Taking Voice Seriously Literature Review

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"This work is emotive and there will always be points of tension based on different experiences, perspectives, thoughts and beliefs. If there isn't, the work is not genuine, authentic or meaningful. Doing the work requires compassion, bravery and a willingness to try, test things out and learn from what works and what doesn't. It's not an easy road to walk, but it is easier when you are walking it along with others." (Newton, 2022:49).

Lived expertise is a key concept within social change thinking, focussed on the belief that entrenched societal challenges such as structural poverty and inequality cannot be detached from meaningful engaged lived expertise (Sandhu, 2017). Lived expertise challenges objectivist values (Beresford, 2003), and yet the value of creating collective knowledges, recognising the diversity of lived, learned and embodied knowledge, holds the potential to achieve real and lasting social change. Participatory approaches to addressing poverty with lived experience allow those with lived expertise control over the research process and influence over how knowledge is shared (Bennett and Roberts, 2004; Broady et al, 2019; Spyropoulos et al., 2023)

Lived experience is a contested term. Sandhu defines lived experience as 'the experience (s) of people on whom a social issue, or combination of issues has had a direct personal impact' (2017:5). Experiential knowledge is held by each person and developed throughout the life course by taking on new experiences (Blume, 2017). This knowledge is embodied, as it is often knowledge only known through doing and held within the human body and mind (Boardman, 2014; Freeman and Sturdy, 2014; Smith-Merry, 2020). Experiential knowledge is difficult to understand for others who do not share the same experiences, and this leads to it being delegitimised within existing hierarchies of knowledge (Smith-Merry, 2020) Whilst there is an emerging set of best practice discussed in evaluation and project reports produced by the voluntary sector, there is still only limited published academic research which focuses on best practice in addressing poverty with lived experience (McIntosh and Wright, 2019 ; Croft, Skelton and Drayak, 2021; Parr, 2023).

This literature review will discuss the value of voice and power; the effects of stigma; the sanitising of stories; the dangers of tokenistic engagement; and principles for action in taking voice seriously. This is not a systematic literature review but a broad-spectrum review of existing literature available. Using a snowballing technique (Ridley, 2012), literature has been gathered from sociology, social care and public health academic databases as well as from a Google search for grey literature. This literature has been reviewed and thematically analysed (Braun and Clarke, 2012) and is presented across themes of power, stigma, best practice, barriers to engagement and strategic lived experience leadership. The literature review concludes with principles for action in addressing poverty with lived experience.

The value of voice

Lived expertise holds strong benefits for the social sector and for experts by experience (Skelton et al, 2023). Sandhu (2017:17) lists over fifteen benefits to the social sector of valuing and including lived expertise within change making; these are focussed around strengthening community credibility, community connections and demonstrating organisational values. Overall the message is clear: 'we won't get where we need to be if we fail to engage with people's realities' (Hawkes et al, 2018:4). Personal narrative is a valid epistemology for storytelling and social good (Clements et al, 2020). However, Newbigging and Ridley (2018) refer to how lived expertise is discredited and discounted in comparison to academic knowledge forms, as epistemic violence. Hawkes et al (2018) argue that policy needs to be based on how the world is and on what people are experiencing in life, not on how policy makers in offices wish the world to be. The values behind lived experience work are central to the ethics of practice (Spyropoulos et al, 2023). Newton (2022) lists these values as honesty, reciprocity, accountability, respect, acceptance, authenticity, diversity, non-judgement, capacity building, creativity, accepting, mutual, strengths based, and person-centred, trusting.

The value of activism for experts with lived experience sits around the sense of dignity built by holding equality of voice as well as practical improvements to mental and physical health through inclusion within the community (Croft, Skelton and Drayak, 2021). Newton (2022) lists the benefits to the individual with lived experience as a route to finding meaning and purpose within our experiences, an increase in self-esteem, an increased sense of belonging and an appreciation of other, as well as increased skills, knowledge and opportunities. There are wider benefits to the community that Sandhu (2017) lists, which include benefits for community cohesion, building of equality and dignity for all and a raising of community consciousness.

