

How to honour storytellers



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Introduction

Reni Eddo-Lodge wrote “Why I’m no longer talking to white people about race” and it triggered a big conversation about where responsibility lies for injustice. She asks to what extent people who are unjustly positioned at the powerless end of the spectrum are expected to fix it all for the powerful people. The elements of Critical Race Theory, including the power of storytelling, may be applied to all excluded groups, of course.

Several times recently I have come across hints that marginalised people should not be asked to tell their stories as it retraumatises them, exposes their vulnerability to the powerful and changes nothing. Worse, it does all this for the titillation of powerful people who get turned on by the poignancy and emotional loading of these stories, which have no more effect than a news report or a Hollywood film. This is reminiscent of the ‘fundraising as pornography’ arguments that emerged after the 1967-70 famine in Biafra.

Two recent examples where marginalised people have been replaced rather than listened to occurred when (i) actors replaced experts by experience to teach healthcare professionals, and (ii) reciprocal mentoring replaced reverse mentoring as a mechanism designed to create opportunities for truth to speak to power. Both seem to me to be predicated on a view of experts by experience as vulnerable. One alternative approach, in which powerholders abdicate responsibility, is to simply ask people if they are willing to tell their story and go with the outcome. This might be considered to have parallels with the view that sex working is entirely OK if that is what the woman says she wants to do. As bethann_5 powerfully observes¹:

Challenge #1

Are there unsuitable stories or unsuitable storytellers? What are suitable conditions for empowering, transformational storytelling?

“...many people have talked, shouted and screamed about their mental health, only to be ignored, neglected, harmed or abused by services. People have continuously asked for help, only to be told they have ‘capacity’ to choose to end their life. Others have put their trust into services, kept talking, only to be abused by those meant to help them. Some have bravely spoken about suicidal thoughts and attempts, only to be prosecuted by police for being ill.”

How do we avoid these pitfalls? It would be good to be explicit about an ethical approach. The answer to misuse is not disuse but right use, but we need more than an aphorism². So this paper is a resource archive that houses comments, references and reflections on the whole field, and from which a series of shorter and more focused documents might arise. This means that this paper will be too long, heavily footnoted and rambling, but will perhaps become a useful repository, more like a stuffed toolroom rather than a piece of handmade furniture.

Various kinds of story

People tell stories for lots of different reasons. Survivors make up stories to reframe their trauma³. Visionaries use fantasy stories to communicate a dream of a better world⁴. Leaders tell change stories by describing the journey from here to there, and then explain how the events of each day fit into that story⁵. Powerholders tell stories to retain their power⁶ and fundraisers tell stories to elicit donations⁷. Children get punished for ‘telling stories’ instead of speaking the truth, and we all gather round a storyteller, eagerly waiting to be amused and entertained. In this paper, a storyteller is someone who tells other people about their own lived experience. This is authentic, true, factually and emotionally rich disclosure that demands openness and trust⁸, that is risky and requires courage.

Challenge #2

Who are the storytellers? How many people are involved? How are they appointed? What is the purpose of storytelling? Which media are used?

But there is more than this. This paper concerns storytellers who can speak of exclusion and marginalisation, perhaps due to neurodiversity, disability, mental distress or use of health or social care services. It may involve racism or age discrimination. It is more than a witness statement or an answer to one’s interrogators, and more than testimony, providing fragments of experience, but rather is crafted to follow a narrative arc, edited for impact, shaped to the intended audience.

The story might be about the pain that unfair treatment has inflicted on the storyteller, but it might be about survival, recovery and flourishing. It might spotlight these experiences, or, by focusing on other aspects of life, demonstrate powerfully that bad stuff has not rendered the good stuff invisible.

The story might be told in words or heard through a passion, read in a smile, decoded from a timetable or viewed in a picture⁹, but it is always inhabited rather than a mere recitation and so retains a true connection to the original events and emotions. It might be presented live, recorded¹⁰, or passed to someone else who recounts the story on behalf of the person. It might be a monologue or revealed through a conversation, like on a TV chat show¹¹. The story might be told to one close friend in a private room or heard by a vast audience of

strangers. Much of the research that has been carried out to date evaluates the impact of recorded stories or representations by actors, rather than live, autobiographical presentations. Paradoxically, we might learn about the process of storytelling by studying silence¹².

Stories are powerful

“Our lives are ceaselessly intertwined in narrative, with the stories that we tell, all of which are reworked in that story of our own lives that we narrate to ourselves”¹³.

Individual stories both shape and are shaped by the dominant narratives of our culture and social structures, whether those big stories are WASP¹⁴, WEIRD¹⁵ or something else. In health and social care, stories have become increasingly fashionable in recent years as a means to understand the lived experience of people using the services that are provided, and to both carry out research and evaluate service effectiveness. Stories are considered able to communicate the aspirations and core values of a service, to anchor evaluation to people’s real experiences and to remotivate and energise jaded or exhausted staff to work for the best outcomes. In these ways, storytelling is not a one-way process where the speaker launches themselves into the void, but rather an interaction, in which the audience and the storyteller both bring something to the exchange, and through which both may be changed.

Why tell your story?

There are lots of reasons that motivate people to become storytellers. Being heard can trigger behaviour change in the storyteller¹⁶. In South Africa’s Truth and Reconciliation Commission, survivors of apartheid who wished to do so could apply for the opportunity to give testimony in public, whilst perpetrators who were willing to make full disclosure were, under certain conditions, granted amnesty. Some people wanted criminal conviction rather than amnesty and reconciliation. McKeown and Spandler¹⁷ have suggested that parallel truth and reconciliation processes might be useful in mental health services, and there is no reason why they wouldn’t be helpful elsewhere too. Meanwhile, in America, the Jerry Springer Show invited guests to tell their unlikely stories with as much violence as possible for the entertainment of the audience. Somewhere between the profound and the profane lie ordinary stories, unexceptional yet unique, mundane yet fascinating.

