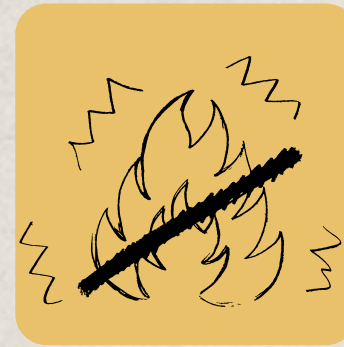


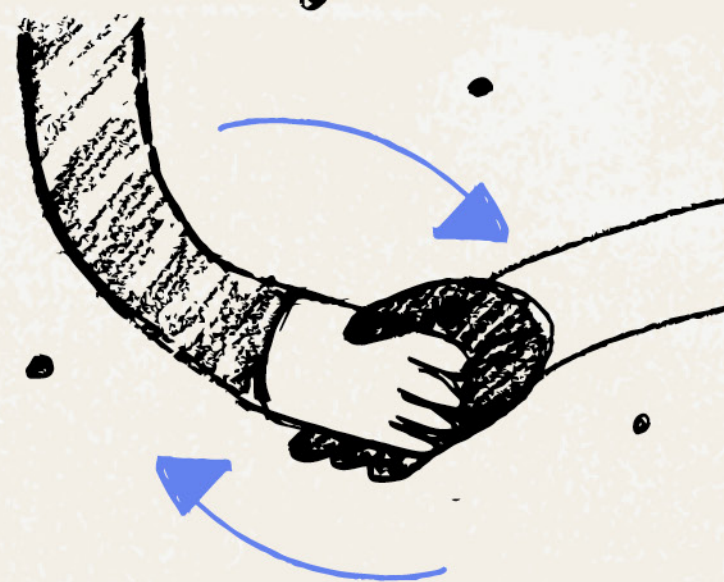
CONSIDER WITH CARE

Resource for working equitably and ethically with people
and their lived experience.



ABOUT THIS RESOURCE

We have created this resource in partnership with people who have shared their lived experiences for campaigning and activism purposes.



This resource is for organisations who want to:

- **Enable** the people they support to inform their policies and services,
- **Engage** with people who have lived experience of the issue they are developing policies for,
- **Utilise** lived experience to promote their work externally through communications and campaigns.

This resource DOES NOT aim to:

- Discourage organisations from incorporating and/or promoting lived experience in their work.
- Prevent people from sharing their lived experiences publicly.



This resource DOES aim to:

- Educate organisations on how to equitably and ethnically incorporate lived experiences in their work.
- Improve the way organisations treat people and their lived experiences.

A note on lived experiences . . .

To communicate the lived experiences we heard during the development of this resource, we have used anonymised quotes from engagement sessions and composite stories to generalise real experiences.



THEMES

This resource is built around four key themes. Click/tap on the theme above to find out more:

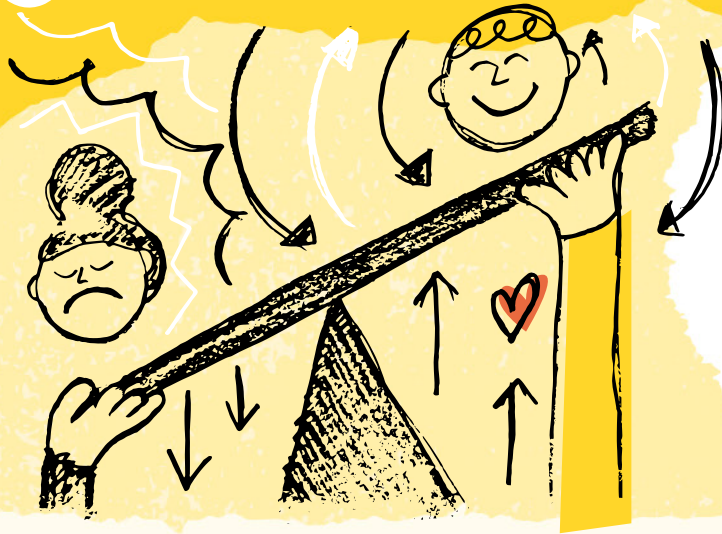
POWER

TRAUMA

IMAGE

BURN OUT

POWER



As an organisation with a role in supporting people, it is important to recognise where the power lies during the engagement process. If you ask a person to share their experiences to inform your services or you ask them to speak publicly about the support they receive on behalf of your organisation, **you hold the power.**

In these scenarios, it is you, as an organisation, who is determining the conditions and designing the platform for the person to speak. Without proper consideration, this can create a power imbalance whereby the lines between an individual's empowerment and exploitation become blurred.

When power between an organisation and an individual is imbalanced, it looks like . . .

- An organisation only seeing value in a person's lived experience instead of all of their personal and professional expertise.
- An individual having little to no say in how their experiences are used.
- An organisation asking a person to change their experiences to fit their organisational narrative better. For example, through sensationalising bad experiences or asking someone to talk to experiences that are not theirs.
- An organisation having a preconceived idea of what their output is, allowing no input from the individual apart from sharing their story.

ARE YOU SHARING POWER?

EMPOWERMENT *noun*

1. Authority or power given to someone to do something.
2. The process of becoming stronger and more confident especially in controlling one's life and claiming one's rights.



LIVED EXPERIENCES OF POWER IMBALANCES ...

“Organisations often think that by giving you a platform to tell your story and promote them that they’re empowering you. But that’s not empowerment because it’s on their terms. True empowerment is when you’re invited into rooms where your voice carries weight to affect change beyond just telling your story. I feel empowered when I’m respected for my whole self and I’m given meaningful opportunities to translate my experiences and expertise into developing better policies to help others.”