Ensuring the diversity of lived experiences can be represented with equality is a challenge that must be addressed. Much of the leadership of the voluntary sector is male and white (Sandhu 2017). Best practice in addressing poverty with lived experience needs to take active steps to ensure a diversity of voices and a diversity of approaches to spotlighting lived experience. Art, poetry, animation, blogs and vlogs are all good routes to communicating voice. Art communicates voice through an 'alternative lens' (Foster, 2015), which is important in offering a diversity of lived experiences. It should be noted that our relationship with our lived experience is not fixed; it is constantly moving and developing as our lived lives progress (Beresford, 2003).

There are some examples of good practice in listening to lived experience in mental health, mostly due to the legislation that requires service user involvement (Community Care Act, 1990 Section 46; The Health and Social Care Act, 2001 Section 11). There are also some examples of progressive practice in the youth sector. Community development, co-production and co-commissioning continues to progress towards meaningful appreciation of expertise by experience (McCormack and Fedorowicz, 2022

Power and Resistance. Challenging Stigma.

"*The greatest misfortune is to know that you count for nothing, to the point where even your suffering is ignored."* (ATD Fourth World in Lister, 2017:140)

Knowledge can be understood as taking various forms. Young (2007) makes the distinction between the knowledge of the powerful and powerful knowledge; knowledge is symbolic and only certain 'types' of knowledge are privileged. Aristotelian categories of knowledge describe three types of knowledge, split into episteme theoretike (knowledge achieved through reasoning), techne (trained ability for rational production) and phronesis (practical wisdom). Facer and Enright (2016) use the term living knowledge to refer to people living in a community that is experiencing an issue. It is here Smith-Merry (2020) argues for the importance of lived experience in its 'situated validity'. As Fraser (2014) noted when discussing the symbolic injustice of a lack of political voice, the shame, stigma and othering linked to living in poverty deny people 'representational agency' (Tyler, 2013:26). Agency can be collective as well as individual (Lister, 2017). Knowledge can be built on a person's ontological identity, their unique sense of self and their categorial identity, their sense of belonging (Taylor, 1998)

Power can be challenged by taking a cognitive justice approach (Visvanathan, 2009), which enables us to engage diverse communities in problem solving based around reciprocity and conversation. Visvanathan (2009) argues that this is a deep form of collectivism. Clancy, Harman and Jones (2022) argue for forms of public pedagogy that consider and scrutinise power differentials, opening up space for critical political action. These shared spaces for power sharing and activism, seeds of hope (Williams, 2013), hold the potential to create stronger networks that span geographic and ideological boundaries. Participatory approaches arguably seek to address the powerlessness associated with living within structural inequality (South, 2015; Skelton et al. 2023). As participatory approaches build voice and control they also build social connectedness, and in so doing build equity (South, 2015). Beresford and Hoban (2005) reinforce the importance of recognising and seeking to clarify power relations within lived-experience-led activism.

The fear that the increased power and voice of experts with lived experience is likely to overshadow those with 'learned' or 'technical' experience is cited as a key barrier to genuine participation (Sandhu, 2017). Bassett et al (2010:10) discuss the changing role of the 'professional', stating that 'professionals will remain important but they will have to recognise that their contribution needs to be made in a different way'. It should be noted that the voluntary sector is not immune to entrenched socio-economic inequalities. Indeed, the grant making and investment world is incredibly privileged, holding considerable power and influence in the social sector (Sandhu, 2017). Sandhu's (2017) research found that smaller charities were frequently modelling good practice in participation and valuing lived experience voices yet the larger charities were often reluctant to follow this good practice.

