**Article:**

Ellis, K. orcid.org/0000-0003-4185-1912 and Sen, R. (2024) Meeting the challenges of participation? Care experienced people’s involvement in social work practice and policy development. European Journal of Social Work. ISSN 1369-1457

https://doi.org/10.1080/13691457.2024.2418874

European Journal of Social Work

ISSN: (Print) (Online) Journal homepage: www.tandfonline.com/journals/cesw20

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**To cite this article:** Katie Ellis & Robin Sen (23 Oct 2024): Meeting the challenges of participation? Care experienced people's involvement in social work practice and policy development, European Journal of Social Work, DOI: 10.1080/13691457.2024.2418874

**To link to this article:** https://doi.org/10.1080/13691457.2024.2418874

EUROPEAN JOURNAL OF SOCIAL WORK
https://doi.org/10.1080/13691457.2024.2418874

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# Meeting the challenges of participation? Care experienced people's involvement in social work practice and policy development

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**ABSTRACT**
Although the last decade has seen policy initiatives in the UK aiming to improve the experiences of children in care and care leavers, most have received criticism for either not involving care experienced people, or for their lack of inclusivity. Indeed, little is known about the extent to which people with lived experience shape practice and policy developments, which reflects a significant gap in our understanding of what trying to make changes to care systems looks, feels and is like from an insider perspective. This paper considers attempts to influence practice and policy from the perspectives of 15 care experienced people who had been involved in substantive public campaign work relating to children in state care and care leavers in Scotland and England. Participants shared their experiences of working to influence change and highlighted good and bad practice that they had encountered working with different individuals and organisations claiming to promote the views of those with lived experience. The paper highlights the motivations, costs, barriers and facilitators for care experienced campaigners working to improve care systems. It concludes by sharing good practice to ensure that participation is properly appreciated, valued, and ethically informed.

**ARTICLE HISTORY**
Received 5 March 2024
Accepted 11 October 2024

**KEYWORDS**
Participation; care experience; policy; activism

## Introduction

This paper draws on 15 in-depth interviews conducted with care experienced activists about their experiences of trying to make changes to the care systems in Scotland and England. We employ the term 'care experienced' to refer to those who have spent any length of time in care as a child. This inclusive term acknowledges the challenges experienced by those who fall outside of statutory definitions of what is a 'care leaver' under the Children (Leaving Care) Act (2000) in England and the Children (Scotland) Act 1995 (as amended) in Scotland. Inclusion of this wider group of people within the category of 'care experienced' is important as '[t]he impacts of the care experience do not end at 18, or 21, or even 25' (Care Experienced Conference Report, 2019, p. 6). While from varied backgrounds, interviewees had engaged in campaigning activities to effect change to the care system in either Scotland or England. Apart from one recent paper on parental advocacy (Saar-Heiman & Gupta, 2024), the perspectives of user activists on their own activism has received scant attention.

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Given its importance for understanding what activists themselves see as the impacts, strengths and limitations of their own activist efforts, and of organisational responses to their activities, this reflects a significant gap in our understanding of what trying to make changes to care systems looks and feels like from an insider perspective. This paper starts to address these gaps by exploring the associated motivations and barriers that are encountered by care experienced campaigners and considers how participation can be facilitated by organisations working to improve policy and practice.

## Literature review

The idea that those receiving state mediated services and care should be able to influence related social policy and systemic change has been prevalent since the 1990s (Beresford, 2010). Children and young people's participation in decision-making was recognised in the United Nations Convention of the Rights of the Child (UNCRC, 1989) and is given further weight by commitments within the Children Act 1989 in England and Wales, and the Children (Scotland) Act 1995, in Scotland. Such rhetorical, ethical and, in some instances, statutory commitments provide a platform for user participation and influence on systemic and policy changes in principle. In practice many gaps persist. Evidence continues to identify that the mechanisms for effectively involving children and young people in decisions – even about their daily care – remain underdeveloped (Diaz et al., 2018). At the level of user influence on policy and systemic change, even greater concern has been noted about the divergence between a rhetoric of inclusivity, and the realities of how policy is shaped in both child and adult services. Beresford (2010) describes how many user-led organisations question state mandated participation initiatives for fear of the co-option of their perspectives without genuine influence. Though Saar-Heiman and Gupta (2024) point to the transformative potential of involving parents with lived experience of child protection services in advocacy, they also acknowledge prior evidence of the co-option of some, radically conceived, advocacy activities by state mandated organisations. Indeed, across the literature one of the most commonly raised concerns is that of 'tokenism': professionally led organisations which employ the discourse of user participation but whose practices are minimally influenced by it (Beresford, 2010; Hill et al., 2004; Lundy, 2007).

