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Critical reflections on public involvement in research: Involving involuntary recipients of social services to improve research quality

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Abstract

Public involvement in research has become a common feature of the research process across health and social sciences. Public involvement means that people with lived experience of the research topic advise on, and sometimes co-produce, any or all stages of the research process from setting the research agenda through to dissemination and impact activities. Social work research has an established record of public involvement, but the literature on involuntary recipients of social services, such as child protection services, is limited. This article reflects on a standing research advisory group of parents in a large children's social care university research centre. All parents in the group have experience of the child protection process. Parents and staff have co-written this article, which engages thematically with critical debates in the literature on public involvement relating to ethics, quality, and impact, and practical barriers.

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Introduction

At its simplest, public or service user involvement in research means 'service users/survivors will actively participate in the *research process* rather than simply being research participants or sources of data' (Sweeney and Morgan 2009: 26). This type of partnership is a widely accepted principle in social work research, service development, and service delivery but, as we argue in this article, is under-developed when it comes to involving those whose contact with children's social services has been of an involuntary nature; specifically, parents with experience of child protection and care proceedings.

This article describes and analyses the work of the parents' group in CASCADE Children's Social Care Research and Development Centre (known as 'CASCADE') in relation to barriers and criticisms of public involvement in research. As group members and staff, we have considered the identified challenges and criticisms and reflected on how they relate to our experiences of developing and operating a public involvement group over a three-year period. This article outlines our reflections and aims to bring further knowledge and analysis to this still-developing field.

CASCADE is a large research centre, with a portfolio of £20 million of funded research over the last decade. CASCADE has had public involvement of those with lived experience of social care at its heart since its launch in 2014. Much of that public involvement work has involved young people who are care-experienced. In recent years, we have developed our public involvement work to involve parents who have experience of child protection services in our research programme, of whom several have had their children removed on an involuntary basis.

In this article, we note that in addition to a flourishing literature describing the benefits of public involvement in health and social care research, there have been critical discussions that have raised matters of ethics and usefulness, as well as practical and resource barriers to authentic public involvement. We have structured our thematic sections to respond to those critiques, noting where our experiences lead us to concur with those critiques, as well as where we argue that we have found ways of overcoming them. We argue that some criticisms regarding representation and meaningfulness may be overcome by partnering with individuals who have had involuntary contact with social services in an ongoing, or 'standing' group, while other common challenges remain within our work, as described in this article.

Authorship

This article is written by seven members of our parents' group and three members of our centre staff, two of whom are employed as public involvement staff and the third as an academic. We have different experiences of engaging with academic and other texts and therefore have contributed in different ways. The social work academic staff member has made contributions on how our work can be seen to sit within existing literature and critical debates on involvement. Involvement staff wrote the staff reflections on how the group was established and operates. The parents' group held three discussions about what they wanted to say about the group, and to continue to develop the article. Parents who wished to become more involved as co-authors reviewed and revised the article through further sessions in which draft sections of the article were read aloud. The final full draft was audio-recorded so that all members could review it before submission. This article therefore developed through verbal and written discussion, evolving until we were all satisfied with the content. We have distinguished between parents' experiences and reflections and those of staff in the thematic sections of this article, because it became apparent that this was the best way to display different experiences and to retain our authentic ways of expressing ourselves.

Terminology

We use the term 'people with lived experience' in this article. Lived experience is more accurate than 'consumer' or 'user' when involvement with social care services has usually been involuntary and 'people with lived experience' is a commonly used term in social work practice and research (Beresford et al. 2023) and serves to distinguish these experts from those whose expertise arises primarily from their professional or academic experience. Sources of people's expertise become more complex when, as in our research centre, some professionals and academics also have lived experience of social care services, and we have set out internal guidance on how to refer to each other's expertise and roles in the centre.

In terms of roles in research, terms vary hugely and can include 'service user researcher', 'expert by experience', 'peer specialist', 'academic user researcher' (Wallcraft et al. 2009: 9) and 'public contributor' (Farr et al. 2021). In CASCADE, we generally refer to 'members of our public involvement groups' and 'people with lived experience'. We additionally use the term 'peer researcher' when individuals are *employed* as part of the research team because of their lived experience. In the parents' group, members and staff tend to refer to participants as 'parents' or 'group members'. Later in this article we discuss the associations of the label 'parent' for some members.