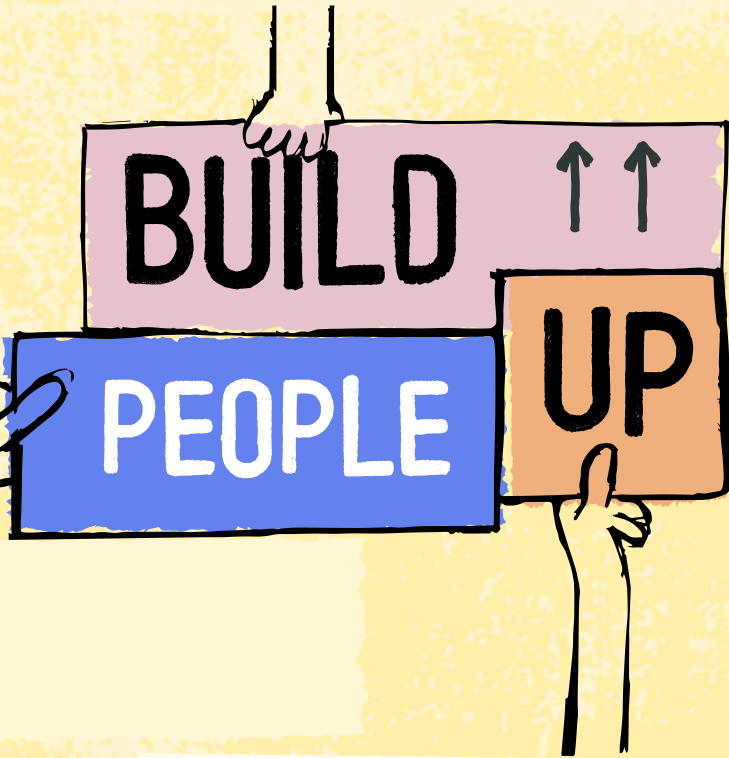
“What I wrote for blogs or articles would be changed at the last minute to ‘pull on the heart strings’ more. I would prepare a speech for days only to be told just before I went on stage that it needs to be more ‘depressing’ to give ‘more trauma’.”

MORE EXPERIENCES OF POWER IMBALANCES ...

“I was asked to speak about my experiences of being separated from my brother. My brother was always the driving force behind my desire for change, and I wanted to do something to make him proud. But as I worked on my speech, I was instructed by the organisation supporting me to discard my own words because they had prepared a script. None of the words felt authentic to me and I had limited freedom to make alterations. After delivering the speech I found myself completely cut off from the organisation. There was no communication, and no post-event support, despite having shared my most personal and intimate story.”



“I would be given a script containing experiences that were not mine but asked to read them in front of camera as if they were. Slowly, I started to realise that the power I had was not power to change the things that mattered to me - I was just a vessel to give power to someone else's agenda.”



When power between an organisation and an individual is equitably shared, it looks like . . .

- An organisation working with an individual to build up their confidence, skills and expertise during the engagement process.
- An individual being offered meaningful opportunities to shape and deliver the work.
- The person who is sharing their lived experience being compensated for their time through remuneration or development opportunities.



“I have come to realise that power lies within each of us to control our own narrative. It’s a matter of recognising that power and ensuring that others do not exploit you for your story. Unfortunately, this realisation came to me much later, after I had ensured the re-traumatisation and exploitation of my own personal experiences.”

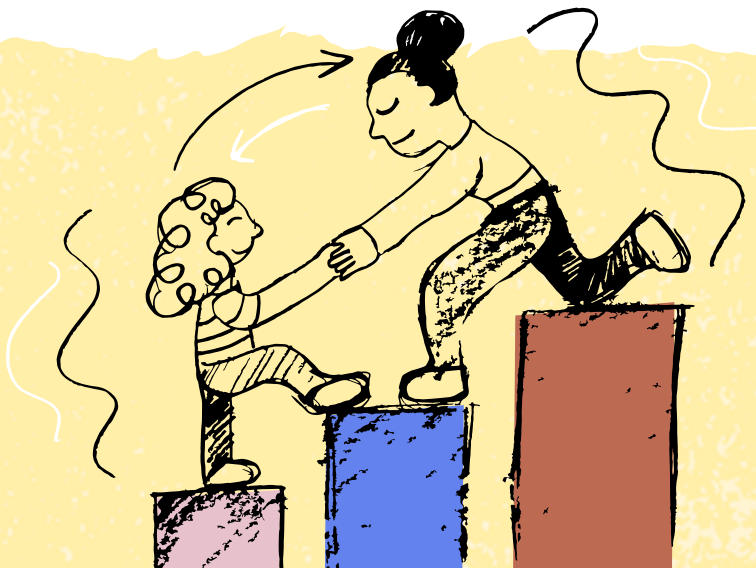


“All of the attention was showered upon me simply because I was unafraid to share my own experiences. However, the reality was quite different. As I repeatedly shared my story, it was if I was tearing open old wounds and pouring salt into them over and over again.”