While there are state generated organisational structures by which children and young people currently in state care might influence strategic level developments, it has never been a statutory requirement. The UK Government White paper *Care Matters: Time for Change* (Department of Education and Skills, 2007) recommended that Children in Care Councils (CiCCs) be established by all Local Authorities in England in order to give children in care a forum to express their views and to provide opportunities to influence the services and support they receive. A national review of CiCCs (A National Voice, 2011) reported that while nearly all Local Authorities had established CiCCs, there was wide variation in their operation. This ranged from some CiCCs reporting that they had a significant impact on Local Authority practices to others reporting that they commanded far less influence with key decision makers. Similar organisational structures exist in some Local Authorities in Scotland via Champions Boards, which are formal forums for those with care experience, usually up to the age of 25, with a specific focus on improving outcomes for looked after children and care leavers (e.g. The City of Edinburgh Council, no date). However, Champions Boards are not in operation in all Local Authorities in Scotland. While these two structures do offer avenues for some younger care experienced young people to influence policy in their own Local Authorities in the two countries, there is no evidence that they routinely do so across either Scotland or England.

This picture has congruence with evidence regarding children and young people's involvement in service and policy development more broadly. Literature in different country contexts highlights that young people having a 'voice' within a particular initiative does not often translate into meaningful influence on service development or policy formation (Adu-Gyamfi, 2013; Cavet & Sloper, 2004; Lundy, 2007). For instance, Adu-Gyamfi's work (2013) in Ghana considered the impacts of two participatory projects aiming to include the views of young people into youth policy formulation. Adu-Gyamfi found that the focus on gaining young people's views did not itself grant those young people the power to influence policy formulation. Instead, young people who were critical of formal policy suggestions were viewed as ‘insolent’.

Similarly there is evidence that adult users can be engaged tokenistically (Beresford, 2010; Saar-Heiman & Gupta, 2024). Tokenism can exist by design. Some organisations may also begin with genuine intentions but lack the capacities, facilities, structures or cultures to facilitate user-led change (Lundy, 2007; Seim & Slettebø, 2010). Lundy (2018) offers the counterpoint that tokenism can provide a platform from which genuine participation may follow. Nonetheless, the involvement of those with lived experience without their influence on service or policy developments, is also potentially corrosive (Adu-Gyamfi, 2013; Lundy, 2007). It is likely to generate cynicism about a particular participation initiative, and may lead to broader questions about the potential for genuine user influence at all.

There is some convergence in the literature about the pre-conditions for the meaningful involvement of users in influencing systemic change. Authors recommend that organisations demonstrate genuine commitments to user influence on practice and policy (Beresford, 2010; Hill et al., 2004) and provide appropriate training for professionals to facilitate engagement (Cavet & Sloper, 2004). Providing a clear sense of what change has occurred based on the inputs given by those with lived experience has also been proposed as key (Hill et al., 2004; Lundy, 2007). However, the observation of Beresford and Degerickx (2022) tempers these findings by suggesting that the influence of those with lived experience on service and policy development is part of an ongoing challenge and struggle for influence and power.

