

'Adults know best': The silencing of young people's voices in mental health



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Introduction

Including the voices and knowledge of people with lived experience is a priority for the disability sector. Resisting the long traditions that positioned people with disabilities as the objects of professional concern or research interest, it is gratifying to see the growing movement underpinned by the mantra: 'Nothing about us without us'. Leslie Swartz, working alongside disability activists and lived experience researchers, has been influential in drawing attention to the voices of people with disabilities and challenging the ways in which they are marginalised, both in relation to social arrangements and the subtle professional discourses that serve to exclude them from discussions about their lives (Swartz 2018; Watermeyer & Swartz 2016).

I began my research career at the University of Cape Town in the late 1980s, where Swartz supervised my Masters' degree with a thesis examining the effects of Apartheid's political repression and violence on children. After a stint at the University of Witwatersrand, I returned to the University of Cape Town in 1994, where I worked closely with Swartz on the development of an approach to clinical psychology which attempted to harness the power and expertise of Black communities in undoing the psychological damage which Apartheid left in its wake. Over the extended period of our association, we co-authored several texts that highlighted the complex operations of power in psychological practice in the South African context (e.g. Gibson & Swartz 2000; eds. Swartz, Gibson & Gelman 2002; Swartz, Gibson & Swartz 1990). I left South Africa for Aotearoa New Zealand in 2003, and my research interests shifted to my current focus on youth mental health. However, my research career has continued to be shaped by Swartz's critical observations on the power of the helping professions and the potential for our practices and ideas to disempower the very people we aim to help.

In this article, I draw inspiration from Swartz to reflect on the way that mental health professionals and discourses have the potential to disempower young people in relation to their own mental health. I argue that powerful discourses operate to silence the voices of those who experience difficulties with their mental health, and that these combine with invalidating representations of young people to legitimise the exclusion of youth from discussions about their own mental health. I conclude with some insights from the Aotearoa New Zealand-based *Mirror Project* that highlight the challenges young people continue to face in making their voices heard on issues related to mental health (Gibson 2021).

Lived experience voices in mental health

While almost all histories of disability representation and care would be likely filled with abhorrent and inhumane accounts, there are some unique aspects associated with conditions understood to affect the mind rather than the body. Read and Dillon (2013) trace the long history of pejorative representations of people with mental health problems and the treatments these enabled. They write about the way that 'madness' in medieval times was linked to witchcraft and demonic possession, deserving of the extreme punishments associated with 'evil' during this period. In the 18th and 19th centuries, Pinel's ideas led to a new 'humane' approach to insanity, one that saw those with mental health problems as in need of incarceration for the purpose of moral rehabilitation. As disease-based explanations of mental health problems began to dominate in the 20th century, these allowed for various radical biological treatments, often without the consent of recipients (e.g. lobotomies, Electroconvulsive Therapy (ECT) and the overuse of medication). Despite some forms of psychoanalysis offering a more emancipatory perspective, this approach reinforced a view of those experiencing mental health problems as fundamentally

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irrational and as unreliable narrators of their own needs. These historical discourses of evil, immorality, irrationality and illness continue to echo in current views of mental health, subtly shaping representations of people with mental health problems and the treatments thought appropriate for them.

The 1960s and 1970s saw the rise of the antipsychiatry movement, which challenged the power of psychiatry and positioned those with mental health experience as the experts (Berlim, Fleck & Shorter 2003). However, this revolutionary perspective collapsed and was quickly superseded by economic interests which favoured the rapid return of the 'client' to full productivity (Dalal 2018). In keeping with a concern for efficiency, mental health treatments in recent decades have seen a focus on 'evidence-based practice', which delivers reliable outcomes in the shortest amount of time possible. While short-term 'talking therapies' such as cognitive behaviour therapy have been popular, recent decades have seen a resurgence in biological explanations and associated pharmaceutical treatments for 'mental illness' (Horwitz & Wakefield 2007). While an approach that equates mental and physical 'illness' seems to offer a more neutral representation of people experiencing mental health problems, the hierarchy that reinforces the expertise of doctors relative to their patients produces a relationship in which the voice of the person with mental health problems is secondary to professional power and knowledge (Bentall 2009).