Involving people with lived experience in research

Public and patient involvement (often shortened to PPI) in research is important for a wide range of reasons, including commitment to a value-based approach to research, to support citizens' human rights to freedom of expression, fair treatment and non-discrimination, to improve the quality of research and because it is now almost ubiquitously expected by funders (Sonuga-Barke et al. 2024). Collaboration and involvement have a long history as an ethical principle in social work research (Butler 2002). It is also an expectation in social work practice (Social Care Wales 2022), as well as legislation, such as the Social Services and Well-being (Wales) Act 2014.

A range of benefits for research quality have been identified including improving research relevance, accessibility of research materials, sensitivity to ethical considerations, improving analysis and recommendations, and aiding dissemination (McLaughlin, 2010; Brett et al. 2014; Greenhalgh et al. 2019). Becker et al.'s (2010) study of 251 social policy researchers found that beliefs that service user involvement improved the quality of all stages of the research process were widely (but not universally) held.

There are also benefits for those involved, including improving self-esteem, feeling respected, and contributing to improving services (Cossar and Neil 2015; Foster et al. 2021). This is particularly important for those who have experienced social care services as disempowering and traumatic.

Lived experience of child protection services

Health services are used by people of all income brackets, educational backgrounds, and professions, whereas social services are concentrated amongst the most disadvantaged in society. There is a risk of stigma attached to using social care services, particularly in settings such as child protection and some mental health interventions.

On top of material disadvantages, parents involved in child protection services are likely to have experienced trauma in their own lives, and many will have been involved with social services as children, often because they themselves experienced neglect or abuse. Many parents will also have a general mistrust of authority figures (Roberts 2021). As Foster et al. (2021) found when involving people with lived experience in a study of homelessness and substance misuse, years of experience of power imbalances and traumatic experience means that those supporting the group had to have a good understanding of trauma and a sensitive approach.

All of this means that involving parents with experiences of child protection services in research governance and strategic advice requires a tailored, supportive approach.

Involving parents who have had involuntary contact with social services in research

Mental health and learning disabilities service users have, over several decades, been involved in, and led, at a grass-roots level, research stimulated by their own poor experiences of services in health and social care (Beresford 2009) and there is an increasing body of work on the involvement of those with experiences of social services in research (Beresford et al. 2023). However, it is rare to find published accounts of research involvement with parents who have had involuntary contact with social care services.

An exception is Cossar and Neil's paper (2015) where they reflect on the process and impact of involving birth parents in an adoption research study. They had to distinguish between a support group and an advisory group and work with some parents individually. Important advice included that signing consent forms might feel too close to signing forms for their children to be adopted and that instructions that you do not need to answer all questions sounds a bit like a police caution when being arrested. Changes to the analysis were made when parents challenged assumptions by researchers on the meaning of terms such as 'coping' and 'acceptance'. Additionally, in a co-authored paper of academics and parents with social services experience, Haworth et al. (2022) reflect on working together to produce evidence for an English care inquiry, and the importance of the process having policy aims rather than knowledge production alone.

While other studies certainly will have involved parents with lived experience of involuntary social services involvement in advising their research (e.g. Mauri 2023), accounts such as Cossar and Neil's that reflect on the process are much rarer than the many accounts of involving people with other types of experiences in research. This article aims to contribute to this literature.

Models for public involvement in research

Through a systematic review and Delphi prioritization exercise, Baines and Regan de Bere (2018) identified essential PPI principles to be equal partnerships, providing the right support and training, clear communication, listening and responding, evaluating and accommodating diverse needs.

Greenhalgh et al. (2019) found a plethora of frameworks when conducting a systematic review relating to PPI in health research. In total, 65 ‘toolkits, tools, frameworks, checklists, benchmarks or maps for informing, guiding, assessing or reporting on patient and/or public involvement in research’ (p.788) were retrieved from the literature. Their taxonomy of frameworks showed that there are frameworks that focus on analysing and acting on power differentials, priority-setting for research, study-focused frameworks (how to meaningfully involve the public in specific studies), frameworks for how to write up involvement in reports, and, lastly, partnership frameworks that relate to governance, accountability, and training. Greenhalgh et al. (2019) note that many frameworks relate to involvement in individual studies. In social care research, as in health research, it is common for service user involvement groups to be set up to advise on specific projects and to cease when the project ends. This has an advantage in ensuring that people are involved who have specific expertise for the study and a larger pool of people can be supported to be involved overall, but the potential disadvantage that members do not have the opportunity to develop skills over time if the project is a short-term one. This single-project model is also deployed in CASCADE, but our parents’ group is different, in that it is a standing group of parents who have advised on multiple studies and who have additionally had some involvement in the governance of our research centre, including advising on research priorities and the conduct of our public involvement and public engagement work.