The majority of the pre-conditions described above understandably emphasise the responsibilities of those in positions of power to respond appropriately when engaging with people with lived experience. This paper will consider another side of this debate and explore the experiences of self-defined activists, with lived experience, working to influence practice and policy. Rather than starting from the role of organisations, we explore user influence that is defined by those with lived experience, rather than ‘granted’ by others. Although there are multiple definitions of activism (McMellon et al., 2023), this paper considers Taylor’s (2022) definition of ‘representative participation in the public sphere’ (p. 7) as one which adequately encapsulates the activism interviewees described in this study. User influence on service and policy development has recently been framed through the lens of activism in regards to children and young people’s participation (Tisdall & Cuevas-Parra, 2022), care experienced people’s involvement in knowledge production (McMellon et al., 2024) and parental advocacy (Saar-Heiman & Gupta, 2024). A thread across these framings is the idea that activism includes more than traditional forms of social protest and can also comprise community organising (Saar-Heiman & Gupta, 2024), online activity (Tisdall & Cuevas-Parras, 2022) and everyday acts of care and relationality (McMellon et al., 2024). There is a risk that extending the definition of activism in these ways reduces its meaning to vacuity, reframing any ‘action’ as ‘activism’. Tisdall and Cuevas-Parras (2022) appear alert to this possibility in suggesting activism as proactive actions that generate ideas *and* make demands for change. This suggestion implies there are parameters to what counts as activism. Drawing on Martin’s (2007) definition, Tisdall and Cuevas-Parras describe activism as actions in support of a social goal that go beyond the routine, and which thereby challenge social norms and the status quo. This framing is wide enough to encompass, under the banner of activism, activities as diverse as traditional social protests, acts of ‘mobilisation’ and ‘confrontation’ (Beresford & Degerickx, 2022), community organisation (Saar-Heiman & Gupta, 2024) and quieter, acts of relationality and care (McMellon et al., 2024). However, there is a *sine qua non* that in order to be classed as activism, the actions need to go beyond the routine, and be aimed at effecting organisational, policy, political or social change.

In summary, in the UK formal discourse suggests the desirability of children and young people in state care and, to a lesser degree, formal ‘care leavers’ influencing practice and policy change within care systems. Yet, scant consideration has been given to these issues considering the more expansive category of ‘care experience’ as an identity which spans the life course from the point of entering state care (The Care Experienced Conference, 2019). Over and above this gap, the literature across children, young people's and adult user involvement in different country contexts suggests that progressive discourse on participation co-exists alongside ongoing challenges via tokenistic responses that militate against meaningful user influence. This paper suggests that the lens of activism offers a useful frame for understanding the potential of user influence which is defined and demanded by those with lived experience, rather than one which is granted by others. It serves to address some current gaps by including the perspectives of activists with care experience in order to consider the motivations, costs, barriers and facilitating factors for those who campaign to change practice and policy on their own terms.

## Study and methods

This study considered the experiences of care experienced campaigners regarding how they had sought to influence change to the care systems in England (n = 10) and Scotland (n = 5). Interviewees were recruited through a mixture of direct approaches to those with public profiles of campaigning, and responses to adverts posted on social media seeking care experienced campaigners in England and Scotland to be interviewed for the study. Three interviewees were women and twelve men – this gender imbalance reflected that a majority who came forward or agreed to be interviewed were male, though a better gender balance would have been preferable. It is not possible to say how the gender balance of interviewees may have influenced our findings. Four activists were from racially minoritised backgrounds and campaigners ranged in age from young twenties to mid-seventies. Semi-structured interviews were conducted which ranged in length from 46 to 85 min. Interview questions focused on interviewees' experiences of trying to make changes to, firstly, local practice developments (changes in practice at a Local Authority wide level) and, secondly, national developments in respect of changes to legislation, national policy or national guidance.

Six interviewees spoke of involvement in activities they classed as activism to change the care system while they were still young people in state care, the rest described that their campaigning activities started after formally leaving care. Campaigning activity had been an attempt to improve care for children in state care and young people leaving care. There was also an acceptance of care experience as a lifelong experience and some campaigning activity had focussed on addressing issues for adult care leavers, such as justice for those who had experienced prior abuse or poor care, or in seeking better support for older adult care leavers.

Ethics approval was granted by the University of Dundee and the University of Edinburgh. All interviewees were contacted with an information sheet prior to interview and asked to consider their participation before formalising their consent. Those who consented received the interview schedule in advance so that questions were expected. Interviewees were given the choice of being entirely unnamed or to be named as a contributor at the end of written outputs by either a pseudonym of their choice, or by their real name. All chose to be named, fourteen by their name, one by a pseudonym. Given that the development of themes and selection of quotations would be, as in any qualitative analysis, dependent on researcher judgement, we did not feel it appropriate to attribute specific quotations to named interviewees. For a similar reason we do not provide individual-level biographical or social characteristic details that could potentially aid identification of specific data as coming from a named individual. Instead, we refer to quotations by interviewee number in the text, and by their agreed name in the acknowledgement section of this paper. Before finalising this paper, we supplied the 14 living interviewees with the key findings to provide an opportunity for comment. We also used this contact to offer interviewees a further chance to opt out of being named as a contributor to the study. Seven interviewees responded to this further contact. All indicated that the findings felt reflective of their experiences, and reiterated their previous wish to be named.