CONSIDER POWER WITH CARE

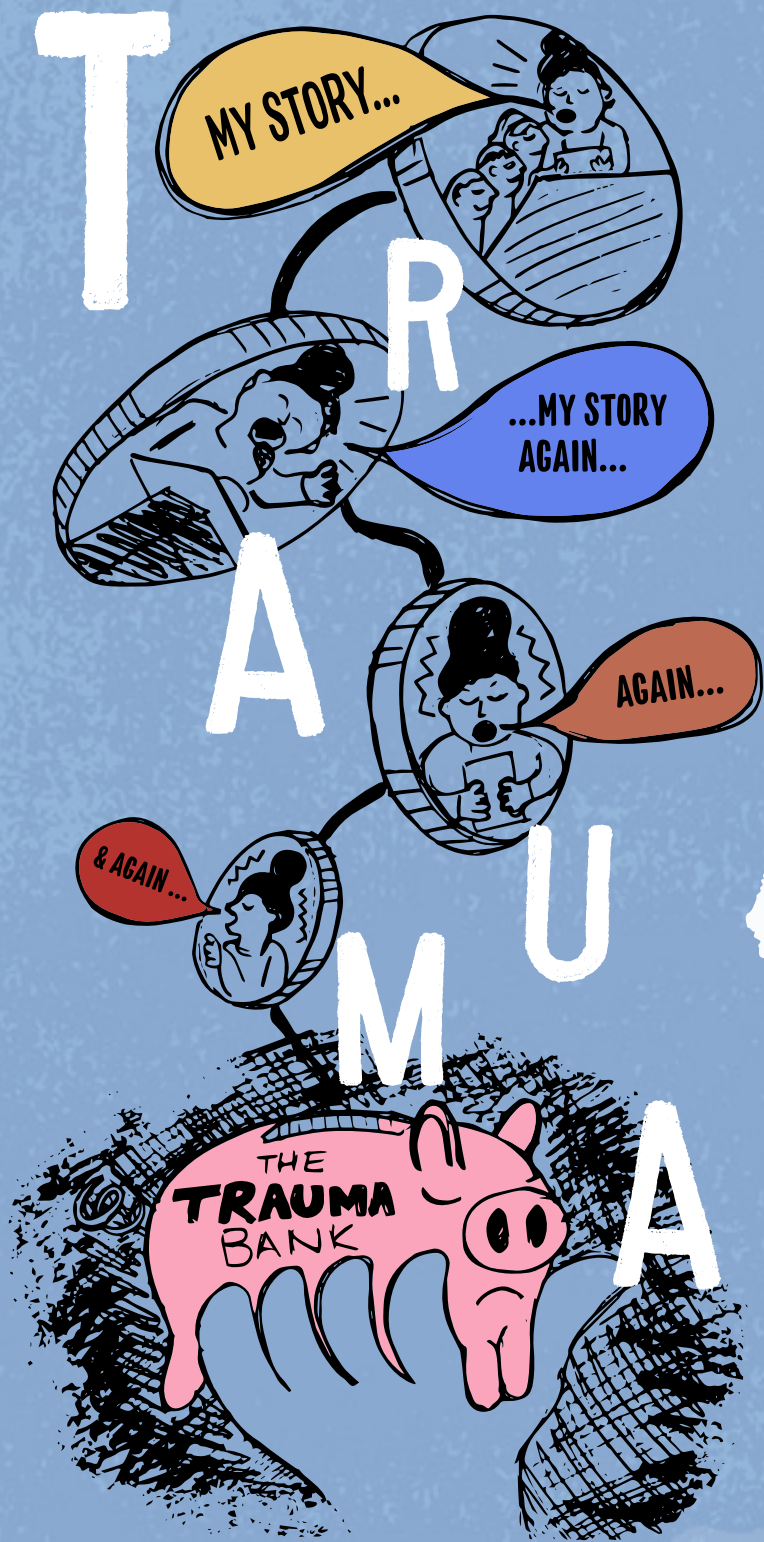
Here are some questions for your organisation to reflect on to avoid exploitative power imbalances when working with people who have lived experience:

- When you are designing an engagement approach to gather lived experiences, are you building in participatory processes to enable meaningful dialogue?
- Is the person sharing their lived experiences compensated for their time? For instance, through remuneration or training opportunities.
- Do you enable people to co-lead the work they are contributing to beyond just sharing their lived experiences?
- Have you set out a clear shared purpose for the work?
- Does the person sharing their lived experiences view the process as mutually beneficial?



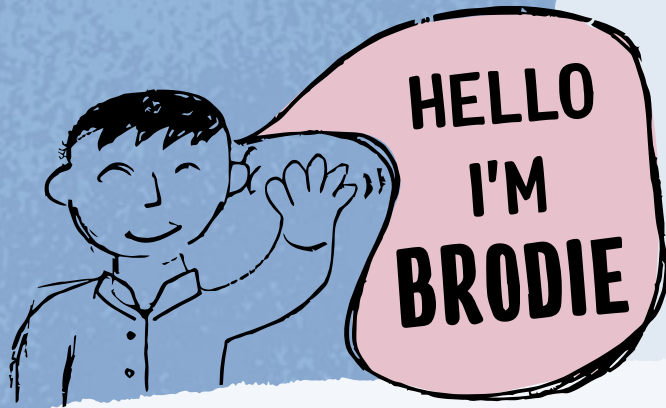
FURTHER READING AND RESOURCES ON POWER

- ★ [Authentic Voice 'Discovery Report'](#)
- ★ [The Value of Lived Experience in Social Change - Baljeet Sandhu](#)



Sometimes, when an organisation wants to include the people they support in their work, they ask them to share their personal experiences of things that have happened to them. When doing this, it is essential that organisations have a duty of care in place so that their interactions are trauma-informed.

In collaboration with individuals who have shared their experiences with organisations in the past, we have heard of practices that organisations should avoid going forward.



