Protecting Individuals With Lived Experience in Public Disclosure

Integrating the experiences of individuals with lived or living experience in substance use disorder projects, campaigns, articles and activities brings invaluable authenticity and depth. When properly stewarded, these stories have the power to build empathy, heal wounds and bridge the gap between knowledge and action. Yet, when stewarded inappropriately in the digital age, these narratives of lived experience can intensify stigma, misrepresentation and harm, commodifying and tokenizing the very individuals that these stories are about.

The Protecting Individuals With Lived Experience in Public Disclosure Guide and the Lived Experience Safeguard Scale (LESS) are designed to help individuals and organizations identify and manage the potential harms involved in publicly sharing addiction recovery stories. These resources enable the evaluation and adoption of strategies for better safeguarding storytellers' wellbeing; the proposed strategies can be mixed and matched depending on the nature of an individual project. Any effort made toward safeguarding wellbeing is valuable.

NATIONAL COUNCIL
for Mental Wellbeing

1. PRIVACY

[The World Health Organization](#) identifies substance use as one of the most stigmatized conditions worldwide. With highly stigmatized conditions, public sharing of lived or living experience is fraught with real risks. When articles and activities reveal the sharer's personal identifying information, these individuals become searchable. This can result in termination or discrimination in employment, housing and legal disputes, such as child custody cases. It also can result in bias and social exclusion in far-reaching scenarios, like online dating.

Recommendations

Use the following to mask geographical or personal identifying information to eliminate the possibility of online searches:

- Alias or first name only, instead of full name

- Wider state or geographical region (e.g., Northeast, Midwest) instead of town or neighborhood

- General employment industry (e.g., hospitality or "job in the development sector") instead of employer name or job title

- Age segment (e.g., teenager, young adult, middle aged) instead of exact age or birth year

2. STABILITY AND EXPERIENCE

For those recovering from addiction or chaotic substance use, the motivations to share one's story are diverse: to inspire others, effect societal change, make amends, seek redemption or respond to perceived pressure. Stories often emerge publicly during early recovery, a period marked by high instability and vulnerability to relapse. Sharing one's story publicly lacks the psychological safety many in recovery are accustomed to inside peer support spaces such as Alcoholics Anonymous. Additional education and experience prior to sharing can ensure that what is shared doesn't unduly expose the individuals to harm or unintentionally perpetuate stigma.

Recommendations

- Select individuals that have five-plus years in recovery, the point at which the individual is [no more likely than anyone else in the general population](#) to develop a substance use disorder again in their lifetime. Five years also ensures that [the most significant quality of life improvements have already occurred](#) for the individual. This added stability and experience in recovery can help to buffer the individual in the event of negative stressors or consequences from public disclosure.

- Select individuals who already have a career in public-facing recovery advocacy, as they likely have practice communicating their narrative, are adept at handling public scrutiny and are familiar with the various risks associated with public disclosure.

- Select individuals who have undergone formal [media training](#) to ensure they possess the necessary skills and knowledge for effective communication. This ensures they can safeguard their privacy and mental wellbeing and constructively shape public perception of addiction. Without such training, there's a risk of accidental oversharing and misrepresentation.

3.   EQUITABLE DECISION-MAKING AND DEI

Individuals with substance use disorder have and continue to experience prejudice and discrimination that often results in being treated as second class citizens. This is compounded for individuals who are part of other marginalized groups as well. To better support those sharing their lived experiences, it's crucial to uphold practices that foster a culture of respect and empowerment. This involves meaningfully incorporating individuals with lived experience into the decision-making process, to avoid tokenization and provide them with genuine power and equitable representation. The portrayal and stewardship of addiction stories requires recognition of diversity within groups and intersecting identities within each person. By sharing power and engaging in collaborative decision-making regarding the depiction of others' addiction journeys, we ensure that their experiences and identities are genuinely and accurately portrayed.

Recommendations

- Forego background checks to prevent reinforcing the criminalization of a chronic relapsing brain disease like substance use disorder. We must avoid unintentionally perpetuating the discriminatory practices that have resulted in people of color being disproportionately arrested and incarcerated for drug-related charges, despite similar substance use rates across racial and ethnic groups.

- In both for-profit and nonprofit settings, fairly compensate individuals who contribute their time and lived experience in activities like speaking engagements or focus groups, aligning with standard rates in other industries. Not providing financial compensation perpetuates the stigmatized undervaluing of those with substance use disorders.

- Openly acknowledge intragroup diversity and the large variations in experiences and recovery pathways that inherently exist. Using one person's story as representative of all those with substance use disorder oversimplifies and sensationalizes a complex condition, further stigmatizing and disempowering affected individuals.

- Fully integrate individuals with lived experience into discussions and decision-making processes at all levels and stages, to ensure authentic representation and shared responsibility. Limited involvement leads to tokenization — making only a symbolic and superficial effort to be inclusive of members of a minority group.