Challenge #3

What alternative settings are available to the storyteller? Do they have friends, private space, a Facebook account? Do audience members have a variety of opportunities to establish a relationship with the storyteller or are they strangers who inhabit parallel worlds?

Philip Roth highlights our ability to scoop stories out of the stream of experience, construct meaning and shape it for ourselves and for our audience: “It isn’t that you subordinate your ideas to the force of the facts in autobiography, but that you construct a sequence of stories to bind up the facts with a persuasive hypothesis that unravels your history’s meaning.”¹⁸ And that meaning is of a certain kind, intended to enhance the humanity of health and social care services, impart hope and promote life, rather than tracing the route to despair,

suicide or terrorism. This means that the process by which raw, fragmented testimony emitted like a radio beacon from ongoing experience is refined and crafted into a story with a limited cast list, with a beginning, a middle and an end, is a process of elimination, of ruthlessly ejecting material until nothing is left but the single, driving and defining purpose¹⁹.

Compressing a life into a story in this way inevitably discards information but also perspective, until we lose focus on the whole experience of the person and fall into error as we mistake the story for the life²⁰. Researchers have been warned against the storytelling of popular science writing, which sometimes rewrites the hypothesis after the results are known and removes contradictory or confusing findings to create a strong narrative²¹. For these reasons and more, the language of ‘story’ itself is sometimes challenged by those who suggest it is used to trivialise real life until it becomes no more than a tale told to children. Of course, the intentional production of story is not confined to experts by experience, and dramaturgical analysis has been used to show how healthcare staff prepare a script backstage before constructing a setting, managing the staging and delivering their onstage performance to the audience²². Others have sought for common humanity by asking commissioners and providers of healthcare to tell their stories too²³.

Some audiences simply cannot hear the story unless it is told by a peer²⁴, and this authenticity gives the story credibility and so imparts hope. While only some managers change their own attitudes and practices through hearing the storyteller, others find that their imagination is haunted²⁵ by the story they have heard and gain confidence to refer people to the storyteller and to sponsor their role in the service provider organisation.

Misuse and right use

The following table searches for language that gives vivid and incisive ways to describe complex, important and yet elusive²⁶ features of storytelling. It challenges us to find ways to honour rather than abuse the storyteller. It is likely to need many further revisions. It is in alphabetical order and may be better if similar items could be grouped together. Many or all of these elements may be in play simultaneously, as shown by the research²⁷ carried out by Gillian Buck and her team, who found that asking people in penal settings to tell their stories was both ‘safe, inclusionary and rewarding; and exclusionary, shame-provoking and precarious’. Getting it wrong can cause harm²⁸.

Abuse	Right use
<p>Appear vulnerable. Lack of respectful support before, during and after²⁹ disclosure. Storytellers regret that they did it. Ride roughshod over boundaries between private and public, testimony and story, freely given voice and ‘intelligence’ gained by undercover means.</p>	<p>Connect with staff experiences – staff also need to tell their own story to their manager. Learn what it feels like to speak truth to power.</p> <p>Adopt ‘in-role’ and ‘out of role’ as a way to distinguish the things that are in and out of the story.</p>

Abuse	Right use
<p>Assign value. The story is set in stone and the storyteller is not permitted to add a new chapter or move beyond the old one. Hearts are moved at the time, but subsequently, powerholders find ways to dismiss the challenge of the story³⁰</p>	<p>Find ways to achieve catharsis and move forward, perhaps choosing to bury this story of who I was³¹. The storyteller can take down old copy, moving a public story back into the realm of memoir where reflection and personal change is a private matter.</p> <p>Draw on the evidence that stories can enhance communication skills and empathy in staff³²,</p>
<p>Be my therapist. Powerholders recruit the storyteller to carry out ethical labour on their behalf, so that they can adopt the resulting values without doing any real work themselves, whether the storyteller wants to help or not.</p> <p>In an alternative situation, the storyteller uses the speaking opportunity to indulge their rage, narcissism or delight in shocking others, so they use the stage for their own benefit, irrespective of the needs of the audience.</p>	<p>Identify triggering content in stories that tip audience members into inappropriate attitudes or behaviours. Find out what helps the audience sift and discard any unhelpful material while retaining the helpful elements. Assess and build readiness for real change³³.</p> <p>Work out the similarities and differences between the message that the storyteller wants to convey and that of other stakeholders. Can everyone's needs be met or is this not the right speaker, story or audience?</p>
<p>Entertainment. Provide a compelling, poignant and tearful story to entertain us³⁴. An ugly approach is to lay on a freak show where voyeurs enjoy their morbid horror and disgust at difference³⁵. In a milder version, powerholders edit the story to make it more amusing or delete strengths to portray a pitiful victim. The narrative arc³⁶ is so neat and clean that it appears more like fiction than untidy reality.</p>	<p>A combination of struggle and successes delivers the most benefit³⁷. Effective stories normalise the experience of people who have been 'othered'.</p> <p>Sometimes the person needs to tell a painful story, and we need to respectfully listen³⁸ to the testimony rather than insist that it is nice for us. Offer warnings before and helplines after distressing content.</p>
<p>Environment. Too many professionals in the room, so the combination of audience size and power is daunting and makes me feel emotionally vulnerable³⁹. The move to recorded electronic media means that the story 'escapes into the wild' and appears in Google searches for years afterwards.</p>	<p>First-hand narratives are powerful. Small audiences may be preferable as they make it easier for the storyteller to read the room and decide whether to disclose. Are all guests invited personally by the storyteller? Find ways for people to exercise their right to be forgotten.</p>
<p>Favoured child. While the internal mechanisms of the coproduction activity look like equality, the external context is loaded with feelings of privilege and gratitude toward a benefactor, so that the whole thing ends up reinforcing inequality.</p>	<p>Move up and down the ladder of decision-making to check that the person has choice and control of the context as well as the internal running of the activity. Make staff use the same consent forms as storytellers.</p>