Continuum of involvement activity

People with lived experience of the research topic may be involved at all stages of the research process from priority-setting through to dissemination and evaluation of the impact of research, although it is common for PPI to be concentrated in the earlier research stages (Dawson et al. 2018). Based on a simpler and more positive version of Arnstein’s ladder, Hanley et al. (2003) categorize involvement as consultation (of), collaboration (with), and control (by), with these not necessarily hierarchical, but an acknowledgement that different approaches will suit different projects. Sweeney and Morgan (2009) include ‘contribution’ as something more significant than ‘consultation’, for example including the employment of user-researchers to conduct interviews, but where decision-making continues to rest with researchers.

The CASCADE parents group

This section describes our group, how it was set up and its everyday functioning, before continuing with a discussion of critiques of PPI, and how our group is positioned in relation to those debates.

Our parents' group is a 'standing' (i.e. continuous) group within CASCADE research centre. Most literature on PPI assumes involvement in single research studies, but some research centres involve users of services in standing advisory groups or as members of part of their governance structure (for example, Green et al. 2023). Parents' group activity has spanned most of the levels of involvement described by Hanley et al. (2003) and Sweeney and Morgan (2009), including consultation, contribution, and collaboration. To this we add employment as peer researchers as will be described below.

Nonetheless, we do not claim to have enabled research that Hanley et al. (2003) would describe as 'control' in their typology, in that we have not enabled parents to *lead* a funded research project, where the 'locus of power' (Sweeney and Morgan 2009: 27) is with parents in terms of decision-making and direction of a project, potentially including funding decisions—yet. However, we plan for this to be part of the next stage of our Centre's development. The range of our group's activity is displayed in Fig. 1.

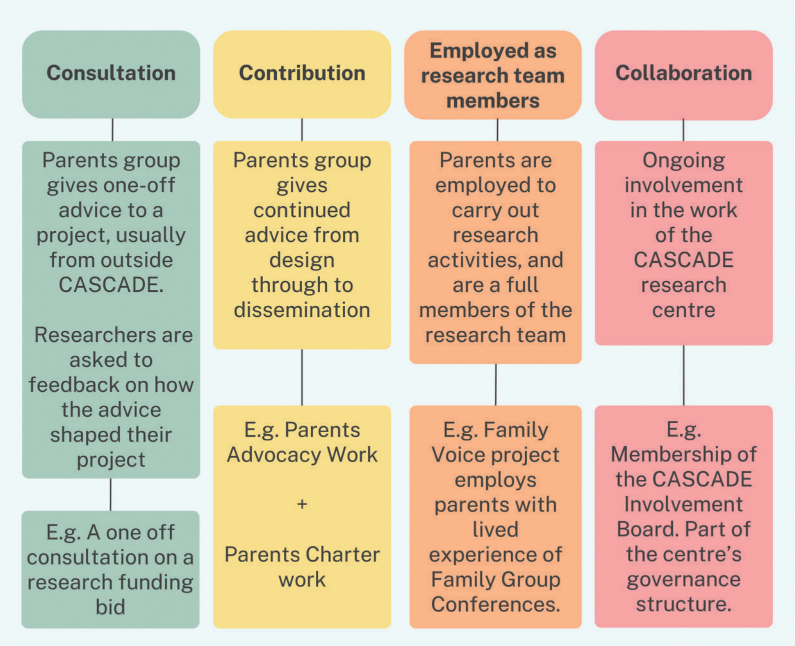

Figure 1. Spectrum of activity involving parents with lived experience of the social care system in CASCADE. These activities are grouped under four headings: consultation, contribution, employed as research team members, and collaboration. In each category there is a definition of the activity and an example of it.

How our group works

Starting up

Our group started in 2021 and was set up to respond to a growing need within our centre for advice and involvement by parents with experiences of children's social care services.

Parents' reflections

It started in the pandemic, and it was really great to do some work and communicate with people outside of the family bubble and get our brains working. Starting online helped, as meeting in person might have been too much but it was good when we met face-to-face for the first time in 2022.

Staff reflections

Our recruitment remit for the group was wide, open to those with some lived experience of social services interventions as birth parents. Those that we recruited were all women, all had child protection experience and many had had a child, or children, removed temporarily and some permanently.

Our initial meeting focused on setting boundaries and expectations. We discussed what the group was, and what it was not (e.g. it was not a support group). We explained how we thought it might work, with different researchers coming to talk about projects and asked what the parents thought it would be useful to know before, during, and after meetings. We settled on monthly meetings.

