Title: Engaging young people in mental health research addressing stigma

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Young Australians are more likely to be anxious and depressed and also to binge drink compared to older people according to the Australian Bureau of Statistics' latest National Health Survey (2022). In 2020-2021, almost 19% of young people aged 15 to 24 reported experiencing anxiety and 14% had depression. Similarly, in the United Kingdom, there has been an increase in reported mental health conditions in young people. Among those aged 6 to 16, one in six had a probable mental health condition in 2021, up from one in nine in 2017 (The Health Foundation, 2022). Despite the growing prevalence of mental health problems among young people, these young people continue to face stigmatisation and discrimination relating to their mental health. There are many negative consequences of stigma including the internalisation of negative stereotypes referred to as self-stigma (Corrigan & Rao, 2012). Self-stigma can lead to feelings of shame, low self-worth and poor self-esteem (Cogan et al, 2019). It can interfere with a young person's ability to seek treatment or to take good care of themselves. Self-stigma during times of adolescence is especially challenging due to the developmental changes experienced by young people as well as social, peer and academic pressures (Taylor et al, 2021).

Why does self-stigma occur?

Self-stigma occurs when young people internalise negative prejudice and discrimination directed at them. This may come as a result of public stigma where negative attitudes and stereotypes are held against people with mental illnesses (Corrigan & Watson, 2002). Common stereotypes about people with mental illness include beliefs that they are dangerous, unpredictable or incompetent. Such stereotypes can lead to prejudices against young people with mental illness including fear, anger and pity (Angermeyer et al, 2010). Such aspects of public stigma are connected since stereotypes are associated with prejudices and discriminatory behaviours (Gärtner, et al, 2022). While there is an increasing understanding of the causes and impacts of mental illness self-stigma, much of what is understood about self-stigma relates to adults' experiences. Little is known about the unique understandings and perspectives of children and young people who experience mental illness self-stigma.

Involving children and young people in mental health research

Involving children and young people as collaborators in youth mental health research is becoming more widely valued and recognised as essential to ensuring that research is relevant and responsive to their needs. Young people are often eager and capable of being involved in all stages of the research process (Mawn et al, 2015) yet little information is available on best practice for their involvement in mental health research. This is particularly true for younger children who have tended to be more the subject of research rather than active participants or partners in research. How researchers engage with children and young people in mental health research is related to how confident and competent they feel in engaging with young people (Faithfull et al, 2022). Whether researchers engage young people in research can also be impacted by the availability of resources, ethical issues,

culture and the structures that their organisations have in place to support youth participation in research. This can be further complicated when considering research on mental illness self-stigma as by virtue this may serve as a barrier to young people feeling confident and willing to engage in research that effectively seeks to understand their lived experiences. So how might such potential challenges and barriers to youth participation in such research be overcome? One possible approach is to adopt participatory methods that include children and young people in the research process, from planning and developing research questions to disseminating the research findings.

Peer-research: the value of lived experience

While levels of youth participation in mental health research can vary from passive involvement as research participants through to active, youth-led research, an innovative approach that has gained increasing interest in recent years involves adopting participatory methods. Participatory methods include children and young people with lived experience of the issues being studied as peer researchers. Peer researchers are partners throughout the research process and are involved in decision making in relation to the research design, developing research tools, collecting and analysing data and/or writing up and disseminating findings. Such participation brings several benefits to the research itself and to the peer researchers involved. It brings the advantage of gaining insight from their experiential knowledge and inside understanding of mental health issues which can enhance the richness and nuance of the research. It aims to empower children and young people to affect positive change by not only participating in research but also leading on it too. The process of engaging with such research has the potential to enable young people to gain transferable skills and gain confidence. It can be a means to minimise the power imbalances between researchers and participants often evident in traditional research methods. It can help in reducing bias and promote improved understandings of children and young people's mental health experiences to inform policy and practice.

Evidence suggests that peer research and engaging with communities makes the research process more sensitive to the needs of participants (MacIntyre et al, 2019). In particular, the lived experiences that peers bring often results in important and insightful research questions being asked. Research participants are more likely to be open and honest in their responses when working with peer researchers. To date, research addressing stigma in young people has rarely used participatory methods and this represents an area for improvement.

How to safely engage children and young people in peer research

In order to achieve the benefits of youth involvement in mental health research addressing stigma, it is essential to consider how best to safely and meaningfully engage children and young people in research. Building trust and relationships among peer researchers and the wider research team in essential. Having an understanding of the developmental stage and needs of the children and young people is important. Engaging in collective decision-making, facilitating open lines of communication and providing support and time to reflect is fundamental to best practice. Involving primary care-givers and/or parents (e.g. to provide consent to participate), when needed, demands dedication and sensitivity to the issues this may raise among the participants, peer researchers and co-researchers. This process takes time to develop and involves complex decision making and awareness of the rights of children and young people throughout the research process (Dewa et al, 2021). Quality research requires the ability to understand and interact with those that experience the impact of mental illness self-stigma. Consulting children and young people as experts by lived experience is a great way of getting an insight into their mental health experiences of stigma and some of the barriers they experience in seeking help and support.

However, it can be challenging to recruit children and young people to engage in such research. Some young people may be unwilling to discuss their lived experiences – they themselves may struggle to make sense of such experiences. For others, it may be simply too painful or traumatic. Experiencing self-stigma may serve as a barrier to partaking in these opportunities because it can lead to feelings of worthlessness and the sense that it would be better to not try – otherwise referred to as the 'why-try' effect (Corrigan et al, 2016). - a sense of behavioural futility ("*Why should I try to do well in school - I'm not worthy*", "*Why should I try out for school sports - I'm not able*"). Educators and researchers can help with supporting young people to take up these opportunities, providing incentives, finding creative solutions to engagement and demonstrating an understanding of some of these challenges. Encouraging young people to talk with the wider research team more openly about their experiences of self-stigma, understanding their support needs for engaging in the research process and introducing a culture where talking about mental health feels safe and supportive is central to best practice. Openness, transparency, and honesty about what it will be like being a peer researcher from the offset will help young people decide whether the opportunity is (or is not) for them. This is important for building trust, rapport and bringing peer researchers into a safe environment. It is essential to allow a flexible environment for young people as peer researchers. This includes flexibility in terms of deadlines, attending meetings, and accessible formats with work. Researchers and educators must show respect, humility and value to young people, as power imbalances can have an impact on self-esteem, self-efficacy, and may lead to imposter syndrome. Ultimately, this could also impact their choice of wanting to participate as a peer researcher.

Supporting best practices

Educators and researchers seeking to conduct peer research with youth involvement need to be able to spot and support those that are struggling to ensure that they are signposted to the correct help and support when needed. Being able to ensure that stigma (self and public) does not prevent children and young people from engaging in research involves recognising that it exists and seeking to challenge it. It is progressive to see the growing body of research which focuses on stigma in mental health within the adult population - more work is needed to support children and young people's mental health in the changing and unique pressures of their lived experiences. This involves awareness and consideration of diverse views and understandings of mental health and the subsequent impacts of stigma. Seeking the perspectives of young people of colour, gender identity diversity, LGBT+ communities and those with diverse religious or spiritual beliefs are just some of the ways to help broaden awareness and understandings of lived experiences of youth mental health and the impact of stigma. This can best be achieved by safely and meaningfully engaging young people in the research process – through supporting children and young people to lead such work moving forward.

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