Participatory action research and disability activism
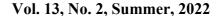
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Abstract

This article centres on my dissertation in Arts, Festival and Cultural Management at Queen Margaret University, Edinburgh. It explored whether participatory action research is appropriate for aiding the formation of disability arts-based policy recommendations in collaboration with Scottish-based disabled artists. These recommendations were intended for Creative Scotland, the national public arts funding body. The article will explain why this project was chosen, revealing that the reasons were partly personal. My upbringing and educational background have created a resolute stance that disabled people are acutely disadvantaged by normative social constructs. As will be contended, the academic and creative realms are not exempt from the shortcomings of an ableist macro paradigm, and this has been central to the research. Some key findings and provisional policy recommendations will be touched upon which suggest that Creative Scotland could learn from paying closer attention to disabled artists' views, and models of good practice elsewhere. A core strand will rest on the interplay between structure and agency - the possibilities for personal agency within the structures of policy and politics. Whilst a central problem in undertaking the research was capacity, in particular the limited duration of the fieldwork, nonetheless the research model enabled unanticipated collaborations, and exposed progressive ideas and routes which, if taken, could potentially lead to enacting change. The article will consider personal reflections on the research and my role within it, uncovering both real and imagined experienced. In doing so, a reminder of the importance of connecting theory to practice surfaced, honing the pivotal qualities a community educator should aim for, namely facilitating dialogue and claiming democratic spaces.

Introduction

Disability activism runs in my family. A vivid early memory is being at the Block Telethon demonstrations when I was six. The mantras being hailed were 'Rights not

Charity' and 'Piss on Pity', the protest focussed on ending televised disability charity campaigns that were viewed by many disabled people as paternalistic and crude. I did not fully grasp the protest motivations, but I clearly recall two people who had stormed the ITV building being thrown down the entrance stairs by burley men. I remember feeling disconcerted and the demonstrators' outrage was palpable. Fast forward 30 years, I now have a deeper understanding and anger at the injustices that disabled people endure.

Studying Community Education heightened my awareness of the maltreatment that disabled people have endured. Historically, disabled people have been positioned by society as sub-standard 'others'. This arc has continued and is 'alarmingly relevant to disabled people in the United Kingdom' (Matthews, 2017, p.1352). In a sense, things have progressed for disabled people over the 25 years which have passed since the UK's Disability Discrimination Act (DDA). However, *plus ça change*: despite legislation enshrining disabled people's rights to employment and independent living, disabled people are all too often marginalised. Moreover, post 2010 austerity policies have ratcheted up 'benefit' conditionality - a drive aided by political and media scapegoating. The result is that many disabled people suffer financially and mentally (Pring, 2017).

Finding and securing fulfilling and stable employment is still extremely difficult for many disabled people. Whilst figures have risen in recent years, the Scottish level of disabled people working within the arts lags behind the UK average (Creative and Cultural Skills, 2018). This demonstrates that policy changes need to happen which ensure that even minor advancements made over recent decades are not in vain. The current forecast is grim. The fallout from Covid-19 is likely to see an increased downward trend (O'Brien, 2020). Not Going Back to Normal (NGBTN), a project which sought the views of disabled artists, evidenced systemic barriers that artists face when trying to get paid work via Creative Scotland (CS) and the creative sector more generally (Giles and Callaghan, 2020). Moreover, critical disability studies are often peripheral in academia and there is a dearth of participatory action research (PAR) that actively involves disabled people (Levy and Young, 2020; Ervelles et al, 2019; Bergold and Thomas, 2012).
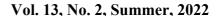
The research

The marginalised status of disabled people in the arts and academic research was the focus of my research and it sought to collectively create policy recommendations with disabled artists in Scotland. I began with a questionnaire that aimed at gaining a deeper understanding of the barriers outlined in NGBTN, along with what people responding to it felt were the key policy recommendations. Of the 33 responses, the options most selected were as follows:

- Ensuring Creative Scotland's regularly funded organisations offer the means for remote working and accessing their art online after the pandemic
- Employing more disabled people within Creative Scotland and on their board
- Supporting disabled artists to make links throughout the Scottish Creative Sector

The questionnaire gave people the option to be involved in four online focus groups, in which issues from NGBTN and the questionnaire would be discussed, with the primary aim of producing a set of policy recommendations for CS consideration. From there, six disabled creatives attended. There was a collective feeling that disabled artists who are at an early stage in their career are disadvantaged under the 'proven track record' model that they feel CS rigidly work to. In line with survey findings, the group believe CS should employ more disabled people. The creative sector overall has a 13% employment level of disabled people, whilst the CS disabled workforce sits at 9% of (Creative Scotland, 2019; Creative and Cultural Skills, 2018).