Abuse	Right use
<p>Hope labour. People are seduced into telling their story and working for nothing by the enticing but empty hope that it will lead to paid work, expand influence and advance the cause. Instead it devalues expertise and in the long term crushes confidence⁴⁰.</p>	<p>If there is an open door into telling one's story for free, ensure that there are equally accessible doorways into paid work. Be honest about future prospects. Build opportunities into a developmental pathway so people do not get into a cul-de-sac</p>
<p>Interrogate. Clinicians who take a history structure the interview, decide what is important, harvest data, encode it in jargon, control its distribution and, in practice, deny the storyteller access. The storyteller becomes a medical exhibit for the benefit of students⁴¹, a story that can be distorted and repeated without my consent. This is so common that people think it is normal.</p>	<p>Total Respect Training is designed and delivered by care-experienced young people. Practised young trainers induct newcomers. The focus is on the training, with personal disclosure stories being relegated to an optional enrichment, rather than the person's sole contribution. Obtain explicit permission for every version and every occasion⁴². Tell of real instances where permission has been revoked and the backup plan has been actioned.</p>
<p>Pay. The expert by experience gets less money than everyone else for the same task.</p>	<p>Create fair working practices. Well-told stories are remembered more accurately and for longer than facts and figures⁴³, so reward this skill properly. This includes drawing on the principles set out by research ethics and checking out how they should apply to everyone⁴⁴. Don't destabilise people's income⁴⁵.</p>
<p>Presume harm. Ignore evidence that good storytelling helps empowerment and self-esteem⁴⁶ and instead focus on the possibility that bad stories⁴⁷ and bad storytelling cause harm, concluding that storytelling is always a bad thing to do⁴⁸.</p>	<p>Include evidence in publications⁴⁹ and resources for academia and practice⁵⁰. Adopt a posture of humility as we all get it wrong from time to time. Draw on evidence from bibliotherapy⁵¹ to show that storytelling can help both speakers and listeners.</p>
<p>Rank. Some kinds of lived experience count for more than others and so people who don't embody and reinforce stereotypes⁵² are dismissed, along with people who do not have tidy experiences that neatly fit into powerholder's categories and agendas.</p>	<p>Should the truth of some lived experiences be confined to individual exchanges and not given a platform at this event? After all, not every manuscript is accepted by the publishers. Nobody speaks on behalf of all. Notice excluded subgroups and remedy.</p>

Abuse	Right use
<p>Samosas. The storyteller challenges interlocking, endemic injustice, and the powerholder adopts one trivial token, claiming this is a sufficient and reasonable adjustment and so wider issues can be dismissed or deflected. A specific example occurs when staff do not really see the person⁵³ or spend time during their ordinary work listening to people's stories, so the 'user story' slot at a conference delivers a rare and artificial opportunity to do so.</p>	<p>The storyteller is released from the obligation to tell it all, but selects a single, symbolic story and uses it to teach a broader theme. Audience members are interested in political analysis as well as personal stories.</p> <p>Create time for good conversations every day rather than package one as a special gift. Add media to life so that the storyteller can express themselves through paint, poetry and performance rather than being confined to a single opportunity. At the storytelling event, ensure that there are breaks and time to talk as well as listen to the formal presentation.</p>
<p>Shame. The person discloses information that makes them a target of rejection and violence⁵⁴. This could be in explicit ways, such as attacks by vigilantes, and in subtle ways, such as when care staff adopt low expectations. The person internalises stigma while powerholders reinforce it by segregation and devaluation.</p>	<p>Effective stories build connections between people rather than dividing them. The organisation has a duty of care⁵⁵ and should discuss with the storyteller how to stay safe. These stories should not be suppressed. Create new ways to allow for pseudonyms⁵⁶ and anonymity, such as using photos rather than video so people can just reveal their best side.</p>
<p>Shoot the messenger. Shift the blame for things being wrong from the powerholder and blame the storyteller instead.</p>	<p>Ask two or three storytellers to share the session so that different perspectives can be heard, individuals are not made to stand proxy for everyone else and people support one another. Form a storytellers group so members get peer support and political power. Some groups mash up their individual stories into a composite⁵⁷.</p>
<p>Single story. When all we know about a person is a single story⁵⁸, then this blinds us to other aspects of their life and entraps them in this stereotypical role⁵⁹. Switching the single story from hero to criminal topples their statue⁶⁰ but continues to treat them as stick people.</p>	<p>Healthcare students mentored in art appreciation by people with dementia⁶¹. Storytellers are valued for their insight, expertise and broader contribution rather than as if they were a human library with containing one book⁶².</p>
<p>Social model. The storyteller may explain how barriers and alienating systems have caused distress, but it is still the casualty who is in the dock, not the perpetrators of injustice.</p>	<p>Invite powerholders to tell their own story of recognition, repentance, reconstruction and review – of themselves and of the services that they manage. See McKeown et al (op cit) on truth and reconciliation and Fricker on testimonial justice⁶³.</p>

