only. I have had major*

*issues with workers just being on their mobile phones all the time. Just there for the money and to do what they like.”*

### **Patience and flexibility incorporated into service delivery**

The importance of workers being flexible and patient to the changing needs of the participants was present throughout the workshops. Workshop participants felt that workers need to be more understanding of individual situations, having adaptability to what is happening for the person and having a back-up plan if the participant needs to cancel support.

*“Flexible – understand if you can’t turn up. Have a safe space. Allocated person they can contact if they are having issues.”*

*“A lot of these things aren’t asking much. Asking people to be patient is not an incredibly hard skill.”*

### **Understand professional boundaries and confidentiality**

Maintaining professionalism through upholding a duty of care, confidentiality, and appropriate boundaries, was a strong theme throughout workshops. Workshop participants expressed feelings of frustration with workers who did not maintain confidentiality, talking about other participants in front of them. Being self-aware of how workers present; appropriate clothing, hygiene and not smoking or drinking, was also viewed as crucial to maintain when providing supports. A skilled use of self-disclosure, ensuring that the worker is not making it about them when sharing, was also felt as essential to maintaining boundaries.

*“Confidentiality – I get sick of workers talking about other clients they work with – it just means they could also be talking about me. They can talk about experiences, don’t need to go into so much description”*

*“Duty of care – workers who hide their kids in the car and then bring them in when I’m not there. If boundaries are set, they’ve got to stay within those boundaries. Otherwise, they take liberties which they shouldn’t.”*

### **Practice non-judgemental and respectful service delivery**

Respecting the individual, their human rights and their home is felt as core competency for workers to possess. Workshop participants reported that workers would touch personal belongings or read paperwork, not demonstrating respecting the participant and their right to privacy. Workers need to possess a willingness to learn and an openness to understanding the participants experiences. Mutual respect, without judgement or bias, was the basis for open communication without assumptions.

*“I have mental health concerns and experiences, but I am not those. I am not ‘schizophrenia’, I am a human. Using labels is disparaging. The language is becoming inhuman and impersonal.”*

## Workers supporting personal recovery

### Highly developed observational and interpersonal skills

Feedback about the importance of high-level interpersonal skills was received from workshop participants. Emphasising the value of a worker who can recognise subtle changes within the individual and adapt accordingly. Effective communication, active listening skills and reflective practices are all reported as key qualities for workers to possess. Participants felt that workers need to be aware of the vulnerability of having someone come into their home, using perceptive emotional intelligence to identify any uncomfortable feelings in the person.

*“I need people that are paying attention to subtle changes and will adjust how they are behaving or supporting, and this is quite a high-level interpersonal skill.”*

### Building rapport with participants and carers

The importance of establishing rapport and trust was noted throughout the workshop feedback. Participants expressed the need for workers to be persistent in creating a bond and connection, essential for a working relationship in which they can grow. Appreciation, empathy and patience towards the participant and their experience was a key point to building trust.

*“I want a worker that looks past all the red tape and sees me as me, not a label or a task, to see the potential.”*

### Active listening and communication in a calm, positive and strengths-based way

Strong feedback from workshop participants about workers actively listening; seeking clarification, verbal, and non-verbal communication, understanding what is being said, and taking the time to listen, was received consistently throughout the workshops. The importance of ensuring that good communication and empathy is used from the beginning is felt as an essential quality for workers to display. As well as utilising strength-based language that is delivered in a calm and positive manner.

*“Listen – How can you be an effective everything if you don’t listen. It’s an inherent function – if you want to talk, you got to listen. Someone who’s aware they don’t have to solve my issues, just walk with me.”*

*“Not just saying ‘that’s not my job’ – know how to say this in a positive way e.g. ‘I’m not sure how that might work, but I’ll talk to someone and find out’.”*

## Honesty and transparency of knowledge and skillset

Transparency and honesty were expressed by workshop participants as essential qualities of workers. Being able to display vulnerability and humanness are felt to reflect authenticity and genuine encounters. Workers who are upfront, and able to say if they didn't know or understand something, but able to seek the necessary information, demonstrate skills of authenticity and willingness. Participants want workers to have appropriate self-reflective skills to seek support and supervision and to better provide better services.

