

Perspective

'They Get It, They've Been Through It': How Lived Experience Can Shape Understandings of Peer Parent Advocacy

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Abstract: Parent advocacy is increasingly being adopted as a means of encouraging parents to understand and engage with child protection professionals. Current research suggests that it is highly valued by parents and professionals alike, but the focus of data collected thus far has largely been on services that have been received, which may make positive assessments more likely. As part of an ongoing project evaluating parent advocacy services across England, researchers consulted a public involvement group consisting of parents with experience of child protection services. The group provided a set of considerations for designing advocacy services by reflecting on the forms of support they would have liked to receive. This represented a subtle but important change in the balance of power, which means that their considerations differed in some ways from what our research participants had said. The group's participation prompted researchers to adapt their developing logic model and to consider how the data collection might have excluded some important perspectives.

Keywords: peer parent advocacy; participation; child protection



Academic Editor: Nigel Parton

Received: 14 March 2025

Revised: 5 May 2025

Accepted: 8 May 2025

Published: 6 June 2025

Citation: Lloyd, Harriet, Cerys Harris, Leanne Cook, Jennifer Williams, Layla Roderick, Zoe Price, and Clive Diaz. 2025. 'They Get It, They've Been Through It': How Lived Experience Can Shape Understandings of Peer Parent Advocacy. *Social Sciences* 14: 361. <https://doi.org/10.3390/socsci14060361>

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1. Introduction

Peer parent advocacy (PPA) has been recognized as having the potential to transform relationships between child protection professionals and parents. However, the parents who have participated in research on advocacy have often responded to questions about services they have received. This means that their positive evaluations have been based on the comparison between these services and what would have happened otherwise, which is often that they would not have received any similar form of support. By contrast, those on a public involvement panel may be better positioned to consider what they would ideally like to happen.

Both researchers and funders of health and social care research have increasingly recognized the benefits of patient and public involvement (PPI). Public involvement in research means research that is performed 'with' or 'by' the public, not 'to' or 'about' them (National Institute for Health and Care Research 2021). It encompasses a range of ways of involving the public, from consultation to user-led research. It is also referred to as 'public participation' in the US. This article considers how consultation with a board of experts by experience has impacted a study on parent advocacy. Differences between these forms of knowledge are often clear-cut, particularly in quantitative research (where forms of data collection are markedly different from discussions with lived experience experts) or where those with lived experience are tasked exclusively with making research decisions. However, the fuzziness of the boundaries between these types of knowledge in the context

of qualitative research has been recognized (Mc Menamin et al. 2022), and qualitative research practices have even been suggested as ways to strengthen PPI (Rolfe et al. 2018).

In the present study, although the group of parents we consulted directly provided invaluable advice on data collection, they also had their own reflections on the topic that they wanted to share. This reflective piece presents these opinions. The research authors also reflect on where these opinions differ from those of the research participants and what such differences might tell us about advocacy, informing our developing Programme Theory (Pawson and Tilley 1997).

Following the example set by Holland et al. (2025), researchers have worked together with those who have shared lived experience via a public involvement group to co-write this paper. Despite the different roles played by researchers and those on the public involvement panel, some of the research authors also have some lived experience of child protection, and some of those on the public involvement panel also have experience of being involved in research.

Background

Over the last 15 years, there have been a growing number of child protection referrals and investigations across the UK (Devine and Parker 2015; Bilson and Martin 2017; Elliott 2020). As a result, social work with children and families is increasingly focused on child protection (Parton 2014; Kelly et al. 2018; MacAlister 2022), which means that more families are engaged with these services involuntarily. The number of children entering care has risen and is increasingly being drawn from the poorest communities (Elliott 2020). The negative impact of imposing investigations on these families has historically not been adequately acknowledged by the professionals or services involved (Devine and Parker 2015; Featherstone et al. 2014).

Parents often feel dehumanized and disempowered when there are concerns about their children's safety (Featherstone et al. 2018; Diaz 2020). Many do not trust child protection social workers (Diaz 2020; Featherstone et al. 2018; Gibson 2017). Marginalized groups, including ethnic minorities, are particularly liable to fear child welfare services (Handulle and Vassenden 2024; Slayter and Križ 2015). Key child welfare meetings, such as child protection conferences, are often experienced as 'daunting and intimidating' (Ghaffar et al. 2012) and are particularly difficult for parents to engage with (Smithson and Gibson 2017; Muench et al. 2017; Diaz 2020).