In recent years, there has been a great deal of talk and writing about including the expertise of those with 'lived experience' of mental health difficulties (Sartor 2023; Sunkel & Sartor 2022). However, invalidating discourses, both past and present, continue to justify the exclusion of those with 'lived experience' from discussions about mental health policy, services and research. Increased recognition of the importance of intersectionality in understanding oppression has provided many examples of the way that marginalised and disempowered groups are particularly silenced in relation to their mental health (Phoenix & Pattynama 2006). Much has been written about the way that psychiatry silences women and invalidates their experience, both historically and very recently (Hirshbein 2010). Working with colleagues, Swartz points out how African knowledges of disability based on lived experience have been excluded from research and understanding (Harvey & Swartz 2024; Ned, Dube & Swartz 2022). Similarly, in Aotearoa New Zealand, Māori and other indigenous groups have also struggled to have their voices and cultural expertise acknowledged in relation to their mental health (Kopua, Kopua & Bracken 2020). The particular constraints on youth voices in mental health also deserve particular consideration.

Although there has been increasing recognition of young people as active participants in society, researchers have noted a gap between the rhetoric and the reality of meaningful inclusion of youth in decision-making (Cockburn 2005; Jacobs & George 2022) and research (Kim 2016). This gap is particularly evidenced in relation to youth mental health,

where the disempowering discourses surrounding practice and research in this field are compounded particularly by the representation of youth as vulnerable and in need of adult guidance.

It was Swartz who first drew my attention to the peculiar way that young people are simultaneously treasured and disempowered. It was during the dark days of Apartheid and the height of the anti-Apartheid struggle where we and our colleagues were concerned to draw attention to the horrific impacts that state repression and political violence were having on South African society. Swartz offered a critical analysis of the way that children (and youth) were represented in the psychological literature on political violence (Swartz & Levett 1989). The gist of their argument was that society readily positions young people as victims in need of protection. While this harnessed support for their plight, it also served to depoliticise political struggles and undermined the moral agency of young people who took part in these. Similar issues play out in youth mental health, as I discuss below.

Power dynamics in youth mental health

The United Nations definition of youth includes young people between 14 years and 25 years. This is an age range that incorporates the period known by developmental theorists as adolescence (Erikson 1968). It also recognises that the boundaries of youth have extended to match the increased time taken for education, the barriers to entering the workforce and delays in achieving independence in many contemporary societies (Arnett 2007). Developmental understandings of youth have become part of everyday discourses about youth in the many countries where Western psychology's influence has spread, even in countries where indigenous knowledge offers different perspectives (Burman 2016).

While developmental theories inform often well-intentioned efforts to support young people, they nonetheless serve to invalidate youth as reliable informants on their own needs or experience. These theories depict children and youth as in a process of becoming (adult), rather than as being, simply as they are (Burman 2016). This has resonances with discourses, challenged by critical disability research, which highlight the way that people with intellectual disabilities are not considered to be fully human (eds. Kittay & Carlson 2010). In more recent years, the idea that the frontal lobes of young people are not fully developed until age 24 has helped to give credence to the idea that young people cannot be trusted to make decisions for themselves (Arain et al. 2013). This is often treated as firm evidence in support of the idea that young people cannot be trusted and ignores cautions about making direct inferences from the structural properties of the brain to behaviour (Poldrack 2018). These claims also ignore the variation in development across the life cycle and contradict social norms which allow young people to work, vote, marry and care for children.