Abuse	Right use
Streaker. Disclosure should be mutual, intimate and beautiful, but some audiences strip the storyteller and laugh. Some people are flashers; others are naturists, challenging the buttoned-up contradictions and absurdities of modern culture. Pimps profit when people do private stuff in public.	Paradoxically, the organisation that is making positive use of stories is likely to also have a strong commitment to upholding the right to privacy. Support people to understand the public/private gradient and disclose in appropriate settings.
Substitute. Powerholders indicate that they can easily get someone else to take your place or roleplay you like Blackface in vaudeville.	Use transparent engagement practices so that chucking someone out can only be done with a defensible reason.
Theft. Audience members hear an authentic story told by the person and then steal the story and retell it for their own purposes. In an online age, these recycled stories are recorded and shared without consent.	Stories are understood to be the property of the person concerned, and those who hear a story do not retell it unless they have permission to do so.
Tick box. The conference has failed unless powerholders include a token story representing the trendy profile of the moment. The storyteller may lack competence and the conference makes no real accommodations, thus indulging in 'lived experience washing' ⁶⁴ .	<p>Advertise the opportunity to speak and use publicly known criteria to select the storyteller⁶⁵.</p> <p>Develop skills in storytelling, so that the story holds the listener's attention with emotional engagement and transportation, leading the listener to care about the characters⁶⁶.</p>
Toxic helper. The powerholder sees himself as a competent helper and reframes the story into a 'victim and rescuer' stereotype. The storyteller internalises this and starts to see themselves in the role of victim ⁶⁷ .	<p>Stories can challenge pessimistic attitudes and stigma⁶⁸ if the person is presented as resourceful (rather than the helper).</p> <p>Genuine listening within a restorative justice framework can help to put things right⁶⁹.</p>
Trolls. Social mores forbid personal questions, but here powerholders intrude, humiliate and satiate their curiosity. Take one moment in the person's journey and use it to destroy their reputation or freeze their contribution, forever stuck at that moment in time.	Encourage people to build rich identities based on multiple roles rather than being submerged in the relationship with services ⁷⁰ . Tell audiences that some topics are off-limits and take responsibility for responding to inappropriate questions or comments, rather than leaving it to the storyteller. Time-limit consent so that it must be renewed before old material can be used again or remain on the website.

Impact of stories on staff

There are several changes that storytellers might hope to achieve in staff by telling their story, including to:

- Assist in the delivery of qualifying training for students of health and social care. Accredited training courses for social workers, doctors, nurses, and professions allied to

medicine all require some of the teaching to be delivered by 'service users and carers'. This demands that facilitators of storytelling sessions are competent⁷¹.

- Encourage the use of recovery narratives as a therapeutic and empowering intervention that has the potential to enhance hope, provide role models and motivate people to live well. If managers hear the story, they will perhaps believe in its value, and create opportunities for the storyteller to work with people using the service.
- Stimulate managers to appoint Peer Support Workers and include lived experience as a desirable attribute in all recruitment and selection decisions.
- Engender hope and optimism based on a conviction that everyone using health and social care services has the capacity to take more control of their life, to live a richer life and to make a greater contribution to the community beyond services.
- Recognise and dismantle those elements of service delivery that segregate and restrict life opportunities.
- Create factual and emotional connection between the powerholder and the storyteller through recognising similarities between their life events and experiences. This can validate the life experiences of both and offer new reference points for thinking about people who use services. It is less likely to happen if the powerholder is experiencing a crisis and has insufficient emotional resources to empathise⁷².

Some storytellers have lived through trauma which overwhelms their sense of safety, belonging and dignity, so it is important that these factors imbue the environment in which they recount these events. Richards and her colleagues⁷³ explain that storytellers can be retraumatised if their story is unacknowledged or dismissed, and so it is important to close the feedback loop by ensuring that the storyteller is aware of the impact their story has had⁷⁴.

What might this mean for practice?

Potential applications for organisations may include:

- Address the homogeneity of the workforce by providing more effective support to minority and previously excluded voices. When we get this right, the organisation will be seen to walk the talk and lead by example.
- Involving Experts by Experience in steering groups, co-research, training and dissemination events will be improved, whether or not people are explicitly invited to tell their story.
- Publicity and communications activities are improved, including how authorship is recognised and acknowledged.
- Shape the mission, values and priorities of the organisation.
- Seek funding to further develop thinking, practice and understanding of storytelling, how to support people who wish to tell their stories to do so well, and to address associated questions⁷⁵, particularly in relation to people who use few or no words⁷⁶.

This discussion has broad application, including training of health professionals⁷⁷ and fundraisers, where the regulatory bodies require storytellers to give some lectures⁷⁸ (whilst also using actors and simulations⁷⁹), Peer Support Workers, coproduction, conference co-chairing⁸⁰ and presentations, reverse and reciprocal mentoring⁸¹, ‘experts by experience’ members of Care and Treatment Reviews, CQC inspection teams, Research Ethics Committees⁸² and more.

What is the status of this paper?

Most of the documents we read are finished pieces of work, carefully crafted and edited in private before being shared with anyone else. This is a different kind of paper – it was shared online [here](#) from the first day, when the initial handful of ideas were incomplete, poorly phrased and tactless. I hope that the work will be edited many times, and on each occasion a revised version will replace the earlier material online. This process has hardly yet begun and so this paper lacks crucial concepts, evidence, structure and grammar. As readers continue to provide feedback⁸³, further insights will be used to update it, so please contact peter.bates96@outlook.com with your contributions.

It is one of a suite of documents that try to open up debate about how to return choice, decision-making and control to people using health and social care services – in research, implementation and evaluation.

This way of writing is risky, as it opens opportunities to those who may misunderstand, mistake the stopping points on the journey for the destination, and misuse or distort the material. This way of writing requires courage, as an early version can damage the reputation of the author or any of its contributors. At least, it can harm those who insist on showing only their ‘best side’ to the camera, who want others to believe that their insights appear fully formed, complete and beautiful in their simplicity. It can harm those who are gagged by their employer or the workplace culture, lest they say something in a discussion that is not the agreed party line. It can harm those who want to profit from their writing, either financially or by having their material accepted by academic journals.