These experiences, while important in themselves, also lead to a range of other consequences that are important for the child(ren) and for the system. The MacAlister review puts this clearly: 'The best route to keeping children safe when there is risk of significant harm, is to engage parents effectively in the child protection process. Helping parents to realize and understand risk and supporting them to make changes is central to ensuring a child's safety. When parents do not engage, it is harder to monitor, understand and respond to changing risks' (MacAlister 2022). This engagement should, of course, not come at the expense of the voice of the child, which is increasingly recognized as both vital for good practice (Ferguson 2017; Jensen et al. 2020; Stafford et al. 2021) and as a fundamental right (United Nations 1989).

Evidence suggests that parents who see the child protection system as exercising power over them, rather than with them, tend to either attempt to fight the system or to superficially engage, concealing or selectively presenting information to professionals (Dumbrill 2006; Featherstone et al. 2018; Gibson 2015; Diaz 2020). Often, parents do not attend child protection conferences or core group meetings (Bilson and Martin 2017; Baginsky 2023). This means that social workers are less able to accurately assess the

situation. Non-engagement or poor engagement by parents can therefore result in an intensification and escalation of child protection involvement (Devine 2017).

This suspicion between parents and social workers is often mutual (Ferguson et al. 2021). Fears that children may be seriously harmed despite social services involvement have been heightened by high-profile cases (Laming 2009). There is also a tendency for some social workers to focus solely on the children rather than on the welfare of the whole family (Diaz 2020). Several reasons may underscore this, including practical constraints, such as heavy workloads and limits on time (Brown et al. 2019), and the ‘caring-controlling’ dilemma, which complicates their role in relation to parents (Damman et al. 2025).

However, it is not always the case that parents and social workers distrust or fear one another. Research has noted the potential for positive relationships between parents and social workers, particularly where there is open and honest communication between both parties and where parents feel heard by their social worker (Platt 2008; Mason 2012). Parents who think that their children are safer as a result of an intervention are significantly more engaged than parents who think that their children are less safe (Gladstone et al. 2012). Indeed, Gladstone et al. (2012) found that the strongest reasons given by parents for positive change were being able to trust their social worker and believing that their worker was knowledgeable about parenting. Ghaffar et al. (2012) also found that, despite difficulties at the beginning of their cases, parents’ and professionals’ views of the cases tended to converge over time. This means that as each side gets to know the other, both the relationship and the case can improve.

Evidence therefore points to the need for practices that facilitate positive working relationships between parents and social workers. Peer parent advocacy (PPA) offers a potential means of forging less adversarial and more positive relationships between parents and social workers, supporting parents to have a more meaningful voice in decision-making processes, and even reducing the need for children to enter state care (Fitz-Symonds et al. 2024; Lalayants 2019; Polinsky et al. 2010). Research over the last two decades has recognized PPA’s potential to support families (Berrick et al. 2011) and to rebalance the roles of professionals and parents in deciding on how children should be supported (Sears et al. 2017).

While PPA is sometimes referred to as peer advocacy, mentoring, or support, at its core is the idea that parents with experience of the child welfare system offer support and advocacy to parents who are new to this system (Lalayants et al. 2014, p. 109). Peer parent advocates are often able to authentically identify with, empathize with, and understand parents. They are also critically conscious of power dynamics and inequalities and are able to challenge these (Lalayants and Merkel-Holguin 2024; Baginsky 2020; Soffer-Elnekave et al. 2020; Castellano 2021; Damman 2018). However, ongoing challenges include a lack of role clarity and some PPA services being placed in resistant bureaucracies (Featherstone and Gupta 2018; Evans et al. 2024).

Typographies of advocates’ roles have generally divided advocacy according to the level of the system they work at. For example, Tobis et al. (2020) divide parent advocacy into the following categories: case advocacy (where an advocate helps a parent directly with their case), program advocacy (where advocates work closely with social service agencies to help parents who are struggling), and policy advocacy (where parents work to effect change at a systemic level by engaging with governmental and NGO policymakers and teaching or training new professionals).

Peer parent advocacy services have developed in diverse ways in different areas of the UK. In the case study sites we have been examining in the present study, advocacy has often developed organically from areas of identified need, highly-motivated individual parents, or new roles created within social services. This has sometimes meant that the opportunity

to consider potential issues for advocates and parents in advance has been limited. By discussing the topic with parents over the course of a year, we had the opportunity to examine potential pitfalls, to explore different points of view, and to reflect on the gaps in both our data and our understanding of what advocacy could mean for parents.