These psychological ideas help to justify the assumption that young people are vulnerable and in need of adult care (Brown 2014). Theorists have also noted the close link between the representation of young people as vulnerable victims and depictions of them as morally underdeveloped and dangerous (Brown 2014). Public discourse often shows young people as irresponsible and likely to engage in risky or even criminal behaviour without necessary adult control (Kelly 2000; Sharland, 2006). While it is true that young people might benefit from support from the adults around them, this idea overlooks young people's capacity to exercise agency and to make thoughtful decisions about their lives. Furthermore, while some young people engage in behaviour that might be considered risky, these risks tend to be overstated and become the basis for controlling policies and practices – including in mental health.

The historical ideas about mental health as punishment, moral rehabilitation and medical expertise are echoed and amplified in relation to youth experiencing mental health problems. They are seen as risky and in need of control and moral correction; they are viewed as vulnerable and in need of care and protection; and they are irrational and lack the wisdom to know what they need. All of this combines to support a perspective that says adults, including parents, mental health professionals and researchers, 'know best' what young people with lived experience of mental health difficulties need.

There is also another important reason why young people's voices are so often ignored in relation to their mental well-being. It is a paradox that to have your voice treated as significant, it needs to be seen as both distinctive and absent from the conversation. The challenge is that adults have, at least at one point in their life, been young. This creates the illusion that having been there themselves, they believe they have sufficient expertise in what it means to be young (Corney et al. 2022). Faced with this pseudo-logic, society seldom recognises the need to pay careful attention to young people's views and experiences. However, while adults might once have known and experienced what it was like to be a young person with little control over their lives, it becomes hard to imagine this experience as they grow comfortable in their adult power. Furthermore, the experience of each generation is fundamentally different. This has probably always been so but is particularly salient for recent generations, which have been marked by rapid social change, underpinned partly by massive development in the digital technologies available to young people. Despite these barriers to adults understanding young people's experiences, youth mental health continues to be dominated by what has been called *adultism* – the myth that adults know best what it is that young people need (LeFrançois 2014).

Young people's experiences of being silenced on mental health issues

In the Aotearoa New Zealand-based *Mirror Project*, we are doing research aimed at getting a better understanding of young people's worlds in this generation and their views on

various aspects of youth mental health (Gibson 2021). We have so far interviewed over 500 young people across a range of studies exploring their experiences of mental health distress, their views of mental health services, their preferences for support in their own online or offline networks and their views on issues such as the causes of youth mental health problems and suicidality. While the research is limited by the fact that I am an adult, I have worked alongside young researchers who are closer in age to the youth who have participated in this project. We have also been experimenting with a range of more inclusive and participatory research methodologies that allow young people's voices to be heard more clearly (Gibson 2022; Stubbing & Gibson 2021). Through this project, we have gained a new appreciation of the struggles that young people continue to face in having their voices heard in relation to their own mental health.

The young people we spoke to conveyed their awareness of public discourses that undermined the validity of their mental health struggles. While this generation of youth have been the recipients of mental health literacy and anti-stigma campaigns (Jorm 2012), they were very aware of negative public views surrounding young people's expressions of mental health distress. Despite the significant existential threat of climate change, economic inequality, political polarisation and an uncertain future, they were conscious that their generation were seen as 'snowflakes' and their problems as trivial. They offered examples of interactions in which young people experiencing mental health distress were described as 'attention-seeking' and how, when they sought help, they were told they would 'grow out of it'.

These invalidating discourses directed specifically to youth played out alongside more general pejorative views about mental health that influenced their ability to talk to the adults around them. These young people recognised that previous generations were constrained by views of mental health as shameful and unacceptable and that this influenced their ability and willingness to talk to young people about their struggles. Others captured how their parents were invested strongly in their success and viewed mental health problems as a kind of failure. In Aotearoa New Zealand, where mental health professionals' fears of suicide contagion have placed limits on the open discussion of suicide in media and public institutions, young people recognised this as a taboo subject. What was intended as protection felt to them like adults trying to pretend the problems they experienced were not happening.