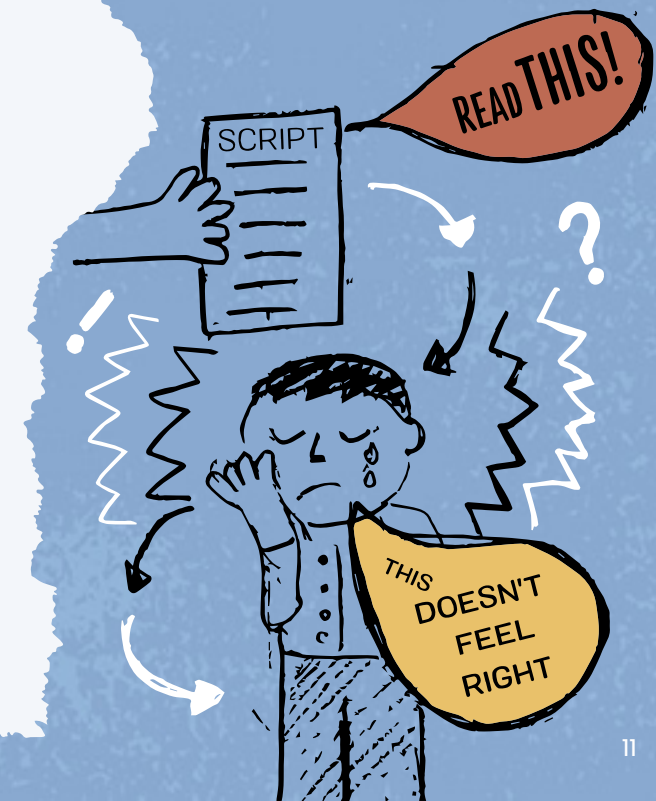
Brodie has lived with four foster families throughout his life. He is now 17, and feels settled with the family he has stayed with for three years. Brodie is supported by an advocacy worker through a charity for children and young people who have been fostered. He really likes his advocacy worker and is grateful to the charity for all their help.

The charity have asked Brodie to speak about his experiences of foster care to help promote their new campaign. Brodie wants to do this to talk about how much he loves his family and how amazing his advocacy worker has been.

The charity have pre-written Brodie a script to read from, using the notes they have on file about his experiences of foster care. The script contains traumatic events from Brodie's past that he has never spoken about publicly. There are no mentions of his family or his advocacy worker.

The charity's campaign has been picked up by several newspapers which has drawn a lot of attention to Brodie's story. This makes Brodie feel uncomfortable as it has resurfaced unresolved trauma for him. One of his previous foster families have sent him nasty messages after reading the paper.

The charity continues to promote their campaign and have asked Brodie to speak on their behalf again.



INDIVIDUALS

ORGANISATIONS

"I WANT TO SHARE MY STORY TO MAKE SURE THE SAME THING DOESN'T HAPPEN TO ANYONE ELSE"



SHARE

THIS IS GREAT FOR US!

"WE CAN SHARE THIS OVER AND OVER..."



TAKE

CAMPAIGNS

SOCIAL MEDIA

ADVERTS

POLICIES

ARTICLES

REPORTS

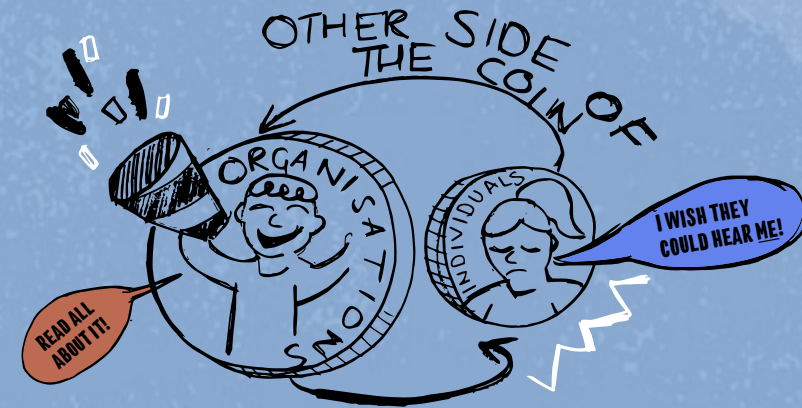
"I SEE MY STORY EVERYWHERE. IT HAS BEEN CHANGED TO FIT DIFFERENT AUDIENCES. IT DOESN'T FEEL LIKE MINE ANYMORE"



I'M SURE I CAN MAKE A DIFFERENCE BEYOND JUST TELLING MY STORY ... DAYS, WEEKS, MONTHS GO BY ... IT'S ALL THAT'S ASKED OF ME.

WHAT HAVING NO DUTY OF CARE LOOKS LIKE ...

“It was only years later that I began to fully comprehend the repercussions of repeatedly sharing my story. As I tried to confront my trauma and work through it, the journey became unbearably difficult. I found myself straining relationships with vital individuals in my life and severing ties with my sole support network, driven by an overwhelming fear that my identity had been reduced to nothing more than my trauma.”



“My entire life story is readily available on Google, accessible to anyone worldwide with just a few clicks. You can simply search my name, and there I am, with uncensored pictures of my life laid bare. As I make the transition into adulthood, this concern looms large in my thoughts.”

CONSIDER TRAUMA WITH CARE

Here are some questions for your organisation to consider when working with people who have experienced trauma:

- What duty of care do you have in place for those who share their experiences of trauma with you?
- Do you use trauma sensitive language when engaging with people?
- How do you embed the principles of trauma-informed practice in your work?
- Do you offer follow up support (check-ins, mental health support, etc.) when you ask someone to speak on behalf of your organisation?