Interviews were recorded, transcribed and returned to interviewees to make additions or corrections: three offered corrections or amendments. A 'codebook' thematic analysis (Gale et al., 2013) was used to analyse the interviews and consisted of initially generating categories from each interview transcript, starting with the interview topics covered. These categories were developed to include data that did not easily fit within the pre-existing topic areas until all interview data was encapsulated by category headings. Overarching themes were agreed collaboratively by the two researchers once data from all interviews had been added. Finally, themes were transferred to a ‘Matrix’ spreadsheet in which each of the themes was mapped against excerpts from each interviewee’s transcript data. The use of the matrix allowed for cross-comparison between the identified themes and individual interviewees’ data, enabling researchers to identify differences, as well as commonalities, in responses. This paper will address issues identified under the theme headings ‘Motivations of Participation’, ‘Impact of Participation’ and ‘Facilitating Activist Participation’ to illustrate the motivations, costs, barriers and facilitators of activism for those with lived experience of care.

## Limitations

Respondents were diverse in background, ages, experiences and career trajectories and drew on a large range of activist experiences in Scotland and England over a number of decades. Although the project was advertised publicly through X (formerly Twitter), our reach was limited by our own social networks and the reach of those choosing to share project postings. To expand our reach, we also approached activists we knew were working to promote change because of their public facing profiles. Our project recruited a relatively small sample of care experienced activists and, as a number of them commented during interviews, they were not representative of all care experienced people in Scotland and England. Additionally, many of our interviewees were working professionals and therefore the voices of those in more marginalised positions are absent from these discussions. Our findings give rich insights into care experienced activism rather than seeking to give a representative summary of it.

## Motivations for participation

Interviewees described an eminent strength of care systems as some of the people who worked within it as carers and professionals. They also unanimously stated that a shortage of resources stopped these systems functioning well. There was a link between interviewees’ views that their national care systems still required large improvements, and negative experiences of care and social work practice which all had either directly witnessed or experienced. Positive experiences of care and social work practice which had been witnessed or experienced were also referred to, but served to highlight that while such good practice could be achieved, it too often was not. The goal of preventing negative experiences of care reoccurring in the lives of children in care and young people leaving care, provided a spur for their activism. Respondent 13 explains:

> I went into care and had a really substandard experience which motivated me to want to improve care for others. **13**

Improving children’s services was described as a key goal of becoming a care experienced activist. It was suggested that worthwhile changes to care systems needed people with direct experiences of those systems to influence decision makers:

> You’re only going to effect change if you can get at the table. I’ve got my strategy, I know what I’m trying to do. **9**

Interviewees generally saw influencing practice and policy developments as a slow, cumbersome process but considered it worthwhile as they believed that targeted working, alongside charities and other care experienced activists, could lead to, and had led to, systemic improvements.

Interviewees also expressed that contributing towards achieving such change positively impacted on their own sense of self-worth and well-being:

> I wanted to be involved in something making a difference for children and young people affected by experiences that relate to my own … It felt really good to raise awareness of how certain decisions can affect young people. **10**

There were though some subtly differing views about the effectiveness of care experienced activism. The literature suggests that public participation yields limited power to change government strategy or policy (Fung, 2015). In contrast, here all interviewees agreed that care experienced activism had in general influenced positive change. Some expressed uncertainty about whether they could tell if specific campaign work had influenced change, or not:

> I do think care experienced campaigners have and can change the whole kind of tenor of debate really and I do think that has value even though there might be some insincere stuff coming from [the national government] off the back of that. I do think ultimately that does effect change. But not in a clear way. **1**

Others were more confident that specific changes to the way that sector organisations now operated could be attributed to care experienced activism, even if the impact of this activism was implied to be gradual and cumulative:

> I think effective ways [of participation] are always through collaboration and engagements with some of the main actors involved in this field … There are a number of care experienced people now who are involved in [a children's charity in England], and [a UK wide social worker member organisation], etc who use those organisations as a platform and help to inform their policy. I think that's a really positive development, I don't recall that being there, say 20 years ago. **15**

This activist explains here how prior campaigning efforts created a space for other care experienced people to subsequently take on positions of influence in relevant organisations. These organisations are ones which themselves lobby governments in respect of changes to practices and policies relating to children in care and care leavers in the UK.

