

#### Submission to the NDIS Provider and Worker Registration Taskforce

**Aspire Recovery Connection** 

Recognising the value of Peer Support and defining quality for people with Psychosocial Disability.



Aspire Recovery Connection (ARC) is a 100% Lived Experience organisation, delivering Recovering Coaching, peer mentoring, counselling and group therapy to people living with mental and emotional distress and in receipt of the NDIS for Psychosocial Disability support needs. We are a community of fifty Lived Experience practitioners and over 200 people who access our services. We have a board of community representatives who govern the quality of our services and co-design our policies. Our community is made up of people who are racially, culturally, gender, and sexually diverse, unbelievably resilient, and overwhelmingly talented. Our community cares deeply about their human rights and that of their peers. We also at times experience mental and emotional distress related to unusual thoughts, feelings, and beliefs, that lead to the removal of our choice and control, stigma and discrimination, forceful interventions, and significant breaches of our human rights.

We are thrilled to have the opportunity to make this submission and are supportive of the Taskforce's recommendation to reform the NDIA registration process and make registration mandatory. We are hopeful that a new registration scheme will be accessible for small grassroots organisations, provide assurance to participants that their human rights will be upheld and recognise both the value of Peer Support services within the NDIS, as well as the unique skill set required to deliver authentic Peer services. Our Board met on the 18<sup>th</sup> of April to codesign this submission with ARC's Managing Director. Ten people participated in the forum which led to the following recommendations.

# 1. Recognise and make available certification of true Lived Experience led, delivered, and governed services.

Peer support services for people living with severe mental health issues have been demonstrated to have enormous benefits to the well-being and recovery of people living with mental and emotional distress (Byrne, 2016 (Davidson, 2012 ). Peer support services have also been demonstrated to significantly reduce re-hospitalisation rates amongst people previously hospitalized for mental health crisis (Sledge, et al., 2011). Equally, the challenges of providing authentic peer support within traditional organisations have been well documented (Mirbahaeddin, 2022). There is an inherent tension between traditional understandings of mental health and peer support approaches. A peer support approach relies on self-determination, experiential knowledge, and walking alongside.

Lived Experience-led, operated, and governed organisations provide very different experiences for people accessing support through the NDIS for psychosocial disability. When Lived Experience is embraced, recognised and embodied within the leadership and governance of an organisation, the depth of understanding of people's experiences and the unwavering drive to uphold human rights produces better quality, more empowering, and more impactful support services.



#### 2. Embed a registration process that recognises the differing skill set between 'doing for' and 'doing with' services.

The skill sets defined within the current NDIS registration process do not distinguish between 'doing for' and 'doing with' services within core support. These differences are real and significant and should be distinguished and recognised as such through a new registration process. This distinction is critical for participants to make a real choice between services that will simply 'do for' them and those that have the ability to build meaningful connections and rapport and walk alongside a person whilst they build their skills and confidence in daily activities.

A 'doing for' service is one that does not require the person receiving the service to be actively engaged. These services are more transactional and such as gardening and cleaning support when the person is not involved. ARC exclusively provides 'doing with' services, which involve a higher skill set to build a meaningful connection with a person and help them develop the skills and confidence to engage in day to day activities. This may also include gardening and cleaning if the person wishes to be actively involved in these activities, it may also include overcoming social anxiety to do grocery shopping and be out and about in the community, attending groups to make new social connections etc.

The skills required to connect with someone, build trust and rapport, and maintain that person's autonomy and agency in all day-to-day situations and without exception, must be defined and recognized within a new registration process. This will allow participants to be able to make an informed choice, whether for example, they're looking for someone to simply clean their house once a week or someone to feel safe in relationship with, to get out and about into the community .

## 3. Define and acknowledge the 'high intensity' skills required to support people who live with distress through a new registration process

It is further recommended that for psychosocial support the current description of 'high intensity' within the NDIA is appropriately understood. Currently 'high intensity' in the NDIA is understood as applying to someone with either complex medical needs or 'behaviours of concern'. Neither of these fit the needs of people who live with significant mental and emotional distress, and who require highly skilled support workers trained in mental health, ideally peer workers. When people with psychosocial disability experience a high level of distress, they may significantly struggle with day to day activities and engaging in support. This may be due to extreme social anxiety, experiencing voices or visions, moving in and out of personality 'parts', experiencing deep sadness, or overwhelming panic and anxiety. It is essential to the ARC community that these experiences are understood as 'distress' and not "behavioural" and that they can feel confident in choosing support workers who understand this distinction and are skilled in supporting them to navigate day-to-day needs whilst experiencing such distress.

ARC's Community Advisory Board believes Peer Workers are best placed to support people with psychosocial disability to navigate day to day life and work towards their aspirations while living with distress. In a recent survey of the ARC community, 92% of respondents (n=70) said it was either 'extremely important' or 'very important' that the people who provide NDIS support services to them have their own personal lived experience of significant mental and emotional distress.



Our Board has developed the following skill descriptors for the NDIS, to describe the skills required for 'high intensity' support for people who live with significant mental and emotional distress:

- Ability to establish rapport and be in meaningful connection with a person experiencing distress
- Ability for Peer Workers to authentically use their own Lived Experience to support people to feel understood and have the confidence to do things in day-to-day life
- Just listening when someone is distressed and not judging or trying to 'fix' the person or situation
- Ability to truly practice 'person-centred' support and offer genuine flexibility based on a person's unique needs
- At an organization level, delivering a support service that is relationship-based, matches support workers to participants, and doesn't have a constant rotation of different workers
- Being able to read, listen, and understand what a person needs when they're in distress and respond to those needs appropriately, without taking away a person's autonomy
- Being able to 'sit' with a person in distress and help them to come back to a sense of safety
- Having strong boundaries and the skills to clearly and respectfully communicate these in the interest of both parties

#### 4. Make the registration process simple and cost-effective

ARC is not currently registered, however we have looked into registration and the process appears extremely complicated, administratively burdensome and costly. As a small, grass roots organisation operating in the NDIS we are unable to absorb the cost and administration required currently to achieve and maintain NDIS registration.

### 5. Ensure the new registration process ensures a person's choice and control, human rights and dignity of risk are upheld.

ARC's community has experienced numerous and repeated breaches of their human rights under other service providers that are registered in the current system. These occurrences are frequent and shocking and include practices of coercion and restriction without authorization, stigma and discrimination against people living with psychosocial disability, and prevent participants from realising their agency and having proper choice and control. These practices are commonly defended by organisations who use them as essential to meet the organisation's 'duty of care'. They override a person's right to choice and control and dignity of risk.

A new registration process must seek to assess an organisations' culture and practice and require a sophisticated and balanced understanding of duty of care and dignity of risk. Such a registration process should seek evidence through policies, procedures, staff training and assessments of culture, that an organization is truly committed to and genuinely practicing dignity of risk over a misguided and patronising notion of 'duty of care'. This process should also seek to educate participants on their rights with regards to dignity of risk, ways in which a service provider might neglect these, and seek verification from participants that their dignity of risk is being upheld.



In summary, ARC is supportive of the Taskforce's recommendation regarding mandatory worker and organization registration. We are hopeful through redefining the NDIS accreditation system, a new registration process will be better able to ensure people's human rights are met, be simpler and more cost effective for smaller organizations to undertake and recognize the value of Lived Experience led organizations and peer support to deliver high-quality services for people living with psychosocial disability.