FURTHER READING AND RESOURCES ON TRAUMA

- ★ 'What is meant by trauma'
- ★ Guidance "Trauma-Informed practice"

IMAGE
IMAGE
IMAGE

To inform this resource, we heard from people who have extensively shared their lived experiences publicly. They spoke of the difficulties they had in separating themselves from a specific cause and/or organisation after their involvement ended. As a result, they expressed experiencing an identity crisis, and struggling with poor self-worth and self-image.

Throughout this theme we want to help your organisation:

- Increase your awareness of the potential repercussions when using a person's external image in your campaigning materials.
- Strengthen your approach to protecting a person's self-image during and after their involvement with your organisation.

IMAGE
IMAGE



EXTERNAL IMAGE

When we say 'external image' we are referring to the ways in which a person's name, image, and experiences are shared externally.

[Go to Page 17](#)

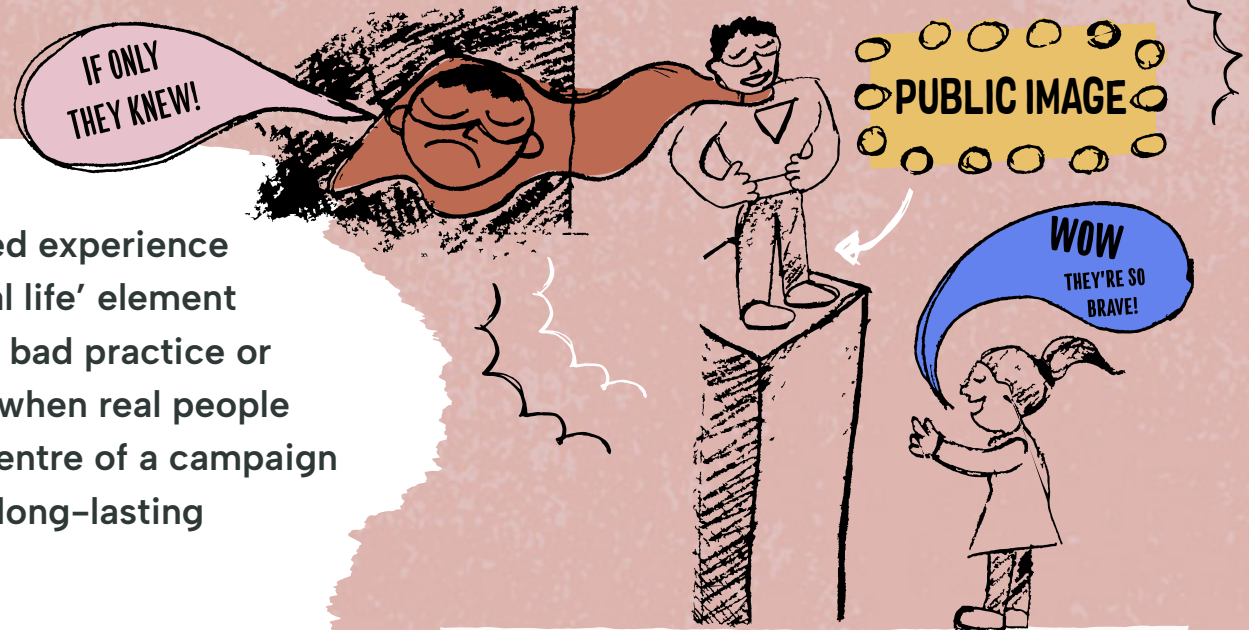
SELF-IMAGE

When we say 'self-image' we are referring to a person's perception of their personality, ambitions, and their value to others.

[Go to Page 19](#)

EXTERNAL IMAGE

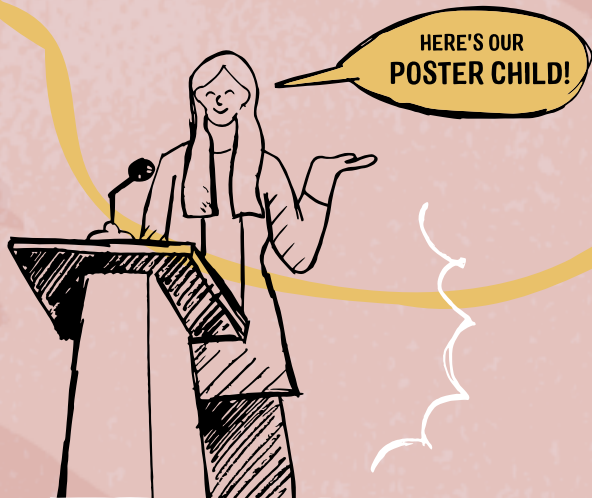
It can be important for campaigns to focus on lived experience of trauma to argue for change. This can add a 'real life' element to a campaign which can be effective to highlight bad practice or spotlight less often heard experiences. However, when real people who have experienced trauma are put front and centre of a campaign without the correct care, it can have unintended, long-lasting consequences on their external image.



When organisations are developing their campaigning materials, they tend to opt for messages which are succinct and simple to generate sound bites. During our engagement sessions, we heard that when this is done without proper care, it can result in a person's real life experiences being sensationalised or misconstrued, harming their external image.



“There is no room for nuance or complexity when sharing your story, it's always one extreme or the other. You're either a success story who beat the odds or you're a stereotype succumbed to your bad environment. Unfortunately shades of grey don't sell as well as black and white, and when your experiences are made to fit the stereotype you can't escape it. That stereotype is always going to be associated with you.”