## Pitfalls of participation: exploitation and tokenism

Almost all interviewees described instances in which their goodwill had been taken for granted, or used by individuals in positions of power, or care organisations, to further self-serving agendas:

> You look at the Ministers … it's been 'let me have a photograph with this care experienced young person', [they] move on [and change roles] … the further removed people get from children, the worse they are at valuing those people's voices. **4**

A minority of interviewees recounted experiences when they had been encouraged to share their personal experiences within the care system as part of a campaign or fundraising initiative for charities in ways that later left them feeling used:

> For a little while I was their poster boy. I say that with resentment and disgust, actually, because the way they went about things wasn't very nice. The way they pick you up and drop you can be quite harmful. **13**

Invitations to participate in public events could be experienced as performative when they only occurred at significant times in the year when organisations looked to publicly demonstrate their concern for care experienced people to an external audience:

> Last week was National Care Leavers' week … it felt quite exploitative in a way that our stories were used for clickbait … there is still this culture of wheeling out care experienced people at an annual staff day, share their very sad story and then wheel them out until next year. **8**

Four problematic behaviours could be identified in this regard. First, the personal emotional labour involved in sharing deeply personal, sometimes traumatic, care experiences, could be overlooked. Interviewees described being encouraged to revisit painful events from their past by individuals or organisations who stated that they were working to implement changes in policy or practice. This could include, on occasion, the public sharing of their stories in ways that were felt to be outside their original purpose. One interviewee described disclosing sensitive personal information to a public official in confidence who went on to share it in a televised forum, without their consent:

> I nearly spat my tea out and nearly burnt my shirt. I was like, 'I didn't agree to that'. 9

Second, after encouraging the disclosure of such personal accounts, there could be a lack of follow through in the positions these individuals or organisations would later publicly articulate. This was viewed as demonstration of a performative commitment to change instead of using influence to try to effect practice and policy changes that could prevent similar experiences recurring for another child in care, or young person leaving care:

> People are all over the negative stories and happy to consume that and happy to take from that, but then when it comes to key asks that are in relation to what you've shared, the interest drops off in a way … that kind of commitment is quite frustrating … .. You'll share something quite personal and then people will say, 'keep speaking up about this'. I find that enormously frustrating because actually why should the onus always be on us? It absolutely shouldn't … there should be no expectations at all. **8**

This example raises a third important issue regarding campaigning work with care experienced people. Some care experienced people will not want to engage in any kind of activism and even those who have done so in the past may not want to engage in a particular initiative at a particular time in a particular way, for a variety of reasons. Interviewees reported that organisations sometimes approached them with an expectation that they should want to be involved with that organisation.

Fourth, some interviewees also described feeling disenfranchised when they agreed to use their experiences to work with organisations but their concerns were not then given due weight in the specific initiative they had been invited to participate in. This finding is consistent with concerns raised in the wider literature (Adu-Gyamfi, 2013; Beresford, 2010; Cavet & Sloper, 2004) and was mentioned particularly in relation to involvement in formal organisational decision-making, such as recruitment processes:

> What annoys me is tokenism – and tokenism is the easiest form of ticking the box, hitting the target and missing the point, if you kind of go 'oh well we've got to have a care experienced interview panel, but we're going to give them 5% of the vote' … if you're going to do it, do it meaningfully. **4**

## Facilitating activism and promoting best practice

Interviewees shared instances of good practice and made suggestions for organisations to better support people with lived experience. While a minority described initially working independently to effect change, all viewed collective, public, activities as an essential component of campaigning. This included online activism in order to enable disparate people to mobilise and petition for change collectively. Working together was framed as means of amplifying voices to achieve greater impact:

> I realised quite quickly that my voice was amplified a millionfold by having that kind of togetherness and shared purpose … if you are organised and if you have opportunities and people supporting you then you can get change as we have done over the last few years. **11**