Everyday functioning

Staff reflections

Once the parameters for how we would start working together as a group were set, we slowly began introducing research projects to the group. Parents continue to offer advice to researchers in all stages of the research process to help to ensure the research is appropriate, relevant, and sensitive to the needs of the population it is focused on. Outside of specific research projects, parents suggest topics they think should be of focus for new research undertaken by the centre, which we promote to researchers.

Parents' reflections

We have been able to contribute to many research programmes and to see how you could really make a difference without having any qualifications. It's honestly quite amazing when you get to an end of the year and realize just how many projects you have been able to take part in. We really enjoy the time when we do meet up in person, but we also really appreciate the fact that we are able to jump online and chat away about some amazing fascinating facts and then just go back to our normal everyday lives.

We have come from so many different backgrounds and experiences. It has been fundamental to get the ideas and experiences from all the members. CASCADE has worked with parents, late in the evenings, to fit around us. It is not just 9–5. We have researchers coming online at 7 pm, so between Emmerdale and Eastenders [*soap operas*]! We can join in our pyjamas! No one feels left out. Fundamental about this group, is the way we all work together. You don't always have to say something. You can just listen if you want. You can also feed in afterwards on email or text.

Debates about service user involvement in research

So far in this article our review of the literature has presented a fairly positive picture of public involvement in research. However, there are many barriers to effective public involvement, alongside some important criticisms that cause us to pause and reflect on the purposes, practices, and claims made for public involvement. We therefore continue our discussion by outlining these debates and reflecting on how they relate to our experiences of developing the parents' group, under the following themes: ethics, quality and impact, and practical barriers.

Ethics (1): power imbalances

A common criticism of public involvement in research is that while making claims of involvement, partnership, and co-production, it fails to address the fundamental power differences between researchers working in universities and members of the public (Cowden and Singh 2007). In social work research this could be a particular barrier, due to the many economic and social challenges that people with lived experiences of services often face. For our group in particular, members additionally face lived experience of the power imbalances between social workers and parents in the child protection system (Dumbrill 2006).

In a similar vein, reporting on a study of researchers, practitioners, and public contributors involved in health research, Farr et al. (2021: 3) report that sharing power can be seen as a 'rhetorical device' to mask inequalities that are almost impossible to break down entirely. Their findings remind us there are many forms of power, including more subtle, such as language and beliefs about whose knowledge is valued. Meanwhile, Becker et al. (2010) divide social policy researchers into three camps on its uses: advocates, agnostics, and antagonists. In their study, the minority of their 251 respondents who are antagonistic towards service user involvement express a range of concerns including that it might exploit vulnerable people.

Such concerns touch on issues we have tried to work with in our parents' group, particularly a desire to ensure the work is authentic and disrupts some of the power imbalances experienced by our members over the years.

Parents' reflections

Even though it is professionals and non-professionals it feels like we are the same. We love the fact that the professionals do not take over. We are not going to know everything as we are not professionals, but our experience comes first. Whether you're a member of staff or whether you are a participant you do not feel any different. The researchers have all treated us with respect.

We have been with other groups, where it is like 'this is so and so', you are there just for a tick box. You are the 'service user'. We think it is so important that this is a safe place to talk about something that is so difficult or such a stigma. Sometimes with everything that has happened, you feel like you have the plague. To feel that inclusivity in this group is powerful. You have also helped us break down barriers by providing us with equipment.

Staff reflections

We do not claim to have removed power differences between university staff and members of our group. Differences in economic circumstances, experiences of services, and formal knowledge of research are evident. However, we have tried to reduce these by increasing our group members' confidence in the process through training, building trust through an informal and flexible style, ensuring members are paid for their expenses and time contributed and ensuring that the researchers they advise provide accessible information and are accountable for what they do with the advice received. As part of our reviews of the group, we check in with members about what they want to get out of being involved, to ensure that they are benefitting in the way they hoped.

While our aim is to create an environment which levels any power imbalances within the group, it is important to acknowledge that we are paid a wage to be part of this group, and the parents are essentially volunteers. There is also a difference in the way experiences are shared within the group, from the perspective of a parent group member as expert, or a staff member, as facilitator. Although we do share our own life experiences as staff to a certain extent, we always do so with an awareness of the need to share within the boundaries of our roles within the group as facilitators, rather than experts. This is another challenge, which we try to continuously be aware of and work on, whilst recognizing that we don't have all the answers.