The young people who participated in our study were also very conscious of their position on the lowest rungs of the social hierarchy and how this served to silence their voices on many aspects of their lives, including mental health. In the neoliberal context of Aotearoa New Zealand, there is an emphasis on youth 'making choices'. However, the reality was that the young people we spoke to felt they had little control of their environments and few options. They were told to listen to their parents and teachers, and even if they earned an income, they often had very little power in their workplaces. We captured many examples of young people's

fear of losing the little power they had if they spoke up about experiencing mental health problems. For those young people who had engaged with mental health services (sometimes involuntarily), their concerns were often borne out as they faced intimidating clinical settings, dominated by adults, and were given few choices over their treatment options. The powerlessness experienced by young people generally was even more pronounced amongst the Māori and Pasifika youth that we spoke to. Generations of colonisation have undermined indigenous ways of understanding and dealing with mental health (Moewaka Barnes & McCreanor 2019). However, there is recent research that shows how *rangatahi* [Māori youth] have been able to draw on traditional cultural resources to support their well-being (Hamley et al. 2023). Despite the value of these models, Māori and Pasifika people in Aotearoa New Zealand continue to face cultural barriers to their participation and influence within a European-dominated mental health system over which they have little influence (Espiner et al. 2021; Fa’alogo-Lilo & Cartwright 2021).

Young people also told us of their frustration at being positioned as the recipients of adult ‘advice’ and how they seldom felt listened to by mental health professionals or other adults in their lives. They provided examples of how hard it was to find their voice as the only young person in a mental health consulting room, surrounded by parents and professionals who took control of the conversation. While ‘talking therapy’ is intended to allow the opportunity to speak, some young people described how contemporary pedagogical forms of therapy sometimes left them feeling like they were pupils in a classroom taking instruction from a teacher.

With a growing awareness of the value of involving young people as ‘lived experience’ experts, more services and research groups are equipping themselves with ‘youth representatives’. In practice, however, this often means that one or maybe two young people are present while a group of powerful adult professionals are engaged in high-level discussions about youth mental health needs. It is very hard for a lone young person (or even a small group) to offer a different point of view in these circumstances. There is a risk that even well-meaning attempts to engage youth in participatory roles in relation to mental health might end up being little more than tokenism.

Our research highlights that despite the recognition of ‘lived experience’ expertise in mental health, it remains very difficult for young people to participate in discussions and decisions about their mental health. Discourses that invalidate their experiences, which deny their knowledge and expertise, and that rob them of their power exclude them from meaningful involvement in issues related to their own lives and well-being.

Conclusion

The importance of listening to young people’s voices in mental health is not only an ethical issue related to their right to be included; it is also driven by a concern that without youth involvement, our understanding of the

causes of mental health issues and the support needed to address these remains a poor fit for the needs of this group. This is particularly concerning, as statistics show rising rates of youth mental health problems around the world and poor engagement of young people with the services available to support them (McGorry et al. 2022). Increasing recognition of lived experience as a valuable source of knowledge in disability more broadly, and mental health in particular, provides a window of opportunity to learn from young people’s direct experience and awareness of their own mental health needs and priorities. Engaging with this properly, however, involves deconstructing the discourses that invalidate people with mental health problems and doubly invalidate the voices of young people who experience mental health distress. We need to actively challenge the representations of young people that normalise their powerlessness and undermine their opportunities to participate effectively.

As there is greater lip service paid to the importance of including ‘youth voice’, we need to be particularly vigilant to the potential for youth engagement to become tokenistic. For example, the practice of having one or two youth advisers on a board dominated by adults does little to facilitate young people’s impact on decision-making. In research, we need not only to offer opportunities for young people to express their views but also to actively challenge the power imbalances in the relationships between youth participants and adult researchers (Wyn & Harris 2004). Co-design approaches to research suggest a helpful way forward in mental health research; however, it is important that engagement with youth is sustained and meaningful (Thabrew et al. 2018). In addition, it is particularly important to make sure that the voices of indigenous youth are heard to capture the nuance of their experience as distinct from that of their elders (Hamley et al. 2023). Finally, we also need to encourage young people’s voices in challenging some of the unhelpful social discourses that act to prevent open conversation on mental health issues, including suicide.

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