All interviewees described visions of transformative change within the care systems in Scotland and England, but some were also keen to highlight that policy development and systemic change are often built from smaller incremental changes. These interviewees also spoke of the need for organisations to be clear about the scope of possible policy change when first brokering care experienced people's participation, a point previously made by Hill et al. (2004). One of the more experienced activists spoke of the need for care experience activists to recognise progressive change as a 'long game', where disappointing organisational responses were part of an ongoing struggle for social justice. This perspective suggested the need for both organisations and care experienced activists to balance a focus on achieving transformative change, with recognition of the realities of what is likely to be achievable within a particular initiative:

> There's a long game here that will last for several years … it's an agenda for change … I see it as something that can be a campaigning tool so that the good things in that [campaign] can be picked out and campaigned on for the next few years at least. So, rather than seeing that as something that's happened and it's going to disappear; it's not, it's out there. **15**

Participants also indicated how framing their participation as a demand for influence (Tisdall & Cuevas-Parras, 2022) could enable organisations to better understand the value of care experienced people's engagement. This point was reiterated by those who argued for recognition of the individual skill sets campaigners bring in addition to their earlier care experiences:

> [we need to be] really good at influencing leadership and helping them understand actually the skills, gifts and assets that people with care experience can bring to the work, rather than selling a sob story of, 'oh you know you need to change this because' … I'm not some poor wee disadvantaged soul – I haven't been that for a long time. **6**

This interviewee described instances in which they had recruited other care experienced people to contribute to practice and policy debates. They pressed the significance of providing high quality support to enable others to present their insights in spaces that were new and unfamiliar:

> If we want to bring people with lived experience into the implementation space … we need to prepare and train them for it … It's one of the things we constantly advocate for – and we don't really do work unless that's included in the budget. **6**

In addition to support and training before an engagement initiative, other interviewees highlighted the importance of preparing activists for the end of their involvement in an initiative:

> A lot of care experienced people … [are] suddenly catapulted into this huge stage … that's taken away from you as soon as the [initiative] is concluded. I just think that's really harmful. It kind of left a lot of people thinking, 'What now? What do I do next?' I was quite disappointed. **12**

In line with recommendations about how best to facilitate the contributions of others, interviewees shared examples where their participation was supported thoroughly, both before and after consultation. Seeing how insights from their experiences were genuinely taken on board by professionals helped to show how the effort of sharing them was sincerely valued:

> I felt very included, I watched other people be very included … it was never going to be easy [for professionals] hearing those really difficult things about your profession … [they] did really, really well to navigate that, and to walk alongside everyone – and they're still doing it. **6**

While interviewees expressed their willingness to contribute to campaigns focussed on improving services for children and young people in care, it was viewed as good practice to pay those termed as 'experts' for these contributions at an appropriate professional rate. Financial recompense was appreciated in its own right but also signalled that contributions were valued:

> [T]hese young people that come in are being treated as experts and told they're experts but not being paid for their time like they're experts or being actually treated in the room like experts … pay them for their time to recognise that contribution. **7**

Interviewees also expressed a willingness to contribute without payment, as long as the purpose and terms of the engagement were clearly articulated at the outset, and interviewees were able to see value in the work which was proposed:

> I value research, and I understand the importance of research, particularly like this. And if we do something like that, we would speak to people and tell them 'this isn't paid because' … and really help them understand why … they will still come. **6**

Where finance is not available to pay care experienced experts in the way they deserve, interviewees suggested organisations should offer other forms of recompense that those people would find valuable and which, in turn, would signify that their contributions were valued:

> What you could do is really invest some time in that person, help them develop their presentation skills, and help them to deliver the session. If you're going to be meaningful about valuing their experience … give them something back, which is your time and effort in building their skills. **4**

## Discussion

While literature considers that practice and policy do benefit from the learning provided by those with lived experience (Askheim, 2011; Cavet & Sloper, 2004; Morison, 2017), our study shares the perspectives of individual activists to consider the factors that have facilitated or restricted contributions to changing practice and policy. The data presented illustrate the impacts of campaigning on activists themselves and explore some of the complexities around speaking out publicly to effect change based on lived experience.

