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Doing peer work with people with intellectual disability

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Background

- Community Disability Advocacy Hunter (CDAH) disability led peer support organisation in the Hunter, NSW
- 2021: CDAH got an Information Linkages and Capacity Grant to support peer work
- 2021: Deakin University's Disability and Inclusion Team engaged to do evaluation:
 - Dr. Louisa Smith
 - Dr. Sue Taylor
 - Dr. Jo Watson
 - Professor Angela Dew



Image: Peer worker Leonie (left) and peer Roy (right) at the Hunter Deaf Social Club





Literature: Peer work and disability

- Peer work = people with lived experience who are trained and employed to support others who face similar challenges
- A peer = someone with shared lived experience and/or similar characteristics
- Shared lived experience most important to fostering connection between peers





CDAH'S Peer Worker Model

Just get alongside people
and be human together

It is enough to have a
peer worker there, they
do not need to know
what to do





Jarrood Sandell-Hay from CDAH





Using lived disability experience

‘I saw that as a form of communication as being a neurodiverse person myself.’

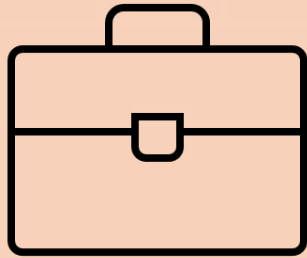
‘One day this could be any of us. We could all end up in some form of group home or institution’

To create an accessible workspace for people with disabilities, how are we going to utilise that lived experience?

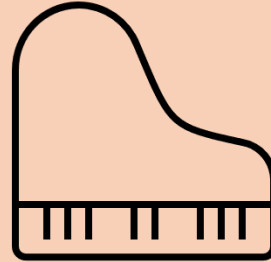




Using experience beyond lived experience of disability



-Professional experiences:
advocacy, social work, human rights educator, peer researcher, mental health supporter and photographer



-Hobbies:
-piano playing, art, photography



-Disability advocacy knowledge:
-human rights, disability support, social role valorisation.





Limitations of lived experience



Culture: e.g Aboriginal man



Age: I am blind and he's blind...apart from that we don't have heaps in common...he's a gentleman, he's probably 15, 16, maybe 20 years older than me. Our lives are completely different



Group home: I was naïve before, it's been a shock to the system to realise the house is really an institution





Feeling unsafe in group homes

Some of them [staff] can be quite dismissive of me. They interact with Lucy [project manager], but not to me.

I felt it was unsafe. I didn't know how to communicate with her [peer]. Because her support workers were actually not in the room, they were actually talking with [the project manager] somewhere else

They [staff] don't think the same as we do, they often say stuff [like] 'It was easier when we [staff and people with disability] were in the institutions





Communication with a peer with complex communication access barriers

'We want peers to try and make connections...but it's really hard to do that when you don't have much of a starting point...it's really hard to find your way in'

'He...he communicates if he wants to send a positive communication to you, he will hold your hand, so we do that a lot'

'That's been quite distressing for me to witness because what I'm seeing is the person saying, "I'm trying to say something here" and no one around her is listening or not taking her seriously'





Needing support

So, you've got to have that skill building, training. You've got to have sort of complex training, dealing with people who are – who has no communication, so having that training in communication

There needs to be a lot of capacity building around preparing an employee to be a peer worker ... I think your lived experience is only valuable if you can communicate or put that into practice in an environment

It's my experience at CDAH that there's pretty much always a really lovely relationship between peers

trust their capacity for a hunch



Pushing back cautiously on gatekeepers

‘Negotiating with the group homes is an ongoing challenge. If we kick up too much then they’ll just tell us to get out...’

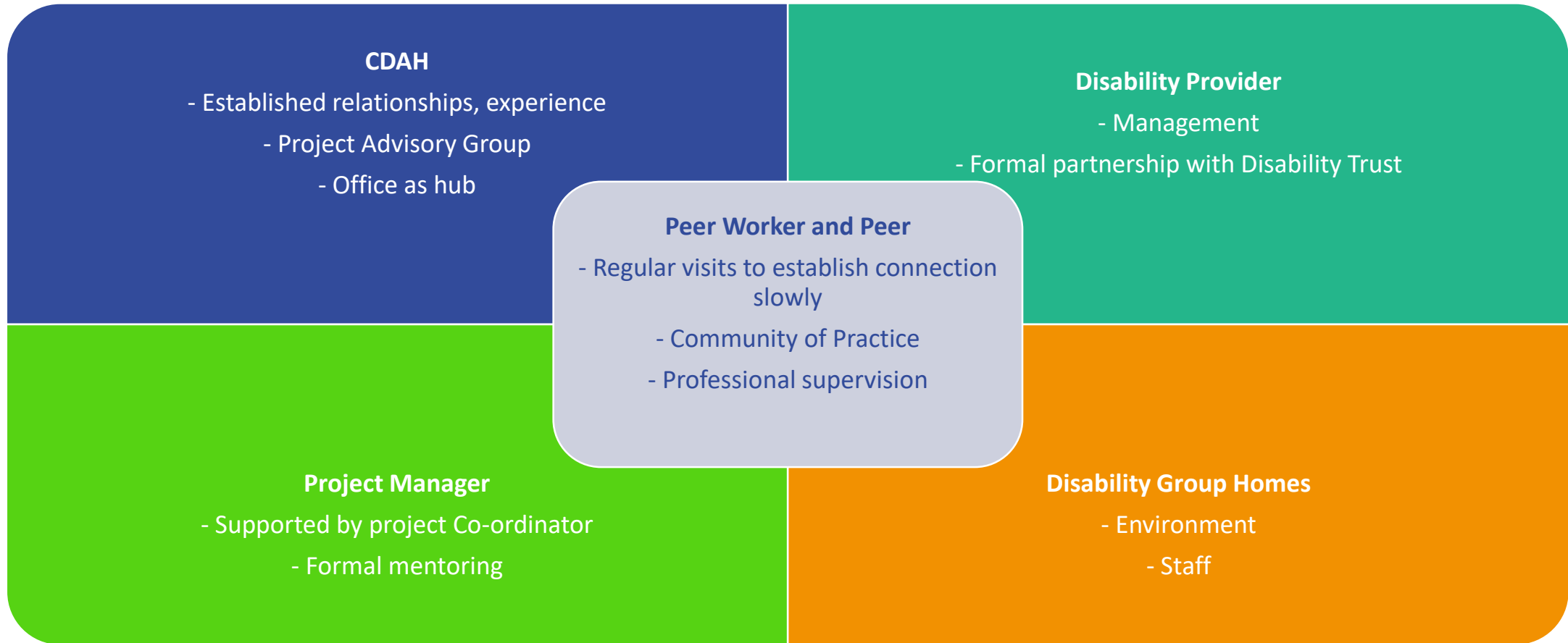
‘Half of the time I’m trying to do my best for the participant and half of the time I’m trying to perform what a good support system looks like in front of managers and staff’

‘I’m a disrupter’





CDAH's peer worker model





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