Perhaps the most promising idea that came from the sessions was a call for a national disability arts organisation akin to Disability Arts Cymru (DAC). DAC has a proven track record for offering disabled artists initiatives that help them to develop as artists by offering training and paid opportunities within the arts. Creating such an organisation in Scotland would require active investment from CS, in terms of finance and cultural capital. Whether or not this recommendation will be taken on board and enacted remains to be seen, but one thing is clear: improving the sector to be more equitable for disabled people rests on increased and sustained commitment from CS.

During fieldwork, I spoke to a CS employee with a background in Equalities, Diversity, and Inclusion (EDI), and they highlighted organisational changes being made around equalities and increasing transparency. They also seemed receptive to the idea of trialling new ideas, and agreed that parallels between Scotland and Wales do exist. Contrariwise, I also experienced CS being unforthcoming in providing subsequent feedback and data. Firstly, several key questions put by the group to the EDI worker were never fully answered. On the back of an initial freedom of information request around the levels of disabled people applying to CS, the proportion of whom are successful in securing funding, the group devised another. They responded that it would cost too much time and money to supply these figures, but that they would look at compiling such data in the future. However, when I emailed back to ask when this would happen, I received no response.

It is possible that such lack of communication is down to a lack of capacity, as one questionnaire response suggested: ramifications of Covid-19 have likely overburdened CS frontline staff as elsewhere. In part, however, it feels like these instances amount to 'kicking the can down the road'. As Eikhof (2020) argues, however, perhaps now is the time to act meaningfully:

> The research and policy task at hand now is to reform our responses to the impact of COVID on inclusion and workforce diversity in the cultural economy before it is too late (Eikhof 2020, p. 244).

At the time of writing, the document capturing the questionnaire responses, key findings and policy recommendations from the focus group is incomplete. At the onset, I took into account the fact that time shortages within academic schedules can curtail meaningful PAR projects (Bergold and Thomas, 2012). Notwithstanding this, I completely underestimated how much could be achieved during an eight-week period in which the four, two-hour long focus groups took place. I still feel that PAR was an appropriate form of inquiry providing clear examples of where connecting personal experiences with theory stimulated ideas for action. Despite busy schedules, the group met earlier this year after my dissertation was completed. The list of policy recommendations has been honed down further, and work on creating a final document is underway. This continued involvement may suggest promise for further exploring

the barriers and possible solutions to disabled people being able to equitably access culture and work within the creative sector. As outlined, this rests on a commitment, one which fosters dialogue and partnerships 'among researchers, practitioners, and policy makers with disability communities [as these] are essential for far-reaching impact on the wide range of constituencies who are or could be involved with the arts' (Keither-Boyd et al. 2018, p. 269).

Disability artivism

Additionally, the PAR model allowed for unanticipated routes to be taken, and creative collaborations emerged as a result. One of these was headed by La Rose (2020), a focus group member, who wrote an article on disability access and the arts in Scotland for Skinny Magazine, in which members of the focus group contributed their views. Another example arose from attending meetings for We Shall Not Be Removed, a UK wide campaign group for ensuring disabled people can access arts and culture post-pandemic. I created an artwork for their forthcoming online zine. Also, from speaking to Clark Reynolds, a NGBTN contributor, about organising an exhibition to mark the 25 years since the inception of the DDA - and to invite more submissions - the conversation moved onto my own artistic work. After mentioning football freestyle, Clarke's interest piqued, and he asked if I could do a work using football as a medium to make impressions on a canvas. This led to creating 'Black Triangle', whereby I did a range of football skills, before placing a painted handprint for each of them on black lino.

This act of 'artivism' centred on how the DDA has been inverted for ideological ends by successive UK governments in the interests of state retrenchment (Mathews, 2017). This, along with post-2010 austerity policies (particularly the welfare-to-work agenda) has led many disabled people to die shortly before or after having inhumane Work Capability Assessments (WCA) (Pring, 2017). Each of the 82 handprints was in memory of people known to have died because of undergoing WCA, receiving diminished social securities or being sanctioned by Job Centre Plus. It could be argued that this unjust policy drive equates to a kind of genocide, which is why the Black Triangle was used - the coding symbol given to 'undesirables', including disabled people under the Nazi occupation. Subsequently, the symbol has been co-opted by

disability activist groups. Below is a picture of the artwork at the exhibition. The video link to the piece being made can be found at: https://youtu.be/jI9TKYt2wrI

Retrospectively, undertaking a piece of work that was not directly related to the research question invariably cut into a tight timeline. In a sense this led to what Noakes and Kelly (2007) term 'gold plating', a process whereby activities that do not relate to the project are taken on, these then protract, and bleed into the main project. In a sense, my decision to create Black Triangle rested on two key strands, one being a feeling of angst that I needed to have things to *show* for an arts-based dissertation. The other primary reason was that I felt it important to take on a political piece of art myself, one which noted the oppressive state tactics utilised to ostensibly reduce state expenditure, and the loss of life which is attributable to political choices. In short, opting to do this work felt right overall, as I believe it necessary to act against social injustices.