This paper seeks to address two distinct but related questions: how would parents design advocacy services and how can public involvement inform both the collection and the interpretation of data in a realist-informed study on peer parent advocacy?

2. Materials and Methods

2.1. *The Parent Advocacy Research Projects*

This paper considers discussions between researchers and a group of seven parents with experience of child welfare services. It also discusses data collected as part of two projects on parental advocacy: one in Wales (concluded in 2024) and one in England (our present study). In the present study across England, there are four sites across which we currently have spoken data from 62 participants (parents, advocates, professionals, and young people), comprising interviews, focus groups, and observations at child protection conferences. Access to participants has been provided by key contacts in the four local authorities who have agreed to take part in this study. In most cases, this is the principal social worker who has encouraged other professionals to take part in interviews and either provided contact with the advocates directly or via an advocacy coordinator. Advocates or social workers have approached parents and in some cases, young people.

Interview and focus group questions have been designed to understand advocates' key areas of work, the motivations and barriers to performing their role, and parents' and professionals' experiences of working with advocates. Data are currently being analyzed, and our initial program theory is being revised in line with new findings. Please see [Fitz-Symonds et al. \(2024\)](#) and [Evans et al. \(2024\)](#) for further explanation of the realist research process and how it can be applied to the topic of parental advocacy. We are running workshops with parents and professionals and carrying out further interviews and observations of practice to refine the developing logic model. The parents' group were not participants in the fieldwork. Researchers have shared some of the interview data and key themes with the PI group, and their views are also being incorporated into the developing logic model.

2.2. *Public Involvement*

The CASCADE Parents Research Advisory Group helps to direct, translate, and disseminate research at CASCADE (Children's Social Care Research and Development Centre), supported by public involvement experts. Many of the members therefore have experience of contributing to research on other topics in the field of children's social care. In this case, they took part in a public involvement board, which is a form of advisory board ([National Institute for Health and Care Research 2021](#)). Four public involvement meetings took place between October 2023 and November 2024 to discuss various aspects of the project. Two of these were online and one in person to accommodate the different requirements and preferences of the group's members. They took between 1 and 2 h each, and each session was attended by 5–7 lived-experience experts and 2–3 researchers, along with 2 public involvement experts. It became clear in the first two meetings that the parents had insights about parent advocacy that they were keen to share and that they were interested in co-writing a paper on the topic. The third meeting was therefore focused on refining important themes for the paper. These meetings were not recorded, but the public involvement team and researchers took notes, which were sent to all attendees.

2.3. Writing and Authorship of the Manuscript

Members of the group are sometimes referred to as the ‘authors’ of this paper, because their contributions significantly shaped our understanding of the topic, and they helped us draft the paper in different creative ways. All authors were invited to comment on earlier drafts, and the research authors produced shorter-format and video-recorded versions to facilitate equitable access to this opportunity. However, authors can play different roles in the development of ideas, and we therefore allowed the expertise of those with lived experience to be expressed verbally, rather than by writing or editing drafts. In line with [National Institute for Health and Care Research’s \(2021\)](#) UK Standards for Public Involvement, we wanted to both address (in the research) and recognize (in publications) the ‘influence, ideas and contributions’ of all members of the group.

2.4. Background and Recruitment of Those with Lived Experience

The CASCADE parents’ group started in 2021, in response to the increasing need for consultation of parents with lived experience of child protection for research projects in the center. Although the recruitment criteria were broad, limited only to those who had experienced child protection services as a parent, all those recruited were mothers. Many had had a child or children removed from their care temporarily and some had a child or children removed permanently. Despite sharing an understanding of the experience of child protection involvement as parents, members of the group have diverse experiences relevant to the topic. Their backgrounds, locations, types of intervention they have received from children’s services, and experiences of involvement with advocacy services all differ. Most members of the group have some experience of receiving advocacy either as parents or as children, experience of peer mentoring, or experience of being trained as advocates themselves.