From the beginning it was clear that for many in the group, this was a new experience. It was new in two key ways. The first was that talking about research was new to almost all members. This meant that for everyone to be meaningfully involved in discussions, we needed to offer training and to think about how to present the information. The second was not a surprise, but was quite stark, which was that we were offering an opportunity and space to come together and discuss child protection research, and many felt they had not been listened to in a very long time, if at all. Several members of the group were also not used to sharing experiences for fear of stigma and discrimination. The research we discuss is necessarily relevant to the topic of social services. This can be an empowering experience for parents, who have told us they value the opportunity to turn their experiences into something positive, but it also means that sometimes it can be quite emotive. We've had to build trust, mutual respect, group methods, skills, and confidence over time, and this has been enabled by having a standing group. The fact that group members have suggested changes to the group, given critical feedback at times, and have had the confidence to present their views and experiences to external audiences may indicate that power differences are not as stark as some of the literature cited in this article.

Ethics (2): diversity, representativeness and involving people with challenging lived experiences

Further ethical issues relate to which members of the public are involved in advising and collaborating in research studies, with concerns raised about lack of diversity leading to the full range of experiences of a service, social experience, or health condition under study not being properly represented (Becker et al. 2010; McLaughlin 2010; Dawson et al. 2018, Farr et al. 2021) Wilson et al. (2015) note that in health research, public contributors are often professionals and academics, and Cowden and Singh (2007: 16) argue that there develops a set of 'professional users' that does not include those who would be more difficult or uncomfortable to listen to. In contrast to this, Boylan et al. (2019) highlight that the difficult experiences often shared by people with lived experience can be difficult for researchers. Interestingly, in Boylan et al.'s study, the potential emotional toll on other group members with lived experience is not included in their findings, but this is a risk that we have paid a great deal of attention to in our Parents' Group.

Staff reflections

It is clear that our group members are not 'professional users' as described by Cowden and Singh, however when groups like ours reach out to 'seldom heard' members of the public there is a need to ensure additional safeguards to protect their emotional safety. Our group members have experienced stigma and trauma. We ensure that, although flexible, there is a structure and focus to our meetings. We are clear on what we are talking about and why. This way, if difficult topics come up, we can manage the conversations and refer back to the research we are supporting or commenting on. Individual members can also ask for a debrief after meetings, and most have taken this up at some point. Our practice is relational, and our specialist staff make a real effort to get to know everyone and make sure sessions are respectful of people's experiences.

Recovering from any form of trauma is not linear, nor is time alone a cure to the struggles this can bring. There have been many individuals from the group who have experienced difficult times while engaging with the group. These difficulties have taken on many forms and have affected individuals in a range of ways but can throw group dynamics off-kilter and create friction. Getting the balance right in these circumstances is a challenge for everyone involved and it can have an impact on the other members of the group. This is largely mitigated by a clear focus for each session on the specific research topic or discussion point, and experienced facilitation. However, we consider this to be an ongoing challenge for staff and group members.

Importantly, when members have shared difficulties, they have received support, understanding, and empathy back from group members. The role that mutual respect and empathy has played in developing the group cannot be understated. While members of the group don't always agree, and we have definitely had some difficult meetings, they are the first to jump in to support each other with words of encouragement and understanding.

On reflecting on their involvement in our group, a key point raised by members was that in other groups they had attended, they had understood that they could not say anything negative about a service or organization. They felt this was a sign that those organizing the group were not really interested in their views or in making any real change. In contrast, they felt the group environment we have created, with its independence from any statutory or support organizations, was a space where they were encouraged to contribute a range of views. The mutual respect created in the group meant they could contribute without fear and were confident they would be listened to and valued. However, we are also aware that we have safeguarding duties as raised by our parent co-authors in the next reflection.

Parents' reflections

Talking about personal things can be hard sometimes. We know we don't have to do that, but sometimes we want to. We have a challenge that if someone is still going through it or being involved with social services, this can be challenging for trust. If something happens in a group, staff will have to report it. We want to have this open and safe space, but that is not guaranteed.

Sometimes we talk about quite difficult things in the meeting, and then you kind of feel like you're in a bubble after it's finished. It is good to know that staff are there if we need to chat about it. During work times, we can always text or phone if we need to.

Quality and impact

Our next theme relating to critiques of PPI is quality and impact. Evidence on quality and impact of public involvement is an underdeveloped field and evaluation of it is rarely built into a research design (Boylan et al. 2019). Wilson et al. (2015) found in a scoping study that public involvement was often under-reported and was unacknowledged in some publications.