“You become associated with that message because your experiences are used to bring it to life. I feel like I’m always going to be known as ‘the person who was abused’ because the worst part of my life was sensationalised in the media. I wish I knew the harm it would bring me down the line when I first got involved”

If a campaign gains a lot of traction, an organisation may want to reuse the materials to continue to promote their message in the future. However, if these materials reference a real person’s name, image, and experiences, then the organisation must consider how reusing the materials can have a long-term impact on the person’s external image.



“I have had campaigns I took part in years ago continue to be promoted using my image and experiences without asking me.”

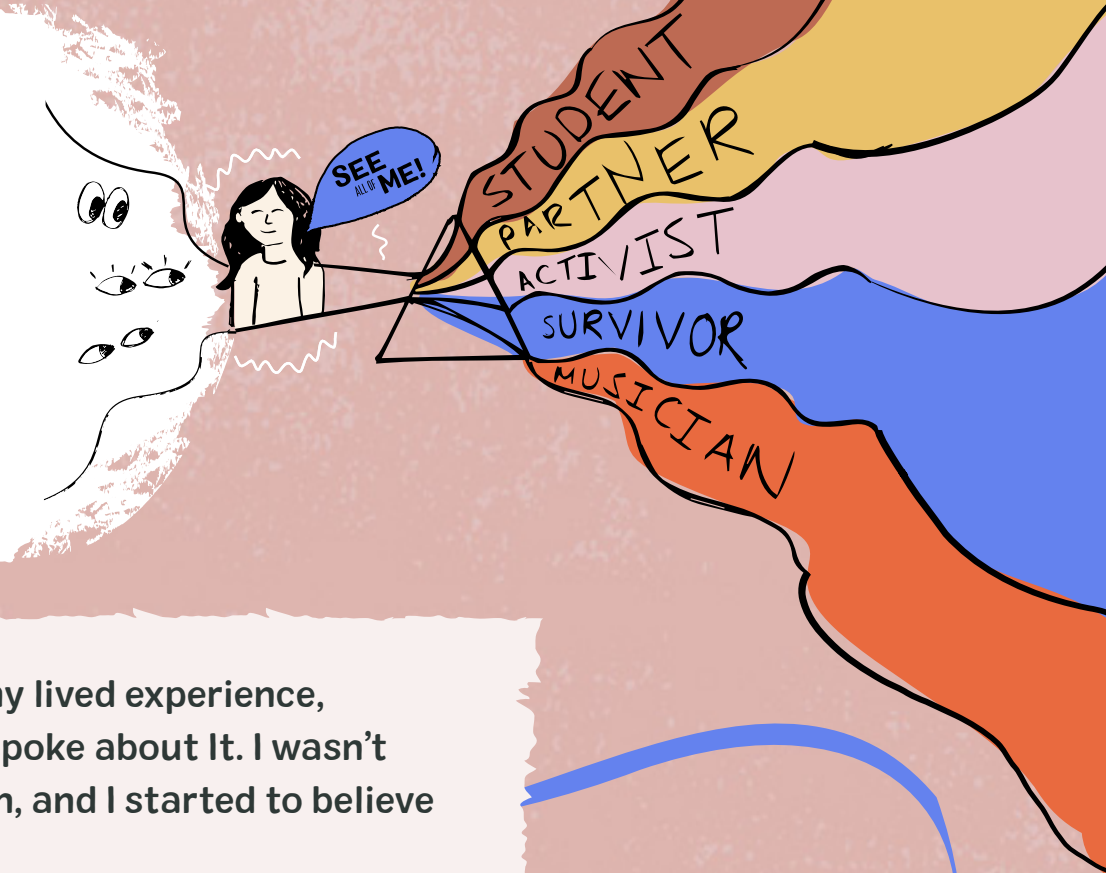


“I worry that this public exposure could impact my employment opportunities and affect my friendships and relationships. It increasingly troubles me that there is a certain image of me in the world, one that I believe should not define me, yet it continues to do so.”

SELF-IMAGE


When a person's external image is handled without care, it can have a detrimental impact on their self-image.

During our engagement sessions, we heard how this was a particular problem for those who had been involved in activism and campaigning in their youth. These individuals shared their struggles of juggling being a public figure and processing their trauma with navigating growing up.




“For so long it felt like I was defined by my lived experience, having to relive my trauma every time I spoke about it. I wasn't seen as anything else by the organisation, and I started to believe I didn't have any other value in life.”

“I've struggled to define myself, and my wants for life, outside of the most traumatic parts of my identity. I have felt boxed into acting as a 'poster child' for a cause. I had an identity crisis when I realised I didn't want to do it anymore, because I didn't know who I was without it.”



When an organisation does not have a duty of care in place to safeguard the person who is sharing their experiences, it can leave the person feeling vulnerable in the aftermath.



“I had never processed my feelings associated with what happened. It just became a statement I would say when talking about my life - a fact that I was desensitised to. But once I said it out loud to a crowd, it couldn't go back in. I found myself so broken by facing the reality of my trauma that I was unable to leave my bed. While the organisation lapped up the opportunity to push forward their agenda, no one checked in on me as I had served my purpose.”

“I gave so much of myself, my time, and my experiences to help them with no thanks in return. I wish they would've done more to help me develop professionally. I was only ever seen as someone who could tell their story but I could do so much more - no one is one dimensional. I feel like it's too late now, it's been tainted for me. I want a complete change and to never be associated with it all again.”