There is a significant social impact of poverty. Poverty is much more than a lack of income; it is about the material deprivation which often leads to poor health, reduced social mobility, social isolation and powerlessness (Walker et al, 2013). Stigma often distorts the reception of experiential knowledge (Smith-Merry, 2020). A sense of shame has structural as well as individual elements, and poverty shame is a gendered experience with more women than men at risk of poverty (Rodogno, 2012). However, the emasculating impact of poverty should not stay muted (Ruxton, 2002). It is noted that shame and experience of stigma reduce agency (Walker et al, 2013). The experience of 'othering' (Lister, 2004) of people living in poverty further exacerbated a feeling of stigma and created barriers to participation and inclusion, leading to a sense of powerlessness (Walker et al, 2023)

It vital that commissioners and senior voluntary sector leaders fund information, awareness and media campaigns which challenge stigma (Alliance, 2022). Listening to lived experience expertise challenges traditional ways of working, and it is important to recognise that organisational change is hard and can be unsettling for members of an organisation's workforce. It is important to put in place support and training to help people understand what listening to lived expertise involves and to prepare people for the change that is to come (Newton, 2002). It is important to recognise that some of the workforce may well have lived experience; assumptions should never be made about what lived experiences people do and do not have (Newton, 2022). Language is a key element in addressing poverty with lived experience well. It is important to recognise that language is never neutral (McKendrick, Marchbank and Sinclair, 2021). Avoiding being typecast as a 'lived experience leader' can be a challenge. Poverty and lived experience activism are strewn with contested terms which can ostracise lived experience experts (McLaughlin, 2009). Lived experience of poverty can lead to labelling (Becker, 1963), marginalisation and othering (Lister, 2015). This impacts on power and voice – story sharing can challenge this stigma but it is a contested methodology in its own right.

Voice, Story Telling and Sanitising Stories

Telling your story is a way of actively engaging in social discourse; indeed 'resistance is theorised by those that engage in it' (Crossley in Clements et al 2020:20). Storytelling can overturn stereotypes and challenge assumptions, as when people go unheard they are easily dehumanised (Clancy, Harman and Jones, 2022) and 'othering' (Lister, 2004) can occur. Through storytelling people's voices can be heard, solidarity can be built, the invisible can become seen, the unheard can be listened to and spaces of learning, activism and voice can be nurtured (Harman, 2022).

Asking a person with lived experience to 'share their story' holds challenges; it invades their privacy and opens the individual up to individualistic criticism. Recognising that story telling can be triggering for those sharing their story and those hearing their story, there are more positive routes to lived experience activism that recognise an individual's experience without causing psychological distress. There is 'emotional labour' (Hochschild, 1983) in the work of sharing one's story and in supporting a person to share their story.

Story sharing can take an emotional toll and both the story teller and those that support them require adequate support to process the emotional labour involved in sharing stories.

A person who has shared their lived experience, which is often re-traumatising then becomes vulnerable to media tropes that demean or victimise their experience (Sandhu, 2017). Philips, Fowler and Westaby (2018) refer to 'ex-smoker syndrome' where inappropriate disclosure can have negative effects. Moving beyond story telling to create safe spaces that are inclusive environments for people with lived experience is important. Asquith, Kikonco and Balch (2022) offer six guiding principles for trauma informed by lived experience experts, focussed on safety, trustworthiness and transparency, peer support, collaboration and mutuality, empowerment voice and choice, and cultural, historical and gender issues. Moving beyond story telling can offer a more collectivised form of activism. It is important to recognise that community centred approaches 'do not tend to deliver neat, simple solutions and outcomes are often connected' (South, 2015:31). This reflects the interconnectedness and messiness of communities (Sparke, 2008). Examples of moving beyond story telling include peer support networks, taking part in activism, informing policy and projects, creating and promoting anti-stigma resources, and delivering anti-stigma training (Alliance, 2022). Moving beyond story telling to collective action is a participatory process (Croft, Skelton and Drayak, 2023). Avoiding tokenism and developing meaningful involvement involves building relationships to enable transformative space making and tackling existing power hierarchies in order to support the creation of equal knowledge development (Marshall, Dolley and Priya, 2018).

Supporting Success; Opportunities for Growth and to Blossom

A good level of meaningful support is needed to nurture and value those that share their lived experiences. As Beresford and Hoban state, 'participation in a meaningless forum is meaningless' (2005). Taking the time to support meeting preparation and to accompany people when attending unfamiliar environments online or in person are key to valuing lived experience participation (CFE Research, 2020). Best practice outcomes can be promoted by developing specific policies that promote role clarity, build in the opportunity to develop qualifications, and access training and specific lived experience supervision (Roennfeldt and Byrne; 2021).