A further criticism of quality has been that some researchers are reported to harbour doubts that public contributors can improve the quality of research studies as they lack expertise in research (Becker et al. 2010; Boylan et al. 2019). This leads to feelings that PPI can be tokenistic and lacks depth or meaning (Pandya-Wood et al. 2017). Indeed, the health researchers in Boylan et al. (2019: 722) study note a 'cycle of tokenism', where researchers who are unconvinced about its effectiveness do public involvement half-heartedly, which in turn leads to ineffective public involvement, reinforcing their beliefs. Cowden and Singh (2007: 15–16) argue there is a risk that,

> The voice of the User becomes a fetish—something which can be held up as a representative of authenticity and truth, but which at the same time has no real influence over decision-making.

Parents' reflections

With everything some of us went through there had to be a reason, none of it made any sense. Working for CASCADE to try and better things has given us a purpose. What we are trying to change is massive, but this has shown that we can make a difference.

Support groups often do not move forward and ultimately reinforce the fact that you are a failed parent. You are so lost when you lose your identity as a mother. You are never going to get over what is happened to you. Painting pebbles does not help, but you can be listened to and make a difference.

We have enjoyed making the podcasts and the video making. The skills we have gained. Some of us have enjoyed the statistics, even though it's completely new. We thought it was going to all be talk and theory but the group has achieved loads which has really been great for our morale.

As we say to all the researchers, it is really great to be able to help them with their project, as they have some brilliant ideas and they are able to form some brilliant changes in the world. But, without us helping them they would not be able to get the projects done and I think that's really a fabulous thing to be able to say that I was a part of these major projects.

Staff reflections

We have struggled to find the most effective ways to systematically measure the impact of our work on research projects and have identified this as a goal for our future development. Nonetheless we have brought in a number of ways to log our impact and to provide that accountability to our members. We ask all researchers who consult with the group to provide feedback and to come back to update the group at a later session. Many come back to the group at each stage of their project and are expected to start each session by explaining how the group has influenced them. We ask them to report on this in their reports and articles, which we hope will counter the issue of under-reporting of PPI activity (Wilson et al. 2015).

Some examples of the way our group has impacted individual projects include discussions on an anonymized data linkage project, where the researcher decided to split up 'learning difficulties' and 'learning disabilities' after discussion with the group. They felt that in their experience, the impact of these were different and should be two separate variables. This was not part of the researcher's original plan and was a direct impact from the group.

In research projects that involved interviewing parents or families directly, the group has provided some clear feedback on the need to provide neutral and safe environments for interviews and to think in detail about how to safeguard families. They have also challenged researchers to think in more detail about what support is provided for families after interviews, questioning whether a list signposting people to support services is enough.

Finally, as the group aim to make a difference, they have challenged researchers around sharing their findings to think about what happens next. Having built experience across a number of research studies, the group have been able to give research teams long lists of ways to promote their research and share findings with other families. 'But what difference will it make?' is an important question for us as a research centre, and often surprisingly difficult to answer definitely, but our Parents' Group makes us reflect on it actively.

Resources, skills, and practical barriers

Our final theme about concerns regarding PPI relates to practical barriers such as financial resources, processes, and staffing. Such concerns appear to be widely shared and include the fact that it can be difficult to find people to take part, it is time-consuming to do properly and university processes can make paying participants difficult due to complex and off-putting processes (Wilson et al. 2015; Boylan et al. 2019; Farr et al. 2021). Other practical barriers can be a lack of skills or experience to make materials accessible (Pandaya-Wood et al. 2017; Boylan et al. 2019).

Parents' reflections

There are lots of practical challenges and worries. Fitting the group around work and childcare responsibilities can be challenging. For one of our members, having evening sessions helps, but her shift patterns are not regular, so she can't always attend. It is good that there are 'drop ins' available if people cannot make it; they can still catch up with what happened.

Another of us worries about how being part of this group may impact on her benefits, if she's doing too many hours. She really likes getting involved in things, but that is a worry.

Another practical concern is funding. We have put in so much work to this, and what happens if we don't get funding for it to continue? Also, the different research projects might not get off the ground, if they don't get the funding.

Staff reflections

As a group, the parents give so much to each project but the nature of the research cycle is that sometimes projects they have been involved in have been in a very early stage, and later may not be funded. For the group this raises the question of how to support meaningful involvement and a sense of having had a good impact. There is also a concern amongst members about whether their group itself will keep going because of funding.