*“I had someone who would do their own shopping on your shift. Or doing a trip during your shift to take their timesheets – they are taking advantage.”*

*“Authentic, honest, genuine, value – I have had workers claim a two-hour shift for cleaning but do a very poor job in 15 minutes and leave the house.”*

## Reliable and conscientious practice

A reliable and trusted worker that is conscientious in their approach and takes the time to do things right, is a consistent theme for the workshop participants. Participants reported that workers need to 'walk the talk' and be punctual, thorough, and reliable to get to appointments on time.

*“Be punctual - my son with autism shuts down when they are not on time.”*

## Emotional regulation support in triggering situations

Participants want workers to possess the right skills to support individuals in managing escalations and emotional deregulation. Being able to keep calm, maintain a 'cool-head' and provide emotional support and presence was felt as essential to supporting stressful situations that may arise. Lived experience was viewed as useful to understanding emotional regulation skills and recognising others fears.

*“The other role I look for is a mentor as I am trying not to rely on my parents, but also find it hard to regulate my own emotions and struggle with functioning, also a de-escalating or calming role”*

## Suicidal ideation or mental health crisis knowledge and support skills

Appropriate skills to support participants experiencing a mental health crisis or suicidal ideation, are expressed as essential skills for workers. Workshop participants felt that suicide training was necessary for workers to understand the experience and not just call '000'. Specific knowledge on how to talk about suicide, ask the hard questions and provide a safe space are some of the least restrictive means suggested by participants. Being thoughtful, non-reactive and able to advocate or escalate concerns, can facilitate a safe space where participants feel that 'someone has your back'.

*"Understands what least restrictive interventions are so they don't just call the ambulance. Familiar with different systems. My support worker was aged care trained and I had to help educate her. We were both new to the NDIS"*

## Understand the impacts of medications

Workshop participants need workers to have a better understanding of medication and the side effects. Including the physical impacts they can have to the body, such as weight gain and fatigue. Participants that do not have a choice in medication want workers to be understanding of the effect lack of autonomy has on their sense of self.

*"We want to avoid mental health system and hospitals, but quite often directed there, 'sedate and stabilise' is sadly a common suggestion"*

## Awareness of everyday barriers and obstacles

### Understanding the impact of trauma and loss to work in a trauma-informed way

Trauma and loss were identified as a common experience for workshop participants. Participants want a worker who has the appropriate training to work in a trauma-informed way and meet the individual's needs of the person. Being responsive and acknowledging the pain and situation the person is experiencing was felt to be respectful to the individual. Communication, openness and understanding, were also key qualities for the worker to provide a safe environment for individuals.

*“I would hope after developing rapport and trust – we would then move onto ‘how do I support you?’  
‘How would you like me to behave when \_\_\_\_ happens?’ to develop a list of triggers.  
‘When do I need to monitor my behaviours for triggers’”*

### Understand that my capacity might be different each day and to move at my pace

There is significant feedback urging the worker/ provider to recognise and understand the changing nature of people's conditions. Workers need to be aware of the requirement not to push too hard, to maintain flexibility and walk beside the person and recognise their daily levels of ability to engage. There needs to be a focus on progressing recovery goals, however adequate time for change and at each person's pace is very important.

*“Because you did this yesterday, people assume you’ll be able to do it today.  
Well, it doesn’t work like that.”*

### Reinforce and understand human rights

There was discussion regarding how participants have had their human rights breached, both in the past and in the present. Workshop participants want workers to have specific knowledge on the human rights surrounding mental health, and when the rights are being breached. Advocating and upholding the rights of individuals, specifically those accessing the NDIS was felt to be essential.

*“If workers don’t know about human rights and social determinants then they shouldn’t  
work in this field.”*

## Workers to collaborate, coordinate and connect

### Support connection with family/informal supports

Recognising the difficulties that can exist between participants and their family or informal supports was voiced at the workshops. Special occasions such as birthday and holidays were felt to be particularly hard for those experiencing strained relationships. Workers need to be considerate that holidays aren't always a happy time for everyone. Just because someone doesn't talk to their family, doesn't mean they don't have one. Being able to engage and tune in to the individuals' relationships can help in supporting them when they are unwell.

### Understanding potential impacts of migration and citizenship

Feedback about understanding the context of citizenship and how a person's history has influenced their present-day situation was received in the workshops. Workshop participants want a worker to understand the dignity of risk, and advocate for the person by asking how they want to be advocated for. Understanding the influence of socioeconomic status, educational background and family history was heard to be a part of seeing the 'whole-person'.