Experts with lived experience should be supported to participate; this could be by working directly with a coordinator to prepare for sessions as well as having transport and accommodation booked in advance to avoid out-of-pocket expenses (CFE Research, 2020). It is essential to ensure that that frontline staff as well as senior management are trauma informed and trauma skilled (Alliance, 2022). Beresford and Hoban (2005) recommend starting where people are and not where they are assumed to be – it is important to avoid assumptions and create accessible user-friendly systems of support without assuming that lived experience experts will fit in with the organisation's 'usual ways of doing things'. National Institute for Health and Care Excellence (NICE) guidance for community engagement is that approaches should be considered in relation to the social context (Bagnall, White and South, 2017).

Avoiding harm is a key commitment to doing lived experience activism ethically, ensuring that there are support systems in place for people in between meetings, and facilitating meetings in a trauma-informed way, allowing participants to contribute and share experiences with dignity, is fundamental to good ethical practice (Newton, 2022; Gupta et al, 2023). Considering the safeguarding needs and vulnerability of lived experience participants can be challenging. A detailed risk assessment, that includes lived experience participation, can be a way of ensuring lived experience voice is part of every element of the project. Creating safe spaces acknowledges that 'you can never truly make this work safe for anybody. There will always be triggers for people within it but you can do your best to create as safe a space as possible so that people can bring their whole selves, including all their different identities, into it' (Newton, 2022:45).

Recognising that people have intersecting identities, having clear role descriptions for participation and ensuring all communication is in inclusive and accessible language are key (Newton, 2022). Thoughtful induction and onboarding that sets out clear expectations is important in developing a range of ways that people can contribute to the work (Newton, 2022). Facilitation of the group is the key to success, recognising that conflict will occur and addressing challenges, and building in a range of ways that people can participate, verbally, via chat functions online, and sending out hard copy documents. Good facilitation of sessions creates spaces where people feel psychologically safe (Newton, 2022). Thinking about timings, online or face to face and duration of groups is important to ensure that people are able to participate fully.

An EMERGES framework was developed by Gupta et al (2023) which reflects and relates visually the identity positions of lived experience researchers and activists. The variety of lived experience roles is acknowledged; professional, service user, integrated / unintegrated into systems change and the liminality of lived experience roles are recognised. Ethical practice is tied to the EMERGES framework relating to enablers and empowerment, motivation to integrate, empathy of self and others, recovery model and medical model, growth and transformation, exclusion (recognising stigma and discrimination) and survivor roots (Gupta et al, 2023).

Addressing poverty with lived experience meaningfully means offering meaningful opportunities for growth, through training or taking on leadership roles (CFE Research, 2020).

"My fractured self was pieced together in pursuit of my newly formed service user identity … I once only had a tiny seed of hope, now this has blossomed giving me a new sense of identity, purpose and direction." Alison Bryant, Service User Advisor (2023) (in Gupta et al, 2023:2)

Identity theories suggest that identities are formulated through group membership or the roles that we inhabit within society. Social identity theory argues that identities are formed in opposition to other social identities. As lived experience activists, liminal identities can be inhabited, reflecting the complexity of lived experience activism which often holds the opportunity to move between lived experience volunteer and peer worker. The liminality of lived experience activism in relation to identity can interact with and impact on identity, similarly to intersectionality (Crenshaw, 1997).

Successful systems change is often 'reliant on the development of trusting relationships between manager / mentors and experts' (CFE Research, 2020:26). It is imperative that frontline staff create safe spaces for trusting and meaningful relationships (Hogan et al, 2020). Collaborating across organisations to build lived experience voices and expertise can be a positive way to amplify voice (Sandhu, 2018).