In contrast, this way of writing can engage people who are not invited to a meeting or asked for their view until the power holders have agreed on the ‘right message’. It can draw in unexpected perspectives, stimulate debate and crowdsource wisdom. It can provide free, leading edge resources.

¹ [The problem with Time To Talk\(TW: iatrogenic harm and suicide\) – A stone in a glass house \(wordpress.com\)](#)

² For an example of a coproduced set of guidelines on storytelling, see Richards D, Strain K, Hawthornthwaite L, Jordan I, Fancott C. (2023) Storytelling at board meetings: A case study of co-developing recommendations. *Patient Experience Journal* 10(1):173-180. doi: 10.35680/2372-0247.1742.

³ Creating fiction can help the writer break down their own self-defence mechanisms, as when the author talks to a body part or bad trait, rewrites the story of a trauma, introduces new characters, or tells the story from a different perspective. This new world does not follow the rules of reality and so can bring internal liberation that strengthens and heals the damaged self that had been weakened by external events. See Celia Hunt *Therapeutic Dimension of Autobiography in Creative Writing*. Also Kate Thompson *Therapeutic Journal Writing*.

An Introduction for Professionals. Also James W Pennebaker & John F. Evans *Expressive Writing: Words That Heal*. (Mikola Nyiri Emese, personal communication, March 2022)

⁴ Finkelstein V (1975) To deny or not to deny disability – what is disability? Available at <https://www.independentliving.org/docs1/finkelstein.html>.

⁵ Bates P & Gilbert P (2008) 'I wanna tell you a story': Leaders as story-tellers *International Journal of Leadership in Public Services*. Vol 4, issue 2 pp4-9. Available at <https://peterbates.org.uk/wp-content/uploads/2017/04/iwannatellyouastory.pdf>.

⁶ For a sophisticated analysis of storytelling, narrative and antinarrative, see Larsen J, Boje DM & Bruun L (2020) *True Storytelling: Seven Principles for an Ethical and Sustainable Change-management Strategy*. Routledge. Also Holmwood C, Jennings S & Jacksties H (2022) *Routledge international handbook of therapeutic stories and storytelling*. Also Wilson M (2022) *Storytelling*. Emerald series on Arts for Health. ISBN: 9781839097591.

⁷ Fundraisers are sometimes told to make the donor the hero of their story rather than the person who is the beneficiary of the charitable organisation. Burnett K (2014) *Story telling can change the world* London: White Lion Press.

⁸ Being trusted by others releases oxytocin which triggers prosocial behaviour – see Zak PJ (2015) Why inspiring stories make us react: the neuroscience of narrative. *Cerebrum*. 2015 Feb 2;2015:2. PMID: 26034526; PMCID: PMC4445577.

⁹ Warrington S & Crombie J (2017) *The people in the pictures: Vital perspectives on Save the Children's image making*. Save the Children.

¹⁰ See *How to choose between digital stories and live presentations* available at <https://peterbates.org.uk/wp-content/uploads/2017/05/How-to-choose-between-digital-stories-and-live-presentations.pdf>

¹¹ The best TV chat show hosts do not ask leading questions. They establish rapport and then fade into the background. They ensure that the storyteller is guided by clear, open-ended questions and that the audience understands. They honour 'no-go' areas.

¹² See [Beyond voice: Experiences, meanings, and ethics of silence in mental disorder — University of Bristol](#)

¹³ Brooks P (1984) *Reading for the plot: Design and intention in narrative*. Harvard University Press.

¹⁴ WASP is an acronym meaning White, Anglo-Saxon Protestant. See <https://wordhistories.net/2018/02/02/wasp-american-sociology/>.

¹⁵ WEIRD is an acronym referring to societies that are Western, Educated, Industrialised, Rich and Democratic – see [WEIRD - RationalWiki](#).

¹⁶ Schwitzgebel paid 'juvenile delinquents' to tell their stories on to tape, as well as engage in other activities, and showed that rates of recidivism fell as they did so. See Schwitzgebel R. (1965) *Streetcorner research: An experimental approach to the juvenile delinquent*. Harvard University Press. See a review at [Street-Corner Research: An Experimental Approach to the Juvenile Delinquent - PMC](#).

¹⁷ Mckeown M & Spandler H (2017) Exploring the Case for Truth and Reconciliation in Mental Health Services. *Mental Health Review Journal*, 22 (2). pp. 83-94. ISSN 1361-9322

¹⁸ Philip Roth's opening letter to Nathan Zuckerman.

¹⁹ Leah Getchell and Teresa Atkinson introduce an online training programme for patient partners to become storytellers who focus on a 'moment in care' rather than a linear chronology, and end with a 'Call to Action' purpose to the story. See [Storytelling for impact: Creating a storytelling program for patient partners in research](#) (November 2024). The module is at <https://cansolveckd.ca/storytelling/#/>

²⁰ Richards DP (2020) Don't call my experience a "patient story" *The BMJ* 18 February, page 190.

