NSW Mental Health Commission Lived Experience Project

Establishing a framework for Consumer Participation, Influence and Leadership

Sydney Consultation Summary

6th June 2016
Background

The NSW Mental Health Commission supported the Lived Experience Project Steering Group host a community consultation with people with lived experience of mental illness (consumers) in Redfern on the 6th of June 2016. The consultations were on lived experience participation, influence and leadership in the mental health system. Over 90 attendees participated in the consultation. The NSW Deputy Mental Health Commissioner Bradley Foxlewin and members of the Lived Experience Project Steering Group, as well as, consumers from regional areas who were supported through travel sponsorship, were in attendance. This event was led and facilitated by people with lived experience.

To prompt discussions, attendees were asked about what leadership and influence means to them, about what structures and attitudes existed in their community that support participation and leadership, and how barriers could be reduced to ensure consumers could influence change.

Sydney’s voice

The following is an outline of the main overarching themes that were identified arising from the questions at the consultation.

Valuing Lived Experience

There was strong emphasis on the lived experience voice needing to be “central” to participation, influence and leadership. Being able to express and articulate experiences was seen as a validating and meaningful recovery method that “makes [our experiences] real”. However, being heard and voicing experiences needed to come with recognition through words and behaviour. This means, among other things: being valued and seen as an equal; being able to give advice without fear of reprisals, and; undertaking work without being second guessed, patronised and put down.

Allowing choices in what people with lived experience choose to participate in is vital. Personal knowledge and experiences should be seen as a strength and people with lived experience should be seen as experts – in their own treatment and recovery, as well as, in roles where they can utilise this experience to drive change.

Reinforcing rights, access and opportunities

Having rights, access to resources and knowing where opportunities lay are viewed as crucial for people to participate and contribute in the sector.

Opportunities for participation, education and training to develop leadership skills are seen as invaluable components in lived experience participation, influence and leadership. It is suggested that opportunities should be diverse and varied so a broad scope of skills can be attained by people with lived experience. Furthermore, diversity of leaders was recommended, so as not to have the same leaders in “all” the leadership roles. A lived experience participation, influence and leadership newsletter is seen as a helpful tool to be kept informed about possible opportunities.

Access without discrimination is fundamental to the growth of the sector. People with lived experience should be included in the whole process and participate at every level; be provided fair treatment, and; be given equal pay to do their work. Access to the contribution of policy formation and service design was mentioned as needing to occur on a much wider and deeper level. People
also want access to decision makers so that information is passed directly to them and so that a more democratic process takes place.

**Strengthening learning, development and support**

There was a clear indication by participants that education and training was essential to progress people’s participation and leadership skills. This though, was mentioned along with adequate and consistent support and professional development, with funding provisions to attain experience and qualifications. Qualifications ranged from: recovery oriented practice and understanding what acute mental health distress is; to trauma informed car and Open Dialogue processes; to resilience and cultural sensitivity training. Programmes that allow the exploration of culture, values and identity was mentioned as much needed here as well.

Mentoring, internship programmes and a buddy system were also cited as alternative manners of professional development. These practices would be more personal and targeted to a specific person in a specific role. Sharing stories and training people on how to purposefully articulate and disclose their experiences that minimises harm to themselves is seen as another avenue of participation, influence and leadership.

Education in more supplementary courses, such as: improving communication methods and the language used with decision makers was seen as necessary to improve leadership capacity too. And having peer support groups to help assist people was seen as a better way to seek out advice and get support if and when needed.

**Enhancing relationships and linkages**

Providing opportunities to share, network and connect is seen as a vital component in participation, influence and leadership. This will decrease isolation and the lack of awareness of what other services and what other people are doing in the sector. These opportunities would establish a collegial environment, and supported by the more experienced workers, would lead to a more positive proximal environment. It would also offer a chance to combine the sectors knowledge base, say for instance, with carers and youth based concerns. These spaces would be ideal in the instigation and formulation of co-creation initiatives.

**Creating positive cultures**

Safety and trust were mentioned multiple times in the consultation. Having space to voice opinions and ask questions, allowing people to stay true to themselves is regarded as essential.

Tackling stigma, as well as self-stigma, is viewed as beneficial to help promote the normalisation of people with lived experience. So to, addressing the culture of shaming and bullying. Furthermore, addressing the manner in which people label and categorise others was seen as an important part of addressing stigma.

Not homogenising people and understanding the diversity of the human race, even the value of diversity itself, is seen as profoundly beneficial. Acknowledging and recognising work done and work being undertaken by people with lived experience would be a welcomed development. Positive stories, it is believed, will decrease tokenism and the many assumptions made by others.

A major part of creating positive cultures is to prevent trauma and retraumatisation through the process of ‘othering’.
Developing better systems and structures

Increased funding to improve and create better systems and structures was expressed in various ways throughout the day. Some of the systems and structures to enable participation, influence and leadership in the sector that were mentioned include: formalised peer supervision; clear employment pathways; encouraging ‘consumer run/managed services’ to develop; allowing smaller organisations to flourish and compete with larger organisations; increasing the lived experience workforce; connecting and integrating services (particularly mental health with the various other disability services); offering work flexibility; creating multiple systems to provide options and catering to the diversity of societal and population groups; lobbying governments and advocating for policy change and reform; mandating leadership levels and numbers, encouraging the public and clinical components of the mental health sector to employ more people with lived experience; minimising red tape so that ideas do not get lost and assistance goes to those who most need and want it; minimising sector hierarchy; increasing collaboration, and; incentivising innovation.

On a more technical level, other ways mentioned in how the sector can improve participation, influence and leadership include: creating a feedback mechanism, including a way to provide feedback to the wider community; measuring change and continually improving in response to sector demands; applying more accountability measures; developing a risk management policy and framework; applying an integrated interdisciplinary approach to participation, influence and leadership; conduct a participation, influence and leadership gap analysis, and; auditing participation, influence and leadership roles, particularly volunteer positions.

Individually speaking and in relation to participation on one’s own recovery, one should be able to choose their own health professionals; agree on case notes before implementation; be able to write up binding Advance Directives, and; apply a multilevel systematic informed care for the whole treating team.