CONSIDER IMAGE WITH CARE



Here are some questions to help you, as an organisation, consider a person's external and self-image with care:

- Before engagement begins, have you established boundaries on what topics should be avoided?
- When asking someone to discuss traumatic events publicly, have you considered how to avoid re-traumatisation?
- Do you offer follow-up mental health support for people who share traumatic experiences with your organisation?
- Do you consider whether you can anonymise or generalise experiences to avoid sensationalising individual experiences?
- Do you offer development opportunities to help an individual achieve their ambitions?
- Do you credit people fairly for their work?
- Do you have an expiry date to stop using a person's external image? For example, a check-in every 6 months to ask whether they are still comfortable with it being used or no longer using their external image after their involvement with your organisation ends.





FURTHER READING AND RESOURCES ON IMAGE

For how to use considerate language when talking about trauma, see:

- ★ [Mindframe: 'A guide for speaking publicly about suicide'](#)

For guidance on using lived experience to inform your messaging without sensationalising individual experiences, see:

- ★ [Joseph Rowntree Foundation 'Framing toolkit: Talking about poverty'](#)
- ★ [Each & Every Child 'The Toolkit'](#)



BURN OUT

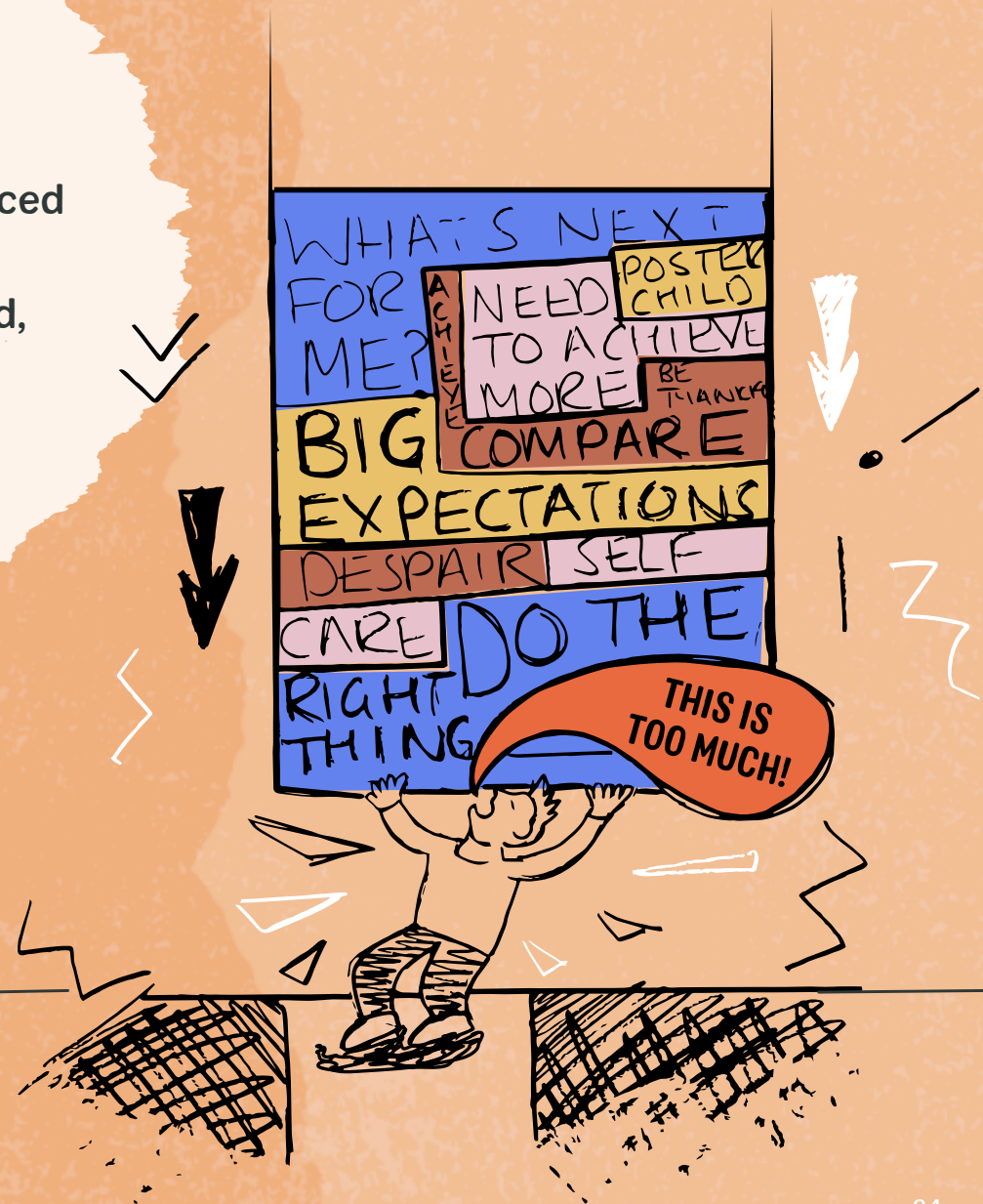
When we say 'burnout' we are referring to the end result of a prolonged period of emotional stress which can cause an individual to feel apathetic, drained and overwhelmed. Burnout is not caused by just one thing, but a series of things that chip away at a person's resilience.

During our engagement sessions, some of the contributing factors to burnout we heard included:

- Becoming aware of power imbalances through a lack of meaningful opportunities to contribute and co-lead.
- Feeling undervalued.
- Lived experiences being treated as a commodity.
- Being subjected to practices which are not trauma-informed, resulting in individuals becoming re-traumatised.
- Not being offered emotional support.
- Feeling pressured to be involved in work and becoming over-stretched.
- Having no separation between work and life.



