



NDIS and Psychosocial Disability Quality and Safety Forum

TRANSCRIPT 2 of 10

Lived Experience Address

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TRANSCRIPT

SAM:

Good morning. So I'm here to acknowledge the lived experience in this room. But before I do that, I would like to begin by acknowledging the traditional custodians of the seas, rivers and lands on which we're meeting today, the Gadigal people of the Eora nation, and pay my respect to the elders, past, present and emerging. Greetings to the Aboriginal and Torres Strait Islander people who are with us today in person and online.

Thank you, Aunty Donna, for that beautiful welcome to country. I lived on Gadigal land for close to 30 years, mostly in Redfern and surrounding suburbs, and I have a deep appreciation of the strength and the resilience of the Aboriginal people who've been gathering around the block for generations.

This has been a heartland of Aboriginal resistance and re-establishing community control over health, housing, childcare, culture and aw. Never forget that this is stolen land. Sovereignty was never ceded. I align myself in sovereignty with First Nations people and recognise the burden of intergenerational trauma which they carry because of colonisation, genocide and assimilation perpetrated by my ancestors and from which I continue to benefit as a white person.



Black lesbian feminists in the 1978 Combahee River Collective Statement acknowledged that their particular task is the development of integrated analysis and practice based on the fact that the major systems of oppression are interlocking. It is not enough for mental health consumer advocates or psychosocial disability activists like me to challenge sanist oppression or simply tweak the NDIS. We must proactively elevate the lived experience of those members of our community who face systemic oppression on multiple interlocking fronts, beginning with our First Nation's elders, sisters, brothers, sister girls and brother boys.

We must prioritise in our systemic advocacy the voices and rights, choice and control of Aboriginal and Torres Strait Islander participants in the NDIS. If the NDIS doesn't offer First Nations people with a psychosocial disability self-determination, it works for none of us. Everything we do as people with lived experience of mental distress, consumer advocates, NDIS participants is predicated upon the devastation with which this nation was forcibly imposed upon Aboriginal and Torres Strait Islander people.

To the NDIS support workers, support coordinators, including my own – Hi, Time - plan managers, NDIS staff, NDIS commission workers and mental health workers gathered here today in person and online, I remind you of the exhortation by Aunty Lilla Watson and fellow Murray activists in the 1970's who said, “If you have come here to help me, you were wasting your time. But if you have come because your liberation is bound up with mine, then let us work together.”

I stand here on the shoulders of giants, the Aboriginal and Torres Strait Islander elders who sustain law, culture, language and respect for the land, the rivers and the seas. The elders of the international consumer movement, psychiatric survivors, and my fellow Mad activists who've advocated for a human rights for choice and control, and particularly in Australia, the National Disability Insurance Scheme, to meaningfully include psychosocial disability. And finally, my logical elders, my chosen aunties and uncles who support and sustain me in my recovery journey.

Thank you for shouldering me up, as Vikki Reynolds says, that I may shoulder others up. The Mental Health Coordinating Council's Embracing



Change Project is for NDIS providers who offer services and supports to people living with psychosocial disability and our loved ones, kinship networks and workers. The project's purpose is to foster greater awareness of the NDIS Practice Standards and Quality Indicators from a psychosocial disability perspective. Project activities support existing and prospective NDIS providers to achieve increasing alignment with the NDIS Practice Standards.

Why is this important for those of us with a psychosocial disability? When our NDIS providers work in alignment with the NDIS Practice Standards, they provide person centred, trauma informed, strengths-based and recovery-oriented supports. When our NDIS sorry - when our NDIS providers work in alignment with the NDIS Practice Standards, we have our best shot at choice and control. When our NDIS providers work in alignment with the NDIS Practice Standards, they are accountable to us.

When our NDIS providers work in alignment with the NDIS Practice Standards, it is they who must be compliant, not us. The work of the Project is guided by an Advisory Group on which Deb Hamilton and I provide an NDIS participant perspective. The Advisory Group has been meeting on a bimonthly basis for the past 18 months and has collaborated on the production of the webinar series, which many of you will have seen.

Deb was a speaker in Webinar 5 and you'll hear from her later this morning. I've been reviewing the language used in guest speakers' presentations to ensure it is person-centred, recovery-oriented, trauma-informed, and strengths-based, and focused specifically on psychosocial disability, not disability generally, not mental health generally, psychosocial disability specifically. The presence at this Forum of people with a lived experience of mental distress who have a stake in the operation of the NDIS is an example of the tenet, "Nothing about us without us", which stems from the Disability Rights Movement of the 1990's.

When James Charlton published his book by the same name in 1998, he could have scarcely imagined how much progress we have made in challenging sanist oppression and empowering ourselves in the intervening decades. The social model of disability reframes our distress



and our functional impairments as the responsibility of society rather than a pathology located within us as individuals. The groundwork for the NDIS was laid when the Australian government signed the United Nations Convention on the Rights of Persons with Disabilities in 2007.

From there, the consumer movement and the mental health sector has had to come to terms with this new idea of a person having a psychosocial disability as opposed to a psychiatric illness. I've got six, last count. Understood from a human rights perspective, it is entirely possible to resolve the seeming dialectic of the psychosocial disability and the possibility of recovery. Seeing through a human rights lens, there is no disconnect between a strength based approach and acknowledging socially constructed functional impairments such as those arising from trauma.

That said, the NDIS access request process could do so much more to assist us and our health professionals to hold these concepts simultaneously. Marsha Linehan, where are you? I would like to acknowledge the lived experience in this room and online at this forum. If, like me, you're a person with a lived experience of mental distress, I see you. If, like me, you're a person with a psychosocial disability and an NDIS participant, I salute you.

I would also like to acknowledge the lived experience of NDIS participants and potential participants with a psychosocial disability who are not at this forum. The people whose experiences I read on Facebook groups like Psychosocial Disability and the NDIS or Mental Health and the NDIS, people with psychosocial disability struggling to navigate the access process, people with the psychosocial disability pursuing choice in and control over the supports they need once they have a plan, people with a psychosocial disability self-advocating with support coordinators, local area coordinators and plan managers.

So as you participate today in today's forum hearing from a wide array of keynote speakers and panel discussions, listen carefully for lived experience perspectives, critically reflect on the ways in which psychosocial disability supports under the NDIS, either those you receive or those you provide, considering the ways they foster human rights,



liberations from interlocking systems of oppression and self-determination. Thank you.