Supporting peer support volunteers, recognising the vicarious trauma of supporting a person to share a traumatic story, is important in order to preserve the emotional health of those in supporting roles (LeBon, 2023). LeBon (2013) suggests mentoring of peer support roles as a positive route to building emotional reliance within lived experience support teams. The range of benefits of paid peer support work sits around the authenticity of being rooted in personal experience (Bassett et al, 2010), there are however challenges. The challenges to paid peer support work sit around maintaining independence, becoming over involved, accessing social security if completing peer support work part-time (Bassett et al, 2010). Alongside these challenges Bassett et al (2010) raise the issue of avoiding 'over professionalisation' in peer support. To use Jensen's (2015) typology of professionalisation, the role of lived experience activist to professional takes place within a continuum from informal collaboration through to specialisation.

Principles for community engagement are detailed by Hogan et al, (2020) and include foregrounding that participants with lived experience are experts, that policy is co-designed, delivered and analysed, that accountability and commitment to equity are measured, that adequate support is allocated to inclusive participation, that each project takes an asset-based mindset, that a culture that values new opinions and diversity of views is nurtured, that sustained and trusting relationships will be supported, and that shared decision making is key. Recognising that relationship building, confidence development and nurturing voices takes time is vital to ensuring ethical lived-experience-led activism. Good quality engaged participation takes place slowly (LeBon, 2013). Principles for community engagement need to actively address the barriers to participation. Avoiding paternalism, embracing participatory governance and ensuring meaningful engagement in participatory decision making are not without challenges, despite being essential for taking voice seriously.

Barriers to Involvement – Practical and Ideological.

Barriers to involvement can be personal, institutional, economic, cultural and technical (Beresford and Hoban, 2005). Balancing competing values of empowerment and safeguarding can be challenging. Individually and collectively these barriers can be addressed. However, an overwhelming barrier to involvement can be a sense that lived experience participation will hold no power or result in no action, whereas ensuring that lived experience activism has the power and potential to result in meaningful change is a motivator for involvement.

Recognising the financial costs and seeking to address them are key to financially valuing people. Offering thank-you vouchers and remuneration for time and expenses is an important part of recognising and attributing economic value to lived expertise (Sandhu, 2017). For some people in receipt of social security payments paying for their time can have negative implications (Newton, 2022), therefore consideration of a person's financial circumstances should be made on a person-by-person basis before payment is offered. Ensuring that out-of-pocket expenses such as meals, travel and accommodation are met in advance is vital to allowing participation of those on low incomes; claiming back expenses in arrears is simply not an option during a cost of living crisis if you live on a low income (Goldstraw et al, 2021). Appropriate thank-yous are important in valuing a person's contribution: 'it can be insulting when you're offered a £10 voucher and a slice of cake for coming to a meeting and sharing personal experiences for other people's consumption' (Newton, 2022:26).

Other ways of valuing people include opportunities and investment in a person's skill development, offering access to training, coaching and mentoring. Supporting people to develop and build on transferrable skills, develop their CVs and apply for paid roles is another important way of valuing people's contributions. Person-centred things matter when valuing people, such as offering meals, providing digital devices and securing Wi-Fi connections to avoid digital exclusion, days out, and providing equipment / clothing to allow a person to feel confident about participating in formal events (for example, formal dress shoes) (Newton, 2022). Sending thank-you cards and remembering special events such as birthdays and weddings are an important part of ensuring people know that they are valued for their contribution (Newton, 2022). Addressing barriers to involvement and offering opportunities to grow in a safe space are routes to meaningful participation.

Tokenism and Ticks in Boxes. Ladders, Wheels and Merry-Go-Rounds of Participation.

"Making Space for Voice is empowering a voice without limitations, Making Space for Voice is not using people and putting words in their mouths, Making Space is not using people and putting words in their mouths, Making space is just the beginning" (On Road Media, Revolving Doors and Women for Refugee Women, 2018:5)

Addressing poverty with lived experience properly needs engaged and participatory approaches which are actively designed to address power differentials within the room. Tokenistic attempts at participation should be avoided: 'people are trying … but a post it note doesn't necessarily make the event less formal' (Sandhu, 2017:28). People with lived experience need to shape their involvement rather than simply comply with the needs of the organisational facilitator (On Road Media et al, 2018). Engagement should always lead to tangible change; to achieve this clarity of purpose is key to creating meaningful (rather than tokenistic) opportunities for involvement (Asquith, Kikonco and Balch, 2022).