²¹ See [Resisting the siren song of storytelling in science - UK Research Integrity Office \(ukrio.org\)](#)

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- ²² See Ramsey L, O'Hara J, Lawton R, Sheard L (2023) A glimpse behind the organisational curtain: A dramaturgical analysis exploring the ways healthcare staff engage with online patient feedback 'front' and 'backstage' at three hospital Trusts in England. *Sociology of Health & Illness*. 2023, pp1-24.
- ²³ This is hinted at but not elaborated in Richards et al (2023, op cit) and Hawthornthwaite L, Roebottom T, Lee L, O'Dowda M, Lingard L. Three sides to every story: preparing patient and family storytellers, facilitators, and audiences. *The Permanente Journal*. 2018;22.
- ²⁴ There is something mysterious about use of language here. People who are experiencing mental distress need to hear a recovery story in the vernacular rather than in the language of professionals (see Roe 2020 et al op cit). Professionals do not want to hear a story presented in their professional style but also prefer the vernacular – so effectiveness is not just matching vocabulary and idiom to the audience.
- ²⁵ Wilson S. Haunting and the knowing and showing of qualitative research. *The Sociological Review*. 2018 Nov;66(6):1209-25.
- ²⁶ Zak found a way of monitoring physiological and behavioural consequences of exposure to a story and found people are not very good at knowing in advance whether a story will be high impact. Novels and films flop despite the investment of time and effort, predicted reactions to TV advertisements do not always match the outturn. So it is not easy to guess in advance whether a story will work. See Zak 2015 op cit.
- ²⁷ Buck G, Tomczak P, Quinn K (2021) This is how it Feels: Activating Lived Experience in the Penal Voluntary Sector, *The British Journal of Criminology*, azab102, <https://doi.org/10.1093/bjc/azab102>.
- ²⁸ Roebottom T, Hawthornthwaite L, Lee L, Lingard LA (2018). Beyond catharsis: the nuanced emotion of patient storytellers in an educational role. *Medical Education*. May;52(5):526-35. **Also** Liabo K, Asare L, Ruthen P, Burton J, Staunton P, Day J. (2024) Emotion in public involvement: a conceptual review. *Health Expectations*. 27:e14020. [doi:10.1111/hex.14020](https://doi.org/10.1111/hex.14020)
- ²⁹ One group told Alice McColl that they wanted to be paid for both the delivery day and the day after telling their story, as this was needed as recovery time.
- ³⁰ Using stories in pre-registration training of students may be received well by learners who are open to having their ideas and values challenged, while presenting stories to older, experienced staff may meet a different response, perhaps mediated by whether they have chosen to attend the storytelling or are under compulsion. See Adams M, Robert G, & Maben J (2015) Exploring the Legacies of Filmed Patient Narratives: The Interpretation and Appropriation of Patient Films by Health Care Staff *Qualitative Health Research* Vol. 25(9) 1241–1250. Available at <http://journals.sagepub.com/doi/pdf/10.1177/1049732314566329>. First-hand stories may provide a vivid intensity which has greater impact in the short-term than reading a textbook. Psychologists used to believe that adding pictures, and especially graphic images would be too gruesome for people to think about, so would reduce the amount of the intended behaviour change. More recent work has found that presenting a message alongside an image, and perhaps a graphic one at that, does lead some people to change their behaviour – see Clarke N, Pechey E, Kosite D, König LM, Mantzari E, Blackwell AK, Marteau TM, Hollands GJ (2020). Impact on selection and consumption of image-and-text and text-only health warning labels on food and alcohol products: systematic review with meta-analysis. Manuscript Under Review. <https://psyarxiv.com/jt52m>.
- ³¹ Consent should be time-limited so that the person is not trapped by continuing demand for another telling of that old story about the situation that no longer defines them.
- ³² Repper J, Breeze J. (2007) User and carer involvement in the training and education of health professionals: a review of the literature. *Int J Nurs Studies*. 44:511–9. doi: 10.1016/j.ijnurstu.2006.05.013.
- ³³ NDTi uses a Readiness Framework to assess whether organisations will benefit from NDTi input. Could it be adapted for use in storytelling scenarios to predict whether the story will make a difference? Are there times and circumstances when offering a story would be unhelpful, such as to a person who is subject to delusional ideas of reference or when an organisation is overwhelmed and has no capacity to listen? Voronka explains how stories are viewed through a pre-existing lens and so the speaker has less control of what happens to them than the hearer - Voronka J (2019) Storytelling beyond the psychiatric gaze. *Canadian Journal of Disability Studies*. Jul 1;8(4):8-30.