*“Don't be a 'benevolent caretaker' – support freedom/physical health/be trauma informed, and aware of the relational aspect.”*

### Develop a goal-focused routine

There was discussion regarding the importance of constructive basic daily routines, a support worker can assist with stabilising positive routines. Sometimes carers and participants feel as though they need to support the workers to develop better understanding of the needs for good routines. There is an issue regarding the life skills of the workers which are sometimes more limited than the person they are supporting. Goal setting is an important area that requires a worker to be able to communicate and assist the person to set realistic and meaningful expectations. Having knowledge about healthy eating and living and sharing these in a constructive way is also helpful. Building a person's skills so they can start to do more for themselves is also important. Building their capacity to access services and attend health appointments.

*“Motivate the way that works for me – without being a cheerleader “*

*“Mentor – Step forward, show, step back, and watch “*

## Safe NDIS access support

While this project is not focussed on the issues related to NDIS access, the workshop members discussed how the difficulties related to access, assessment and planning have ongoing negative impacts on confidence in the scheme and have dampened positive expectations of what the NDIS could offer. People see this as having a material impact on the ongoing recovery orientation of the work.

*“NDIS funding a ‘godsend’ but difficult due to condition and very hard for carer to help. Amazing support worker has developed trust – coordinators and allied health assistant roles keep changing. Hard for consumer due to trust – very hard to start new relationships and activities. Great potential... Consistency is a key issue.”*

*“Looking forward to something bright in the future. Possibilities are endless. But it’s an awful journey to get there.”*

## Recovery Oriented Support from the top level

### Clarify roles and provide definitions at systemic level

Clarity of roles and expectations was discussed and there was a desire for clearer information from providers and the NDIS about what a support coordinator should be doing, and how is that different from a specialist support coordinator, recovery coach will assist all involved to understand the responsibilities and how teams can better collaborate.

### Acknowledge the heavy burden carers have to coordinate supports and fill in the gaps if there is not sufficient plan funding

Carers often reported that they felt they were needing to orient the workers to their roles. Carers notice when workers appear to be untrained and very confused about their role with the participant. Carers talked of feeling like they were the driving force behind the work. CALD carers expressed a concern that since the NDIS they have never been busier and that the introduction of NDIS has disturbed a lot of processes that were working in the past. Carers also spoke about the need to be kept in the loop and informed of changes:

*“There’s always so much. An app would be great. Need something legislated to help carers with being able to navigate everything.”*

## Invest in a well-trained Lived Experience Workforce

### Peer workers should know how to use their lived experience appropriately

Participants want workers to be trained in using their lived experience appropriately, lived experience doesn't necessarily mean you are suitable for the role. Issues of the inappropriate use of self were identified in workshops, and better understanding on how to communicate and not 'push solutions' that worked for them onto the individual are emphasised.

*"Lived experience worker – sometimes it's good and sometimes it's not"*

## What's next for the ROPDS Project?

We have developed this document to try to represent a summary of 'what we heard' from those who participated in our codesign workshop series.

We have sent this document to you to give you an opportunity to review and to let us know if you think it is a good representation of the types of conversations and issues that were raised in the session/s you attended. Please respond with any feedback and advice by Friday 5 November, and we will do our best to include this in the final version of this report.

We intend to place this report on our MHV web page to share with all who are interested in the content.

The La Trobe University research team will then consider the details of what you said about your current experiences of Recovery Oriented Psychosocial Disability Support (ROPDS) in the NDIS. They intend to use this report as a key aspect of the final project synthesis report. The Stage 3 Codesign Synthesis Report will build on the Project's evidence base that was developed for the [Current Landscape](#) and [Future Horizon](#) reports. During December 2021 we will release the Stage 3 report which will be guided by your experiences of ROPDS in the NDIS.

Once again, we thank you for your active and insightful contribution to our work. We hope that you found the experience meaningful and worthwhile.

## Appendix

### Appendix 1: List of Peak Body Lived Experience Organisation across the Country

ACT	ACT Mental Health Consumer Network
ACT	Carers ACT
NSW	Mental Health Carers NSW
NT	NTLEN
NT	MHACA
QLD	QAMH/ARAFMI
SA	LELAN
TAS	Mental Health Families & Friends Tasmania
VIC	Tandem
VIC/NSW	Participant First
WA	CoMHWA
WA	MHM2