The accounts of the activists in this study reinforce how strong the contemporary imperatives are for organisations to be seen to engage the 'care experienced voice' in participation initiatives regarding the care system. While such a discursive space allows opportunities for genuine influence (Lundy, 2018), the challenges of tokenism continue for care experienced activists, as in other areas of user participation (Beresford, 2010; Hill et al., 2004; Lundy, 2007). At one level this may be unsurprising if user influence on service and policy development are located within wider societal power relationships (Hill et al., 2004) and ongoing political struggles for influence over the direction of practice and policy (Beresford & Degerickx, 2022). Indeed, interviewees themselves recognised some of the complexities of their attempts to influence policy. While their accounts spoke to the essentialness of foregrounding care experienced people's perspectives within practice and policy developments on care systems, there was recognition of the multiple, sometimes competing, factors which influence policy. This realism on their part further highlights the need for organisations engaging with care experienced people to be as candid as they can be about what change is likely based on a care experienced person's participation with them (Hill et al., 2004): this includes transparency where they themselves are uncertain about what impact a particular initiative might achieve. From their experiences of trying to make changes to the care system over time, activists recognised some of the limitations to what influence they, or care experienced people as a group, might expect to exert. But there was also a strong suggestion that newer care experienced activists – including in some cases their younger selves – may not have realised this at the outset of their campaigning careers, creating the conditions for later disillusionment if organisations did not do their bit to prepare activists for the 'long road' of policy change ahead.

The findings also indicate cause for concern that organisational responses could be costly for care experienced activists in a way that was both predictable and avoidable. At worst interviewees recounted painful personal experiences of feeling used by organisations without regard for their individual welfare, or awareness of the emotional trauma that can arise from re-visiting difficult past experiences of care, particularly in a public space. Some interviewees' accounts were even suggestive of 'organisational betrayal' whereby institutions fail to respond appropriately to prior interpersonal trauma, thereby re-opening or deepening it (Christi et al., 2024). It was striking to us that some similar criticisms were made of organisations who were seen to have adorned their public events with 'a care experienced voice' in the most performative of ways, and organisations who were considered to be doing important work in their field to effect genuine change to care systems. The latter organisations were, though, described as paying insufficient attention to the welfare of individual care experienced activists when seeking to engage them in organisational campaigning or promotional work.

Given these experiences, interviewees strongly advocated for significant training and preparation for care experienced people prior to their actual involvement in a given initiative, especially those new to the campaigning space. Without it, the risk is that user participation becomes, to use Seim and Slettebø's (2010) descriptor, a 'facade'. However, the activists in this study also emphasised the need for organisations to offer follow up, checking in or aftercare support to activists with lived experienced *after* an engagement initiative: the latter issue is currently scantily covered in literature on user participation initiatives.

User participation can strengthen and improve administrative and professional systems (Seim and Slettebø, 2010). The activist narratives here also suggested that personal benefits and opportunities for individuals could arise from activism. As previously illustrated by Schön (2015), interviewees in this study all described some link between their prior experiences in, or of, care systems and their motivation to try to improve them. The framing of activism as a demand for influence (Tisdall & Cuevas-Parra, 2022) was consistent with how interviewees conceptualised care experienced participation in practice and policy development, although some cautioned of the need to work incrementally with those in positions of power to exercise such influence as well. A few interviewees spoke of working to support younger care experienced people to see campaigning activity in this way, and described how understanding participation as a demand for influence could be of value to both activists and policy makers. Such an understanding was tempered, for some, by the sense that it was necessary to be in the right forums to be able to influence service development and policy change. The differences between approaches seeking to exert 'soft' influence and those more publicly, and perhaps confrontationally, talking 'truth to power' are ones that run through the history of activist movements, including user-led participation initiatives in the social welfare sphere (Beresford & Degerickx, 2022). The tensions between these strategies could be identified in some of the different views expressed by interviewees in this study, and sometimes within an individual interviewee's account. Despite framing their activism as a demand for influence, a number of interviewees were also critical of expectations that they should speak out about their experiences if approached to do so. Prior research centring the views of those with care experience shows how many have felt stigmatised by individual and institutional responses to their care backgrounds (Baker, 2024, Ellis & Johnston, 2024). As a result, some may want to refrain from publicly sharing their care experienced identity (Dansey et al., 2019), or refrain from doing so in a particular moment and context that is not of their own choosing. It is important that organisations work sensitively to ensure that their engagement practices are voluntary and non-coercive. It is also important that they foreground the individual well-being of care experienced activists they engage in addition to the important end goal of influencing change within care systems.

