

A FIVE PART SERIES ON STIGMA AND ITS IMPACTS

USING STORYTELLING APPROACHES TO REDUCE STIGMA

People with lived experience have used storytelling to make positive change across many sectors.

Lived experience storytelling occurs through in-person events, news articles, videos, podcasts, and more. There are many ways in which stories are told by people with lived experience, such as a person sharing their personal recovery journey. Storytelling has been found to reduce mental health-related stigma, especially when told in-person and from a first-person point of view.¹

However, it is important that organisations do not co-opt or control the narrative when involving people with lived experience in telling their stories. Stigma reduction activity requires meaningful and ongoing lived experience input, collaboration, and leadership across all levels of an organisation. Relying solely on storytelling, when done in a non-collaborative way, risks being tokenistic and disempowering.

Stigma is a [priority to action](#). **This Brief** overviews some pathways to scalability for organisations wishing to implement new storytelling initiatives, or incorporate storytelling into their existing stigma reduction activities.

LIVED-EXPERIENCE PERSPECTIVES ON STORYTELLING

As a result of sharing their stories, many lived experience speakers report:^{2,3}

- A sense of empowerment and altruism
- Reframing their own experiences in a way that is personally meaningful and valuable
- Feeling connected to, and helping, others.

However, many speakers also report challenges, such as experiencing distress as a result of:²⁻⁵

- Needing to edit or 'sanitise' their stories to fit an organisational agenda
- Losing ownership of their story once it is available to the public
- Experiencing discrimination (such as losing job and housing opportunities) after sharing a story attached to their name
- Organisations failing to recognise diversity of experiences and perspectives, and privileging certain stories over others.

Furthermore, although some representations of mental ill-health and suicide can be powerful and validating to audiences with lived experience, [others can be harmful](#).

Generally, the literature should be interpreted with caution, as research is often created and interpreted without people with lived experience.

SCALABILITY TARGETS

Scalability refers to the challenge of how to transfer what may have worked in a research context, into practice or policy settings. Key considerations may include: the credibility or evidence regarding the impact of storytelling; the benefit and relevance for people involved in storytelling; the cost to benefit ratio compared to other approaches; and usability and alignment of storytelling initiatives with the values and norms of the setting. Elements of storytelling for stigma reduction have been well-researched, but there are few models for storytelling which have been evaluated in real-world environments. Considerations are outlined over the page.⁶

Action is needed to ensure that lived experience storytelling activities are implemented in a way that is ethical and effective. The following table highlights pathways to support implementation that can assist in the absence of models ready to scale.

PATHWAYS TO SUPPORT IMPLEMENTATION

<p>Engaging and supporting speakers</p>	<ul style="list-style-type: none"> • People with lived experience should be central to any storytelling project, and included in roles in addition to those as storytellers, including as project leaders, depending on their preferences and skills • Consider your audience and be purposeful in your selection of speakers based on different characteristics and experiences • Support and give autonomy to speakers as they prepare their stories including how they prefer to craft their message/s and establish boundaries • Leverage existing resources such as the Mental Health Coordinating Council's safe storytelling training, and Mindframe's lived experience speaker resources and language guidelines • Consider linking with organisations that can provide resources, such as SANE, beyond blue and Roses in the Ocean • Offer to pay speakers for their preparation, time, and reasonable travel costs. If the story will be used for profit, offer compensation beyond a single honorarium
<p>Story-telling medium and approach</p>	<ul style="list-style-type: none"> • Consider how the storytelling medium, and its limitations (e.g. video vs. in-person) might impact on a range of areas <ul style="list-style-type: none"> • These include: speaker readiness, accessibility, budget, staffing requirements, storytelling complexity, messaging, reach, and scalability • Be mindful of the need to balance an organisation's aims with the need to stay authentic to a speaker's story, allowing space for speakers to provide opinions, critiques, and opposition which do not always neatly fit into an organisation's agenda • Give the speaker control over the messaging, medium and timing of the presentation, within practicalities • Be mindful of ethical issues and limitations relating to using testimonials for advertising health services
<p>Informed consent</p>	<ul style="list-style-type: none"> • Clearly communicate information about the speaking engagement with speakers at the outset <ul style="list-style-type: none"> • This includes: the purpose; format; how any video/audio/written stories might be edited; the audience; remuneration; privacy considerations; future usage • If possible, provide the option to share stories anonymously, or give due credit where a person wishes to be named • Obtain permission to use a speaker's story in specified ways (e.g., through Talent Release Forms) • Provide speakers with the right to review, provide feedback, and withdraw their story prior to any publication, and a clear process for how to do so • Provide debriefing opportunities and ongoing support
<p>Impact</p>	<ul style="list-style-type: none"> • Seek feedback from the perspective of both the speaker and the audience • If possible, evaluate the impact of storytelling on stigmatising attitudes, behaviours, or other outcomes. • Integrate lived experience researchers and evaluators into such activity

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