Participatory approaches to knowledge sharing can build knowledge sharing from input to influence (Bennett and Roberts, 2004). Godrie (2017) introduced three levels of participation: consultation, collaboration and control. Ladders (Arnstein, 1969) and wheels (Pickering et at, 2015 of participation exist to map the levels of voice, from involvement to power sharing, but as Sandhu notes 'sharing power with experts is rare' (2017:7). Barriers to involving lived experience expertise within change making roles include involvement that can be tokenistic, involvement where power remains with the hosting organisation rather than participants, the language of the forum focussing on deficit (for example, service users) rather than expertise, the focus on individualised story telling than can mask collective discrimination and lack of funding to support lived expertise forums. Needham and Carr (2009) presented differing levels of participation, from basic, where people use services but have limited voice in terms of their strategic development, to intermediate, to transformation, where the power and control sit with users. Other approaches to participation include methodologies such as Deliberative Democracy and Citizens' Panels (Bell and Reed, 2022).

Participation trees are a way of structuring participation (Bell and Reed, 2022). In participation trees the complexity of participation is represented by the roots, focussed on inclusivity, building safe spaces and removing barriers. The trunk of the participation tree represents the politics, processes and culture of participation. The leaves on the tree represent accountability, agency, power and transparency. This approach reflects the complexity of participatory approaches and the multiplicity of intersecting variables that impact on the power of lived voices to be heard. Clements et al (2020) introduce the notion of a community of trees, where the ground of lived experience feeds communities of trees and they are then nurtured by what the trees produce –it is in this way that lived expertise, taking personal narrative as praxis, informs system change, social justice and direct service improvements. Within the community of trees lived expertise is vital knowledge for any systems change. Meaningful and ethical participatory approaches are emancipatory, co-producing both the phenomenology and hermeneutics of research (Boardy et al, 2019). Meaningful support is vital to facilitate lived experience participation in deep participatory work at grassroots and strategic levels.

Strategic Level Voice. A Co-Production Accreditation.

Lived expertise needs to be embedded at strategic level (CFE Research, 2020). CFE Research (2020) examined the role of lived experience in creating systems change and highlighted the need to have lived expertise embedded at the strategic level within voluntary organisations. Being involved from the design stage is important in establishing from the outset that projects are designed with the needs and preferences of people living in poverty in mind (CFE Research, 2020). Adapting good practice that incorporates flexibility to respond to local context, history and culture is key (Hogan et al, 2020). Lived-experience-led leadership should, according to Loughead et al (2020), be understood in relation to the concepts of peer relationships, recovery and change. Loughead et al (2020) argue that we need to improve lived experience leadership at a global level.

We need what Gordon (2005) describes as a paradigm shift from lived experience participation towards lived experience leadership. Stewart et al (2019) set out principles for lived experience leadership around applying lived experience to policy development and contributing to an organisational culture of lived expertise inclusion and support. In order to have strategic value the lived experience roles need to be clearly defined and have authentic support within organisational settings (Scholz, Gordon and Happell, 2017). CFE Research (2020) has identified that in some cases a co-production accreditation programme is being established to ensure good practice. Developing strategic level voice offers an opportunity for lived expertise to be valued across all social action, from grassroots activism to national policy change.

Conclusion

This literature review has discussed the value of voice, power and powerlessness. The importance of story telling has been discussed, reinforcing the importance of collective voice. The importance of good practice to support lived experience activism and address barriers to participation was discussed. The opportunities to develop strategic level voice were then reviewed.

Taking voice seriously is complex, challenging and constantly growing, changing and developing. Addressing poverty with lived experience, building dignity for all, involves facilitating supportive safe spaces for voice and addressing barriers to participation such as stigma and financial exclusion. Promoting voice and agency is key to ethical praxis (Popke, 2010; Freire, 2021). For voice to have power at grassroots level and strategic impact at national policy level, activists need support and opportunities for growth and collective participation.

This literature review has been written by Dr Katy Goldstraw, building on Taking Voice Seriously Work with the APLE Collective, establishing our knowledge and expertise in addressing poverty with lived experience.

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