From a practical perspective, if group members are paid in cash, we need to be mindful of the potential for this to impact on benefit entitlement, amongst other financial implications. We want to actively avoid a situation where taking part in the group is detrimental to members financially. We are also acutely aware of the precarious financial predicament of some of our members. We try to overcome this, by offering vouchers of choice, at a level that matches national guidance (HCRW 2023). We also recompense members of the group for any travel costs or other expenses. We are currently working out how we ensure that nobody is digitally excluded from the group, by finding schemes which might offer devices or internet access. Although these are not ideal solutions, they are compromises we have arrived at. We continue to review this situation and learn from others in the field about how they renumerate lived experience contributors.

Discussion

The challenges and barriers to effective and ethical public involvement in social care and health research have been clearly outlined in numerous research studies and critical commentaries over the last decade. As people with lived experience who advise on research and staff working in children's social care research, these challenges are familiar to us. In our reviews of the literature, we have been unable to find evidence of another standing group of research advisors who have all experienced children protection investigations, and we would suggest that our group therefore challenges a perception that public contributors tend to be 'professional users' (Cowden and Singh 2007) who may not bring difficult or challenging experiences to the advice table.

The fact that our parents' group is an ongoing 'standing' group means that we can develop trust, relationships, skills, and knowledge in a way that a time-limited advice group for a single research project may not be able to do. This means that we can attempt to reduce the power differences regularly identified in the literature that can be seen and experienced through income and formal education, alongside subtler cultural cues such as knowing how universities and other large institutions operate.

Having a standing group does mean that there is a smaller pool of experiences being drawn on (Wilson et al. 2015), but for our larger and longer projects, or those concerning different areas of children's social care, we recruit specific advisory groups which bring in a wider pool of lived experiences to our research centre (Fig. 1). Additionally, we work with third sector and statutory partners to diversify the populations advising our centre. Over the three years of our group's existence we have brought in a number of new members, whose experiences of child protection systems and social backgrounds are varied.

Our group is still relatively new, and our reflections in meetings preparing this article have helped us consider together where we go next and how we strengthen our contribution in relation to the barriers and criticisms outlined here. We have eight current members and are actively recruiting additional members, hopefully bringing different experiences and diversity to widen our expertise. We are planning to allocate our research centre resources in such a way that our Parents' Group will be able to lead some of our research. We are also working on more systematic ways to measure our impact which will help with our members' concerns about securing future funding and help us reflect further on critiques that PPI can be tokenistic and does not fundamentally improve research.

Conclusion

Our understanding and practice of public involvement in health and social care research is still relatively recent. Our parents' group is typical in that it exemplifies many of the barriers identified by others, including practical difficulties of making such activities work within a university environment and the need to take care of participants and researchers due to the emotional challenges of sharing experiences. We also believe that our parents' group is atypical in the level of marginalization that our members have faced. We believe that our members' commitment to creating change out of their own negative experiences is unique and powerful. We have shared our reflections in order to encourage others to consider both the advantages and the need for care in involving those who have had involuntary contact with social services in their research governance.

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References

Baines, R. L., and Regan de Bere, S. (2018) ‘Optimizing Patient and Public Involvement (PPI): Identifying Its “Essential” and “Desirable” Principles Using a Systematic Review and Modified Delphi Methodology’, *Health Expectations: An International Journal of Public Participation in Health Care and Health Policy*, 21: 327–35.

Beresford, P. (2009) ‘Control’, in J. Wallcraft, B. Schrank, and M. Amering (eds) *The Handbook of Service User Involvement in Mental Health Research*, pp. 181–98. Chichester: Wiley-Blackwell.

Becker, S., Sempik, J., and Bryman, A. (2010) ‘Advocates, Agnostics and Adversaries: Researchers’ Perceptions of Service User Involvement in Social Policy Research’, *Social Policy and Society*, 9: 355–66. https://doi.org/10.1017/S1474746410000072

Beresford, P. et al. (2023) ‘Editorial—Special Issue’, *The British Journal of Social Work*, 53: 1275–81. https://doi.org/10.1093/bjsw/bcad112

Boylan, A. M. et al. (2019) ‘“About Sixty Per Cent I Want To Do It”: Health Researchers’ Attitudes To, and Experiences of, Patient and Public Involvement (PPI)—A Qualitative Interview Study’, *Health Expectations: An International Journal of Public Participation in Health Care and Health Policy*, 22: 721–30.

Brett, J. O. et al. (2014) ‘Mapping the Impact of Patient and Public Involvement on Health and Social Care Research: A Systematic Review’, *Health Expectations: An International Journal of Public Participation in Health Care and Health Policy*, 17: 637–50.

Butler, I. (2002) ‘A Code of Ethics for Social Work and Social Care Research’, *The British Journal of Social Work*, 32: 239–48. https://www.jstor.org/stable/23716761

Cossar, J., and Neil, E. (2015) ‘Service User Involvement in Social Work Research: Learning from an Adoption Research Project’, *British Journal of Social Work*, 45: 225–40.