Despite previous claims that activism can yield limited results (Adu-Gyamfi, 2013; Beresford, 2010; Cavet & Sloper, 2004; Fung, 2015), interviewees were all of the view that care experienced activism could, and sometimes had, made a difference to service and policy developments within the care systems in their own countries. Some activists expressed more uncertainty about the direct influence of their own, or other care experienced people's, specific work on a given campaign. Perhaps this reflected, in part, a reluctance to claim personal credit for progressive changes when it is hard to estimate the impact of campaigning activities on those in positions of decision-making power in care services or government. The messiness and opaqueness of these decision-making processes mean it is hard to know whether or not a particular initiative, or campaign, has directly influenced change. Nonetheless, all interviewees strongly believed that care experienced campaigners had positively influenced the overall direction of travel of services and policy development, despite this opaqueness. Seim and Slettebø (2010) note that participation without power to influence outcomes is likely to result in a performative show of 'user involvement' rather than effecting real change. Other work though (e.g. Askheim, 2012) indicates that the very expression of users' views can be a powerful mechanism for challenging attitudes and disrupting stigma. As such, even those interviewees in this study who were more hesitant about making claims for individual campaigning efforts believed that care experienced activism had, in the words of one of them, 'changed the whole … tenor of debate' in respect of developments within care systems. Other activists provided specific examples where they believed care experienced activism had more directly influenced service, policy or legislative development. Again, there was nuance in that these interviewees also suggested the subsequent difficulties of trying to ensure that any changes were implemented as promised and intended, particularly in an era of endemic resource shortages.

## Conclusions

This paper has considered the perspectives of care experienced activists who have campaigned to make changes to the care systems for children and young people in Scotland and England. Although a number of care experienced activists are associated with influencing changes in practice and policy, their experiences of contributing to campaigns to improve care systems have been widely ignored by researchers and the policy sector. We hope that this paper acts as a conduit for an enhanced consideration of this topic within the academic, practice and policy spheres and that careful thought is given to improving the mechanisms for the inclusion of people with care experience in practice and policy development work.

While the findings illustrate how insider knowledge of care systems has the potential to strengthen practice and policy developments, long-standing concerns about the willingness of those in positions of power to meaningfully share power with people who have lived experience were in evidence in the accounts shared here. These campaigners also spoke of times when they, or other campaigners, had been able to find the space to nonetheless exert some influence over the direction of services or policy. Some interviewees also voiced caution that campaigning efforts, as Beresford and Degerickx (2022) suggest, can be subject to setbacks and institutional subversion, as well as achieving gains.

The findings also highlight challenges that care experienced campaigners encountered with some organisations who sought to showcase care experienced voices. The expectation that they, or other care experienced people, would not only agree to be involved but do so by sharing previous traumatic experiences as part of their involvement was found to be especially problematic. This expectation needs to be addressed by organisations seeking to engage care experienced people in their work: care experienced people have no duty to speak out, and if they choose to do so it should be on their own terms. While the personal stories of care experienced people are undoubtedly powerful campaigning tools for sector organisations doing important work to influence positive change, it is vital that they also foreground the individual well-being of those sharing their experiences, offering appropriate support afterwards, as well as before and during. Beyond the sharing of personal stories, the experiences of campaign work described in this paper reinforce the importance of organisations who engage care experienced people demonstrating the value of this involvement back to them. This necessitates, at the very least, organisations articulating back to those care experienced peope they have engaged what change has occured as a result of the work they have been involved with, alongside acknowledgement of any recommended changes which were not possible to enact, and why.

## Acknowledgements

We dedicate this paper to the memory of Ian Dickson, who was an inspiration to many seeking to improve the care systems in the UK. Ian was also one of the interviewees for this study. He passed away in late 2022 and his loss continues to be felt. We also extend our sincere gratitude to the 14 other care experienced activists listed below, who generously shared their time and expertise for this research. We appreciate your knowledge and insight and admire the campaigning work that you do. Please note names are listed below in alphabetical order and the listing order does not reflect the interviewee numbering used next to data excerpts in the main body of the paper. CJ Hamilton, Charlotte Armitage, David Akinsanya, David Anderson, Ian, Jim Goddard, John Radoux, Jonny Hoyle, Mark Kerr, Mark Ormerod, Phil Frampton, Rebekah Pierre, Shumela Ahmed and Terry Galloway.

## Disclosure statement

No potential conflict of interest was reported by the author(s).

## Funding

This work was supported by British Academy.

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