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- ³⁴ After giving her presentation, a Public co-presenter reported that she felt like the researcher's performing monkey. See Foster, V. (2016). *Collaborative arts-based research for social justice*. Routledge.
- ³⁵ Bogdan R (1990) *Freak show: Presenting human oddities for amusement and profit*. University of Chicago Press; 1990. For material on the human disgust response, see Bates P (2014) *Vile Bodies: understanding the neglect of personal hygiene in a sterile society*. Available at <https://peterbates.org.uk/wp-content/uploads/2017/04/vilebodies - most recent.pdf>.
- ³⁶ A narrative arc follows a formula beginning with a baseline situation followed by disruption, climax and resolution. Jennifer Ruthe explains that, 'Generally speaking the greater the contrast between before and after, the more impact your story will have.' Available at <https://writtenbyjen.wixsite.com/writtenbyjen-blog/post/episode-5-storytelling>.
- ³⁷ See [The mechanisms and processes of connection: developing a causal chain model capturing impacts of receiving recorded mental health recovery narratives | BMC Psychiatry | Full Text \(biomedcentral.com\)](#). Also the wider evidence from the NEON study of the impact of recovery narratives. As well as struggle, these recovery narratives include strengths, successes and survival.
- ³⁸ Lea L, Holttum S, Butters V, Byrne D, Cable H, Morris D, Richardson J, Riley L & Warren H (2019) Now they're listening: involvement in clinical psychology training. *Mental Health and Social Inclusion*, Vol. 23 No. 1, pp. 23-29. doi:10.1108/MHSI-07-2018-0027
- ³⁹ Holttum S, Lea L, Morris D, Riley L & Byrne D (2011) Now I have a voice: service user and carer involvement in clinical psychology training, *Mental Health and Social Inclusion*, Vol. 15 No. 4, pp. 190-197. doi:10.1108/20428301111186831
- ⁴⁰ See [\(3\) Neurodiversity: 'No hope' labour | LinkedIn](#).
- ⁴¹ Rose D, Kalathil J. Power, privilege and knowledge: the untenable promise of co-production in mental "health". *Frontiers in Sociology*. 2019 Jul 16;4:57.
- ⁴² Lisa Haythornthwaite never releases stories into the public domain, so will not publish a video story on Youtube, for example. The storyteller has the opportunity to be present and to speak when their video is shown (personal communication 13/02/2025).
- ⁴³ Boris V (2017) What makes storytelling so effective for learning? *Harvard Business Review Blog* available at <https://www.harvardbusiness.org/what-makes-storytelling-so-effective-for-learning/>.
- ⁴⁴ In the UK, research ethics are mostly concerned with research participants and the rules do not cover people who coproduce research, so would not be a requirement for co-researchers. However, ethicists have (within limits) captured some useful concepts that can assist others to review practices. For a review of this topic, see the suite of papers under the heading 'Ethical Research Practice' at <https://peterbates.org.uk/home/linking-academics-and-communities/how-to-guides/>.
- ⁴⁵ Naïve approaches to payment can lead to people being disqualified from claiming welfare benefits so agencies that engage people have a duty of care not to leave people destitute.
- ⁴⁶ Mayer C & McKenzie K (2017) '... it shows that there's no limits': the psychological impact of co-production for experts by experience working in youth mental health. *Health & social care in the community*, 25(3): p. 1181-1189.
- ⁴⁷ Bell J, Mok K, Gardiner E, Pirkis J (2018) Suicide-related internet use among suicidal young people in the UK: Characteristics of users, effects of use, and barriers to offline help-seeking. *Archives of Suicide Research*. Apr 3;22(2):263-77.
- ⁴⁸ I get the impression think that the whole simulated patient literature has done this, while advocates of reciprocal mentoring may have acted in a similar way towards those who support reverse mentoring.
- ⁴⁹ Hawthornthwaite et al (2018, op cit)
- ⁵⁰ The Open University and perhaps other academic environments draw on publications from NDTi. Our materials could underline some of the ways to honour storytellers.
- ⁵¹ For reviews of evidence on the use of bibliotherapy see Glavin CE, Montgomery P (2017) Creative bibliotherapy for post-traumatic stress disorder (PTSD): a systematic review. *Journal of Poetry Therapy* Apr
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3;30(2):95-107. Also Wang S, Bressington DT, Leung AY, Davidson PM, Cheung DS (2020) The effects of bibliotherapy on the mental well-being of informal caregivers of people with neurocognitive disorder: a systematic review and meta-analysis. *International journal of nursing studies*. Sep 1;109:103643. Also Sommer R (2003) The use of autobiography in psychotherapy. *J Clin Psychol*. 59:197–205. doi: 10.1002/jclp.10146. Also Cuijpers P (1997) Bibliotherapy in unipolar depression: a meta-analysis. *J Behav Ther Exp Psychiatry* 8:139–47. doi: 10.1016/S0005-7916(97)00005-0. Also Apodaca TR, Miller WR (2003). A meta-analysis of the effectiveness of bibliotherapy for alcohol problems. *J Clin Psychol*. 59:289–304. doi: 10.1002/jclp.10130. Also van Lankveld JJDM (1998) Bibliotherapy in the treatment of sexual dysfunctions: a meta-analysis. *J Consult Clin Psychol*. 66:702–8. doi: 10.1037/0022-006X.66.4.702

⁵² Wolfensberger lists eight stereotypes of people with intellectual disabilities: (i) less than human; (ii) a burden upon society; (iii) a menace to society; (iv) sick; (v) mentally ill; (vi) objects of pity; (vii) eternal children; and (viii) holy innocents. See Wolfensberger W (1972) *The Principle of Normalisation in Human Services*. Toronto: National Institute of Mental Retardation.

⁵³ See Ellison R (1952) *Invisible Man* Random House.

⁵⁴ Ronson J (2016) *So you've been publicly shamed*. Riverhead Books.

⁵⁵ See <https://peterbates.org.uk/wp-content/uploads/2017/10/Blog-on-duty-of-care.pdf>.

⁵⁶ See <https://peterbates.org.uk/home/garden-shed/can-authors-use-a-pseudonym/>.

⁵⁷ Misfits Theatre Company have sometimes created a single story by blending true elements drawn from all their members, so everything is true, but no one person stands in the glare of the spotlight. Their use of improvisation rather than scripts reclaims some of the power. For a written version of fiction built from true fragments, see Bates P (2007) Church on Sunday morning in Coyte ME, Gilbert P & Nicholls V (eds) (2007) *Spirituality, Values and Mental Health: Jewels for the Journey* London: Jessica Kingsley. Available at <https://peterbates.org.uk/wp-content/uploads/2017/04/churchonsundaymorning.pdf>.

⁵⁸ See *The danger of a single story* by Chimamanda Ngozi Adichie at <https://www.youtube.com/watch?v=D9lhs241zeg>.

⁵⁹ This links with the feminist critique of ‘essentialism’ that posits that factors such as gender and race dictate many other aspects of the person.

⁶⁰ Edward Colston was honoured with a statue for giving his fortune to local charities in Bristol. Black Lives Matter removed it in June 2020 as he made that money by enslaving people.

⁶¹ Shifrin S, Gelo F & Mitchell A (2020) ARTZ @ Jefferson: How Arts-Based Experiences Support People With Dementia as Mentors and Aid in Dignity Preservation. *Innov Aging*. Dec 16;4(Suppl 1):842. doi: 10.1093/geroni/igaa057.3087. PMID: PMC7743415.