- Let individuals review or approve questions prior to interviews or activities. Refrain from asking additional, unapproved questions or conducting long and unstructured interviews on camera, as that can lead to oversharing or overexposure.

- Create ongoing feedback mechanisms (or loops), allowing individuals to continuously review and contribute their perspectives on the way they have been represented throughout the process.

4.   AFFIRMATIVE ORIENTATION

Affirmative content combats the prevalent deficit-based narratives and imagery that often surround stigmatized conditions like substance use disorder. All too often, stories of addiction are used to incite fear and distrust of an already marginalized population. Strengths-based content moves away from a sensationalized focus on disease progression and active addiction, instead highlighting change actions, treatment and recovery. This method affirms the human capacity for growth and positive change and fosters unity by emphasizing connections, shared values and community strength. It aims to disrupt the digital tendency toward trauma voyeurism: the societal obsession with and consumption of distressing content that depicts suffering in ways that divert attention away from the genuine empathy and understanding that stories of lived experience merit.

Recommendations

- Use affirmative imagery that is vibrant and colorful to emphasize solutions, the strength of communities and personal growth. Replace dark, substance-focused visuals that can trigger those in early recovery with positive and hopeful representations.

- Use narrative approaches such as Solutions Journalism or Values-centered Storytelling to craft stories of lived experiences that empower both the storytellers and their audience. These approaches concentrate on showcasing resilience, community strength and specific actions leading to positive change. By doing so, they avoid negatively skewing the narrative through an excessive focus on the stage of active addiction, the plunge to rock bottom, or the rock bottom of overdose. By focusing on solutions, narratives steer away from sensationalism and toward empowering stories that foster understanding, empathy and informed conversations about stigmatized health conditions such as substance use disorder.

5.   PSYCHOLOGICAL SAFETY

Retelling stories of lived experience requires a certain level of emotional vulnerability, and it often involves revisiting traumatic experiences. Unpredictable and potentially negative reactions in a public setting can have emotional impacts on the sharer, causing re-traumatization, creating new sources of pain or embarrassment, or simply bringing up feelings of shame. The immortalization of old narratives can also disallow for healing or personal growth, especially when an individual relapses after their recovery story is published or simply experiences an evolution in their beliefs or interpretations of past events post publication. Additionally, while there are risks to every individual sharing their story, individuals from marginalized communities may experience a compounding effect that amplifies their risk of harm.

Recommendations

- Set a two-year time limit for how long personal narratives can "live" online, and/or have established pathways for individuals to request removal of their stories at any time, giving them control over how long their personal journey is shared with the world.

- Turn off the comment function or routinely monitor comment sections to provide a more psychologically safe environment for individuals sharing their lived experience. This can help to mitigate the spread of stigmatizing misinformation and prevent the emotional harm caused by personal attacks, threats or derogatory remarks.

- Have support resources available to assist individuals sharing their lived experience, to ensure that they have access to counseling or support services if necessary. Not every individual will need this support, but having a plan in place will better safeguard the individuals wellbeing if harms arise from the public disclosure.

Plante, A., & Lovell, C. (2024). Protecting individuals with lived experience in public disclosure guide. National Council for Mental Wellbeing. https://www.then-ationalcouncil.org/protecting-individuals-with-lived-experience-in-public-disclosure-guide/

LIVED EXPERIENCE SAFEGUARD SCALE

Individuals and organizations incorporating personal narratives of addiction and recovery can use the Lived Experience Safeguard Scale (LESS) for self-evaluation. This scale allows you to assess your current prioritization of safeguard measures to mitigate potential harms inherent to public disclosure of addiction and recovery stories, and to more effectively represent and empower the individuals whose stories of lived and living experience are being shared. Proposed strategies for responsible stewardship can be mixed and matched depending on the individual nature of a project or article, and any effort made toward this aim is significant.

Please place a checkmark next to each criterion you meet

Speaker Selection Criteria:

Select a speaker with 5+ years in recovery/healing pathway

Select a speaker with a career in public advocacy

Select a speaker with or provide formal media training

Content Development Criteria:

Use first name or alias only

Masked geographical or personal identifying information

Use affirmative imagery

Use affirmative narrative frameworks such as Solutions Journalism or Value-centered Storytelling

Acknowledge intragroup diversity

Process Criteria:

Avoid criminal background checks

Allow for pre-review of all interview questions

Share power and decision-making responsibility

Establish continuous feedback loops

Set a time limit and/or offer removal options

Turn off or routinely monitor comments sections

Provide fair compensation

Make predetermined support resources available

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Scoring:

11-16 is high prioritization of the wellbeing of the individual sharing their story.

5-10 is medium prioritization of the wellbeing of the individual sharing their story.

0-4 is low prioritization of the wellbeing of the individual sharing their story.

Plante, A., & Lovell, C. (2024). Lived experience safeguard scale. National Council for Mental Wellbeing. https://www.thenationalcouncil.org/lived-experience-safeguard-scale/