Cowden, S., and Singh, G. (2007) ‘The ‘User’: Friend, Foe or Fetish? A Critical Exploration of User Involvement in Health and Social Care’, *Critical Social Policy*, 27: 5–23.

Dawson, S. et al. (2018) ‘Black and Minority Ethnic Group Involvement in Health and Social Care Research: A Stematic Review’, *Health Expectations*, 21: 3–22. https://doi.org/10.1111/hex.12597

Dumbrill, G. C. (2006) ‘Parental Experience of Child Protection Intervention: A Qualitative Study’, *Child Abuse & Neglect*, 30: 27–37.

Farr, M. et al. (2021) ‘Co-Producing Knowledge in Health and Social Care Research: Reflections on the Challenges and Ways to Enable More Equal Relationships’, *Humanities and Social Science Communications*, 8. https://doi.org/10.1057/s41599-021-00782-1

Foster, R. et al. (2021) ‘“PPI? That Sounds like Payment Protection Insurance”: Reflections and Learning from a Substance Use and Homelessness Study Experts by Experience group’, *Research Involvement and Engagement*, 7. https://doi.org/10.1186/s40900-021-00324-8.

Green, D. et al. (2023) ‘Then There Were Seven: A Commentary on Creating a Public Involvement Strategy Group for a Policy Research Unit in Behavioural Science’, *Research Involvement and Engagement*, 9: 1.

Greenhalgh, T. et al. (2019) 'Frameworks for Supporting Patient and Public Involvement in Research: Systematic Review and Co-Design Pilot', *Health Expectations: An International Journal of Public Participation in Health Care and Health Policy*, 22: 785–801. https://doi.org/10.1111/hex.12888

Haworth, S. et al. (2022) 'Parental Partnership, Advocacy and Engagement: The Way Forward', *Social Sciences*, 11: 353.

Hanley, B. et al. (2003) Involving the Public in NHS, Public health and Social Care Research: Briefing Notes for Researchers, Involve. https://www.cerrisweb.com/wp-content/uploads/Recherche-participative-Hanley.pdf.

HCRW (2023) 'Health and Care Public Involvement and Engagement Guidance on Payment for Expenses and Offer of Payment for Time for Individuals Registered with the Involvement Community', https://healthandcareresearchwales.org/sites/default/files/2020-10/Expenses_and_payment_for_time_v6.0.pdf, accessed 17 Jun. 2024.

Mauri, D. (2023) 'Becoming Parents as Mending the Past: Care-Experienced Parents and the Relationship with their Birth Family', *Children and Youth Services Review*, 148: 106911.

McLaughlin, H. (2010) 'Keeping Service User Involvement in Research Honest', *British Journal of Social Work*, 40: 1591–608.

Pandya-Wood, R., Barron, D. S., and Elliott, J. (2017) 'A Framework for Public Involvement at the Design Stage of NHS Health and Social Care Research: Time to Develop Ethically Conscious Standards', *Research Involvement and Engagement*, 3: 6–21.

Roberts, L. (2021) *The Children of Looked after Children: outcomes, Experiences and Ensuring Meaningful Support to Young Parents in and Leaving Care*. Bristol: Policy Press.

Social Care Wales (2022) 'Codes of Practice for the Social Services and… | Social Care Wales', https://socialcare.wales/dealing-with-concerns/codes-of-practice-and-guidance, accessed 06 Jun. 2024.

Sonuga-Barke, E. J. S. et al. (2024) 'Participatory Translational Science of Neurodivergence: Model for Attention-Deficit/Hyperactivity Disorder and Autism Research', *The British Journal of Psychiatry: The Journal of Mental Science*, 224: 127–31. https://doi.org/10.1192/bjp.2023.151

Sweeney, A., and Morgan, L. (2009) 'The Levels and Stages of Service User/Survivor Involvement in Research', in J. Wallcraft, B. Schrank, and M. Amering (eds) *The Handbook of Service User Involvement in Mental Health Research*, pp. 25–36. Chichester: Wiley-Blackwell.

Wallcraft, J., Schrank B., and Amering M. (eds) (2009) *The Handbook of Service User Involvement in Mental Health Research*. Chichester: Wiley-Blackwell.

Wilson, P. et al. (2015) 'Research with Patient and Public Involvement: A Realist Evaluation: The RAPPORT Study', *Health Services and Delivery Research*, 3: 1.

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