⁶² Here is the paradox in the title of this paper. Perhaps the best way to honour storytellers is to stop calling them storytellers and instead relegate their story to a small but significant part of their contribution while promoting their broader analysis, insight and experience.

⁶³ [EPIC seminar series: Miranda Fricker - Zoom](#). Fricker describes several forms of epistemic and hermeneutical justice and what happens when these kinds of injustice prevails in healthcare systems.

⁶⁴ See Laura’s blog at [Lived Experience Washing - NSUN website](#).

⁶⁵ Taylor N (2021) *7 ways to tell stories ethically: the journey from exploited program participant to empowered storyteller*. Blog at <https://communitycentricfundraising.org/2021/01/06/7-ways-to-tell-stories-ethically-the-journey-from-exploited-program-participant-to-empowered-storyteller/>.

⁶⁶ Gerrig RJ (1993) *Experiencing Narrative Worlds: On the Psychological Activities of Reading*, New Haven: Yale University Press.

⁶⁷ War veterans sometimes nostalgically relive this most exciting part of their lives. Conversion testimonies simplify a complex story into a ‘I once was lost but now I’m found’ melodrama from all bad to all good. Sometimes there are profits to be made from getting stuck in these viewpoints.

⁶⁸ Pinfold V, Thornicroft G, Huxley P, Farmer P (2005) Active ingredients in anti-stigma programmes in mental health. *Int Rev Psychiatry*. (2005) 17:123–31. Doi: 10.1080/09540260500073638. Also Thornicroft G, Mehta N, Clement S, Evans-Lacko S, Doherty M, Rose D, et al (2016) Evidence for effective interventions to reduce

mental-health-related stigma and discrimination. *Lancet*. 387:1123–32. doi: 10.1016/S0140-6736(15)00298-6. Also Roe J, Brown S, Yeo C, Rennick-Egglestone S, Repper J, Ng F, Llewelyn-Beardsley J, Hui A, Cuijpers P, Thornicroft G, Manley D (2020) Opportunities, enablers, and barriers to the use of recorded recovery narratives in clinical settings. *Frontiers in Psychiatry*.11.

⁶⁹ Layton Z (2021) *Papercuts: restorative approaches and cumulative harm in mental health care*. Blog published 26 March. Available at <https://seriousmentalhealth.com/2021/03/26/papercuts-restorative-approaches-and-cumulative-harm-in-mental-health-care/>.

⁷⁰ One person called this a ‘professional service user’. Alcoholics Anonymous refer to people who have become abstinent but who continue to live as if they were drinking as ‘dry drunks’. Some people want to focus their life on reforming services, but the service is failing if a disproportionate percentage of people end up doing this.

⁷¹ See [OHT Learning Series - Session #2: Bearing Witness to Lived Experience](#)

⁷² Rennick-Egglestone S, Ramsay A, McGranahan R, Llewelyn-Beardsley J, Hui A, Pollock K, Repper J, Yeo C, Ng F, Roe J, Gillard S (2019) The impact of mental health recovery narratives on recipients experiencing mental health problems: Qualitative analysis and change model. *PLoS one*. Dec 13;14(12):e0226201.

⁷³ Richards et al (2023, op cit).

⁷⁴ See Yasmin (2025) [Monetising my mental health: the price of trauma - NSUN website](#)

⁷⁵ Mencap Wales will host a 12-month MRes project from October 2021 titled [The efficacy of storytelling for building identity and agency with people with Learning Disabilities](#). Further information from Dr Emily Underwood-Lee at emily.underwood-lee@southwales.ac.uk.

⁷⁶ Cally Ward’s son is involved in the group that produces *Books without Words*.

⁷⁷ See, for example, resources on service users and carers in nurse education at <https://peterbates.org.uk/home/service-user-and-carer-involvement-in-nurse-education/>.

⁷⁸ See *How to involve the public as lecturers* available at <https://peterbates.org.uk/wp-content/uploads/2017/04/How-to-engage-the-public-as-lecturers.pdf>

⁷⁹ See <https://peterbates.org.uk/wp-content/uploads/2017/10/How-to-choose-between-an-actor-and-an-expert-by-experience-1.pdf>. The artificiality of this debate is revealed by the assumption of a binary ‘actor or expert by experience’ division when organisations such as the Misfits Theatre Company cheerfully celebrate their dual qualification. Sue Turner is a Trustee of Misfits.

⁸⁰ See *How to involve the public as Board members* available at <https://peterbates.org.uk/wp-content/uploads/2017/04/how-to-involve-the-public-as-board-members.pdf>.

⁸¹ See *How to do reverse and reciprocal mentoring* Available at <https://peterbates.org.uk/wp-content/uploads/2021/03/How-to-do-reverse-mentoring-1.pdf>.

⁸² See *How to make the case that Public Contributors are Citizen Ethicists* available at <https://peterbates.org.uk/wp-content/uploads/2020/12/How-to-make-the-case-that-Public-Contributors-are-Citizen-Ethicists.pdf>. Also *How to engage Public Contributors as Citizen Ethicists* available at <https://peterbates.org.uk/wp-content/uploads/2020/11/How-to-engage-Public-Contributors-as-Citizen-Ethicists-1.pdf>.

⁸³ Contributions and challenges have been offered by Drew Edwards, Alison Giraud Saunders, Lyn Griffiths, Tracy Hammond, Gail Hanrahan, Caroline Harding, Carol Hayden, Anna Marriott, Victoria Mason-Angelow, Alice McColl., Ann Memmott, Kate Mercer, Colin Newton, John O’Brien, Gail Petty, Fiona Ritchie, Jennifer Ruthe, Steph Thompson, Sue Turner and Cally Ward, although all errors and weaknesses that remain in this document are the responsibility of the author.