Losing our neurodivergent son at 15 by suicide sent shockwaves through a entire community. This is how we learnt of the over representation of our neurodiverse in the suicide statistics (likely underestimated). Estimates of rates at 5-9% of the general population, with life expectancy in their middle ages largely as a consequence. We too, call for the recognition of our neurodiverse in the national suicide strategy as a population of concern. Our neurodiverse are overrepresented in suicide and despite being a minority population, appear as a dominant majority mental health care. Their outcomes are commonly inhibited by the medical model still dominating mental health approaches. Expectation of care aligned with current understandings around the neurodivergent paradigm and person centred social models of disability are infrequently met. The significance of the delay in knowledge translation from research should not be understated.

Long aware of lagging knowledge around neurodiversity and stigma around mental health, the taboo around suicide is ‘next level’. In all cases knowledge holds the key to better understanding. The fear around suicide aligns with the magnitude of its impact but if we do not enable the learnings from each story, the trauma continues and the same outcomes repeat. We sit with the loss of a child but also the knowledge of increased suicidality risk for all those impacted by his suicide. Following the loss of our son I have countless meaningful conversations with researchers, peak bodies, educators, leaders and families highlighting the gaps in the system and in knowledge. All the while knowing first hand the impact on lives of systems failing to demonstrate current knowledge, and sharing in the journey of others in my working life in mental health. Twelve months on I continue to look for the mechanisms to empower change, restricted by systems operating without urgency.

I acknowledge the mechanisms shaping the many failures of our current systems are complex. Knowing research has a vital place in holding knowledge and understanding we have to consider the shortfalls. Whilst we respect the value of research, we consider inhibitors meaning only research that will attract funding is completed, providing an incomplete picture. Ethics priorities directing research scope due to an inability to hold risk similarly restrictive. The breadth of research into mental ill health is restricted by this, evidenced broadly including in the minimal innovation in treatments. Entities held in regard in society directed by fear of litigation rather than moral responsibility and enabling progress, effectively inhibiting learning and innovation. Richness in knowledge without opportunity for its translation prohibiting better understanding and outcomes. The movement toward harnessing the current knowledge in lived experience is a crucial enabler of accelerating better outcomes and having a role in considering risk differently. There are some things that can never been scientifically proven owing to the uniqueness of the journey (the sample size may never be adequate) but there is value in anecdotal knowledge that should not be overlooked.

The voices of lived experience hold wisdoms that can direct change and enable learning, and our respect of their experience can enable healing and support their resilience. The inability to sit with risk leaves gaps in research, and knowledge held in research too often fails to translate to knowledge and change on the ground. Lived experience sit with that risk, they have no choice. They may not have a PhD but the learnings of life have depth and worth, and maybe better placed to enable timely change. If we listen with curiosity not to fix, there is much to learn. This learning has the capacity to capture nuance in real time. This nuance enables the innovation needed. Those encountering the system we expect to support them must be heard when we consider the solutions to the gaps they experience.

Whilst entities have little choice to put energy and resources into gaining funding with ever changing goal posts the progression of knowledge is lost - too much focus on competing for funding rather than ‘doing the work’. Too often effort, knowledge and understanding has no follow through as a result of the funding pressures and lack of funding continuity. Beyond this too many people are repeating the same work, the same conversations, holding the same understanding without the mechanisms to enable translation of great intention into functioning initiatives. Whilst funding continues to be directed at large to services grounded in medical models of delivery, opportunities to innovate and implement new knowledge are few, to the detriment of everyone. The competitive nature of funding hindering the sharing of knowledge and so its progression.

Workforces despite the very best of intentions are wilting in inefficient systems often operating at a great distance from current best practice and at length from innovation. Person centred care continues to be largely overshadowed by a default deficit based medical model. Ironically the training and understanding of our medical professionals placed as the first point of contact is often limited and shaped by dated bias. For those able to muster the energy to seek support, it is often impossible to jump through the hoops to access recommended care, even if available. There are countless opportunities for improvement and the countering of stigma to enable an understanding that this is health knowledge that benefits everyone is crucial. Innovation toward group engagement is possible to broaden access to knowledge and counter the struggles accessing professionals in short supply. Multidisciplinary engagements, early intervention and knowledge sharing are crucial in improving outcomes. We are held back by separating mental and physical health. We are held back by not normalising the experience of mental ill health. We are held back by the stigma and taboo.

Not all improvement is complicated. Consider the simplicity of embracing the expression of emotional and social wellbeing held by our indigenous community as a passage to dissipating stigma around times of mental health challenges, whilst speaking quietly but with strength to the role we all play in enabling wellbeing. .

“If we are not able to sit with the discomfort of these conversations how is anything going to change”

Grateful for your consideration in memory of those lost by suicide and with respect to those mustering the strength to continue navigating a system that is yet to work with them as they work toward improved emotional and social wellbeing, grateful to the workforce persisting within a system failing many.