

***The PC is seeking examples of barriers to the genuine participation and influence of people with lived and living experience in governance forums. How could successful inclusion and engagement of people with lived and living experience in governance be measured?***

I guess ask the people that are and have been on governance committees whether they felt included and valued. I am aware of the mental health consumer and carer committee at the local LHD that sits in line with their executive. I am aware that Health management are using the committee as a tick box exercise and not valuing their input. I am also aware that it is Health staff, the same people that invalidate and shut down change proposals that choose who come to the committee. Participation at the committee should be guided by local consumers and carers not Health staff who have demonstrated extreme resistance to the valuable and relevant advice of consumer and carer representatives to drive change and save lives.

***The PC is looking for case studies to highlight best practice in integrating peer workers in clinical mental health and suicide prevention settings, particularly by improving clinician awareness of the peer workforce. Are there examples of best practice that could be adopted in other organisations or settings?***

I believe that best practice of influencing change in a life affirming way sits with Just Listening Community delivered in Adelaide:

<https://www.justlistening.com.au/just-listening-report>  
<https://humaneclinic.com.au/approaches/just-listening/>

This is an extract from their website: *“Just Listening offers a person a supportive space to share their story and and make meaning towards choices in their own life at time of distress.”*

Together with Soteria style respite, funding Just Listening will likely bring much needed validation, meaning and maybe a choice to continue living for people in distress.

While Just Listening isn't designed to be delivered by peer workers rather community members trained in the model, this is a life affirming service worthy of funding.

I also feel Just Listening needs to be delivered online, by phone and chat, to traverse difficulty being in a face to face setting, trouble leaving the house, to reach people in family violence situations and people who are not able to verbalise all the time.

I have personal experience with and sincerely believe that Just Listening's partner Humane Clinic has saved my life and extended my life by being treated with constant validation, being treated as an equal and someone of value.

While I was involuntarily hospitalised in the local LHD inpatient unit due to extreme distress caused by the public community health team, I had inpatient staff raising their voice, pointing their finger in my face and threatening me. This is not an isolated incident. Mental

Health inpatient staff cause repeated interpersonal trauma to consumers every single shift. There is limited kindness, limited compassion and next to no safe and effective care. What they do in the local publicly funded inpatient units is not life affirming. Staff behaviour is not a funding issue it is a culture that has been accepted by the organisation. It is the individual staff that cause harm. It is the physically violent security personnel. I had a hospital security guard pull me by my hoodie because I went to look out the door. No communication, no introduction, no offering of food or comfort, straight out violence enabled by the organisation. I have been chemically and physically restrained in ED on multiple occasions for trying to leave. No compassion, no cup of tea, hours of waiting while distressed. I have had clinical staff tell me I like injections when they were restraining me every night. They didn't stop their taunting when I told them to stop. I think they just don't know how to talk to consumers. The physical and verbal violence is traumatic. There is no evidence of trauma informed care in publicly funded mental health services. Just delivery of ongoing coercive practices and trauma. I just cannot tolerate the pain from the distressing memories of years of involuntary community and inpatient public mental health interaction. The cumulative effects of the service delivered trauma is not life sustaining.

I had a blood sugar level of 2.7mmol/L in the ambulance being transported to another hospital from ED, just from waiting in ED. A normal and safe blood sugar is over 4.0mmol/L. In the local LHD mental health unit I was asked by the junior doctor to increase my oral intake or they would have to cannulate for intravenous glucose again. I said I'm happy to have a biscuit and tea. Turns out in that unit there are restrictions in when consumers can have tea and biscuits and that wasn't the right time, not even to stabilise blood sugar levels. The unit definitely does not operate to a least restrictive care model. Limited care and ongoing service defined restrictions. I went on to learn that if a consumer wanted morning or afternoon tea, they had to walk through that busy unit and wait at the nursing station to ask for it. This does not fit the needs of someone with psychosocial disability, where social anxiety, difficulty with communication and interaction will impact their nutritional intake because it is too difficult to access and their staff definitely won't help.

While I was detained in the taxpayer funded unit, with staff waiving their finger in my face, I still had my phone which life savingly enabled my contact with Humane clinic, with the clinician talking me through how we can keep going. It is extremely imperative that consumers have access to their supports and phones while in inpatient units. Without a phone I don't know how I would have found a turning point. The therapy, care and compassion came from an external organisation outside the publicly funded mental health unit.

I had a very good experience during my time with the HASI program.

<https://www.neamination.org.au/services/neami-nepean-penrith/>

The flexibility of outreach, friendliness of staff and assertive engagement within HASI met my needs, they even ensured that I got NDIS funding. The LHD community mental health team did nothing in regards to my NDIS application, apart from getting angry with me when I said I wanted to apply.

I really wish that I could purchase a HASI style package from my NDIS money. I've met some nice workers but the way NDIS works it is so easy to disengage and not every service is keen to reach out.

Through previous experience I trusted another non government organisation with my support coordination and support worker funding.

<https://www.flourishaustralia.org.au/how-can-we-help/i-would-information-about-ndis>

The community assertive treatment team told me on multiple occasions to find a more reliable provider but I stayed. Now \$12,000 of support coordination later, I only have 1 support worker who I haven't heard from for nearly 2 weeks and no ongoing therapy. They are good at drawing down my money but connecting with me to understand my needs is too difficult. I am extremely disappointed by their approach. I recently trialled a new worker with them, I was so distressed by the interaction and lack of choice that I ended up on my floor after the visit for about 8 hours no food, no toileting, just defeated. I have one very good worker who I think genuinely delivers life-affirming support. The organisation seeks feedback through an automated system, which sounds good in practice but they stopped responding to feedback about 2 years ago. They don't seem to understand that getting support through NDIS is essential, they do nothing if a visit is cancelled. They at times also cancel by text so they have no idea how the person is doing that they cancel on. I was sick recently and had to cancel as per their policy and they didn't even offer to do a grocery drop. It's quite disruptive when the support organisation is not able to take the person to a doctor when they are funded for it and do absolutely nothing to get alternate support through a support coordinator even through their own organisation. The NDIS funding is for my disability needs like shopping, nutrition and medical appointments. The non government organisation recently sent me a text a day before my visit to cancel when they knew well in advance that my worker would be on leave. They charge me \$17 for appointment reminder texts but they can't charge to cancel so maybe that is why they don't bother to give me notice. An organised and connected person would be able to reach out to another provider independently or through their support coordinator to fill the visit but this non government organisation doesn't give people that choice and control in their lives. Taking away choice and control all adds up and the consequence is not life affirming.

Preventing suicide doesn't happen at the pointy end. It's not achieved through coercion and control, through containment and seclusion. Suicide prevention happens through our everyday interactions, through compassion, warmth and validation. Through relationship and connection, by the individual and through organisational systems designed to treat people as valued human beings. It's not just a funding issue, it's having the right people providing care issue.