“The constant demands to perform, speak and conform can be incredibly draining, even exhausting. This becomes even more pronounced when you’re sharing and elucidating the most challenging aspects of your life with the world, all in the hope of effecting change, with no guarantee of success.”

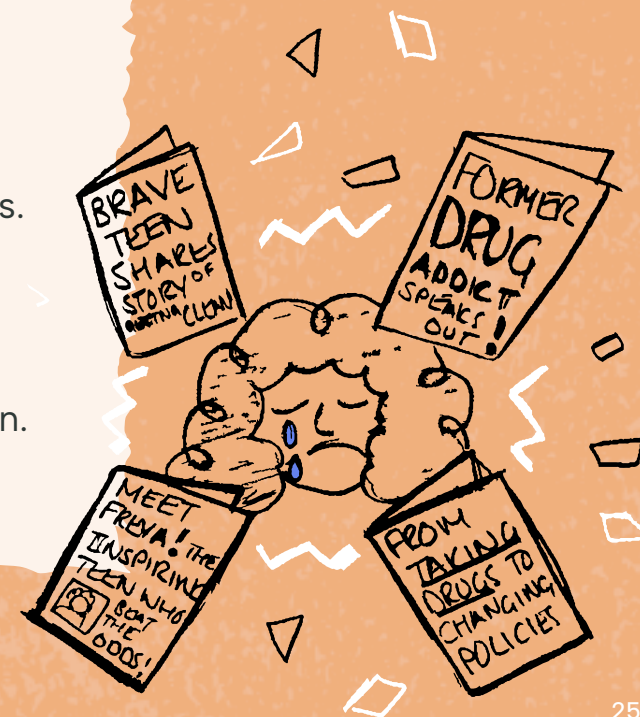




Freya's struggles with addiction began in her teenage years. When she was 19, she started to receive support from a charity. On her 20th birthday, she reached her first milestone of a year in recovery.

The charity are proud of Freya, and have asked her to talk publicly about her story to raise awareness of people in recovery. Freya is praised by others and is often told how 'inspiring' and 'brave' she is for speaking out. She feels that sharing her story is leading to success – which the charity reiterates to her – and she feels a pressure to continue doing so.

Behind the scenes, Freya finds it difficult to cope. She struggles to live up to the pressure of being labelled as 'recovered' and acting as a role model to others. Her recovery is not a linear process, and she feels overwhelmed by the burden of having to act like it is. In addition to this, Freya finds it hard to be defined by her addiction as her name has become synonymous with 'recovered addict'. Freya feels like she is at breaking point but she does not want to let anyone down.



CONSIDER BURNOUT WITH CARE

To help you mitigate the effects of burnout when working with people and their lived experiences, we have created a check-in and exit checklist to ask yourself throughout your engagement process.

CHECK-IN CHECKLIST

I have established boundaries of what a person does and does not feel comfortable talking about. I continue to check if the boundaries are still applicable but I do not breach these boundaries under any circumstances.

I make people feel safe and comfortable during engagement sessions. If they do not, I halt engagement to make changes until they are.

I provide clear and transparent information on how a person's contributions will be used. I offer to anonymise or generalise their experiences if it makes them feel safe. I provide credit where credit is due for their contributions.

I give the individuals who have shared their contributions the final say on the output to confirm it reflects what they want to be heard.

I help to prepare people to share their experiences in a trauma-informed way. If they are sharing their experiences publicly, I ensure that they have pre-support and follow-up support available.

I make those sharing their experiences aware of the potential risks to their external image, and work to mitigate them on their behalf.

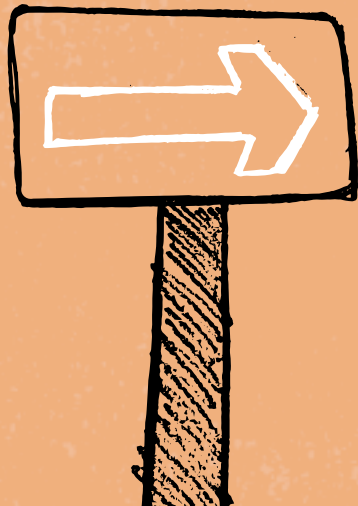
EXIT CHECKLIST

I offer the individuals sharing their experiences a break away from the process at different intervals so they do not feel overwhelmed.

I build in an expiry date for when their contributions are no longer used by my organisation. I ensure that once their involvement ends, my organisation no longer uses any materials relating to their external image.

I support an individual's personal development, helping them to reach their goals even if that means they are no longer involved in my organisation.

I make people aware that they are able to leave the process at any point. I make sure this is a smooth process, placing no undue stress on the individual exiting.



FURTHER READING AND RESOURCES ON BURNOUT

- ★ [Activist Handbook: 'Activist Burnout'](#)

ACTIVITY

Now that you have finished the resource, we invite you to read Brodie and Freya's experiences again. We have created this canvas for your organisation to consider what you would do differently to support them.



POWER

Where could power be shared more equitably?
Think: opportunities, control . . .

TRAUMA

What duty of care should be in place?
Think: trauma-informed, check-ins . . .

BURNOUT

What can be done to mitigate the symptoms of burnout?
Think: pre-support, follow-up support . . .

IMAGE

What are the potential repercussions to their image?
Think: boundaries, long-term impact . . .



You can print this page or make your own to refer back to when working with people and their lived experiences in the future.



Social Action Inquiry Scotland

This resource was developed by Social Action Inquiry Scotland in partnership with people who have shared their lived experiences for campaigning and activism purposes.

hello@socialaction.scot | socialaction.scot

Designed by [Stein Design](#)