Tensions and dilemmas

Conducting the research created some mental tensions, which in part were remedied by theory and conversation. A key question I continually tussled with was this: does experiencing depression, anxiety and PTSD render me a disabled person? Solvang

(2012) argues that some artists with mild and invisible disabilities have difficulties in 'coming out' and disclosing their personal circumstances. Moreover, mainstream cultural representations of disability often focus on visible impairments and this can further marginalise people with hidden disabilities (Grue, 2016). Talking to members of the group about hidden disabilities demonstrated that other people experience similar feelings of trying to prove their conditions to others and that this is mentally draining. I often still struggle over disclosing my mental health difficulties. The social stigma around talking about mental health still feels very real in certain situations. This can be alienating, and feeds into a personal sense of 'imposter syndrome', whereby people can feel they have gained success through fortunate oversights or mere chance, not their own competence (Moore, 2018). A key lesson I took from the dissertation is that manifestations of imposter syndrome are not purely down to the problem of the individual, but that structural and contextual factors are also central in creating these feelings (Feenstra, et al. 2020). Recognising this does not automatically eradicate self-doubt and loathing - such feelings are clearly multi-layered - but it does act as a useful reminder when experiencing pangs of ill-feeling towards myself.

In similar terms, I have regularly questioned my legitimacy for working in paid disability arts roles. On reading Hadley (2020) who outlines different forms of allyship with disabled people and lived experience of disability, things became clearer. 'Allies of convenience' are classed as people who align to disability arts for financial remuneration and/or to further their professional development, doing so without sustained engagement with disabled artists. Regarding levels of lived experience of disability, Hadley (2020) also notes that some people who have relationships with disabled people, or experience unseen disabilities feel they have lived experience of disability, on an invisible level, or by proxy. Personally, I fall into both camps, in that I have relatives who are disabled, and I myself experience long-term mental health difficulties. Moreover, I have been raised to realise the need to fight for disabled people's rights. On reflection, all these factors have proved instrumental in forming my approach and identity on both a professional and personal level.

Awareness of the systemic injustices that disabled people experience has set me on a path to work alongside disabled people, with the aim of highlighting disability issues.

However, as a non-disabled person, I acutely realise the dangers of feeling and stating that I understand the lived experience of disabled people. My background does not automatically equate to having 'special insight into disabled people's ontology, epistemology, perspectives, and views' (Hadley, 2020, p. 182). The heterogenous nature of disability is vast, and many disabled people experience intersectional barriers due to various factors, such as their gender, sexuality, and ethnicity (Berghs and Dyson, 2020). Therefore, believing I have a firm grasp of other people's disabilities, and their personal experiences would suggest ignorance, and potentially lead to speaking *for* disabled people (Hadley, 2020).

Lovett (1982) argues that a community educator's core role includes forming links within communities, developing knowledge, and identifying resources, as these are intrinsic to initiating change. When reflecting on my active position outside of the focus groups, I feel to a large degree, I was acting as a 'fact' finder and building links between disabled artists and organisations. This highlights the importance of active listening and empathising with what people have to say. Whilst I had to make numerous decisions myself, the members and I agreed that making connections and forming alliances can help to bolster a case for CS to seriously consider implementing progressive disability policies. Whether such advancements are enacted, claiming spaces for dialogue is an intrinsic cornerstone for championing change. After all, such spaces 'give us the strength and focus to be able to work in the invited spaces and not become absorbed in the demands of services and policy makers.' (O'Donnell and Sapouna 2017, p.531).

Conclusion

In summary, participatory action research can be conducive to developing policy recommendations, but time constraints can curtail their formation. This is not a reason to avoid undertaking such work in areas such as disability and access to the arts. As shown, there is a great lack of such research and a pressing need to advance change within Scotland's Creative Sector. PAR proved to be a fruitful model for investigating the barriers disabled people face, and for working out possible solutions to some of these. However, one lead researcher doing a dissertation and a small group of disabled artists can only achieve so much on a voluntary basis. Creative Scotland need to not only pay lip service to the barriers and concerns that disabled artists experience, they

need to meaningfully listen and act. Models such as DAC could help pave the way for addressing barriers disabled people face. In the end, PAR enabled unforeseen projects to materialise, projects which helped illuminate barriers that disabled people face within the arts and wider society.

In the process of conducting this research, I went on a personal journey which forced me to ask professional and personal questions. Some of the barriers I face are purely personal, but others are socially constructed and affect many people. Engaging in conversation with others and reading relevant literature can help to ease the cognitive dissonance that often results when social issues are presented as, or conflated with, private troubles. Bearing this in mind, the importance of community educators facilitating and initiating claimed spaces for critical dialogue rings louder than ever before. After all, such arenas can allow for the 'subverting of subversion' (Cornwall and Coelho 2007, p.14).

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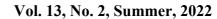
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