The fact that those who have engaged with the public involvement group to date have all been mothers, despite efforts to recruit fathers, reflects the well-recognized predominance of engagement with mothers in child protection social work (e.g., [Scourfield et al. 2024a](#)). As part of the data collection process, we are working with professionals to recruit fathers who have been supported by advocates, but these individuals form a much smaller population. We have observed a group specifically for fathers at one of our case study sites, and some observations of case conferences have included fathers. However, as few fathers have become advocates in our case study sites, our interviews with advocates often exclude male perspectives. In interviews, professionals have often spoken about their concern over this gap and their efforts to recruit more fathers into advocacy roles.

The public involvement group can be considered an ‘appropriate population’ ([Newman 2023](#)) in that they reflect this imbalance across the population that is usually engaged in child protection social work. However, excluding groups from PPI can risk reinforcing biases in services. For example, those who face barriers to accessing health or social care services cannot redress these barriers if they are not included in PPI groups ([Shimmin et al. 2017](#)). For some projects, the center’s public involvement experts draw on their network of contacts with related organizations, including those that represent fathers. The prevalence of male violence against partners where there are child protection concerns ([Scourfield 2006](#); [Hearn 1999](#)) means that mothers may feel more comfortable talking about their experiences with child protection in separate groups. We reflect on the limitations of having a PPI group made up of mothers in the discussion.

While the primary focus of the paper is on the group’s views of parental advocacy (and peer parent advocacy in particular), we also reflect on how these views reinforce or contest our research findings.

2.5. Public Involvement Insights vs. Research Participation

Before reflecting on the similarities and differences between the recommendations of our public involvement group and the views of our participants across the various case study sites, it is worth reiterating the difference between these forms of knowledge. Both the parents who formed the group and the parents who we interviewed at the case study sites had experienced child protection involvement in their children's lives, but the parents in the public involvement group had not all experienced advocacy services. Regardless of these experiences, they were not asked to reflect on a service they had received but instead gave their views on what they felt a "good" parental advocacy service would look like. This difference also means a subtle change in the balance of power, because parents in the public involvement group were able to imaginatively design their own service rather than respond to one that had already been designed on their behalf.

3. Results

3.1. Overview

Parents in the group strongly supported the idea of providing advocacy for parents going through the child protection process. In some cases, support for this idea was based on their positive experiences of receiving different forms of support (such as being part of peer support groups) and their anticipation that peer parent advocates would perform a similar role. In many cases, however, the parents reflected on instances in which they would have benefitted from the support of an advocate, having felt isolated and confused as they navigated the system without this support. Parents felt strongly that advocacy support should be provided throughout the process from the beginning of their involvement with social services, until their families no longer had social services involvement. This was not happening consistently at any of our case study sites, often because of a lack of resources in terms of advocates and support for advocates. Working with a limited number of advocates meant that not all parents could be offered support all the way through their cases.

Different sites prioritized these resources differently. Some prioritized those with Child Protection plans over those with Child in Need plans and focused attention around the initial child protection conference (ICPC). This was based on the understanding that ICPCs were where both parental need for support ([Smithson and Gibson 2017](#), p. 569) and the implications of non-engagement were highest.

If a child is judged at risk of 'significant harm' (as defined in section 47 of the Children Act 1989), an initial child protection conference (ICPC) is held ([Richardson Foster et al. 2021](#)). At the conference, practitioners, parents, and sometimes children discuss the concerns raised and decide whether a child protection plan is needed to keep the child safe, or whether a (less serious) Child in Need plan may be appropriate. These plans are revisited at subsequent review conferences. Lack of compliance with recommendations in a Child Protection plan has more serious consequences, including the risk of removal via the courts.

In other areas, advocates provided support for family group conferences. Family group conferences (FGCs) in child welfare bring both immediate and extended family members and other supportive adults together to decide on the best way to meet a child's needs. Unlike professionally led meetings, the aim is for decisions to be made by or with family members initially ([Scourfield et al. 2024b](#)). As these are voluntary and often experienced more positively by parents ([What Works Centre for Children's Social Care n.d.](#)), advocates are able to build confidence in supporting parents in FGCs before supporting parents at ICPCs.

3.2. *Advocates' Roles*

When asked how advocates might be able to help parents, it is unsurprising that the group foregrounded case advocacy, because this is the form of advocacy that operates at the level of individual parents or cases (Tobis et al. 2020). Their answers referred to both practical tasks and emotional support. The group thought that parents would benefit from advocates supporting them to complete paperwork, assist with reading and writing statements, take notes during meetings, and explain terminology. Our data tell us that these seemingly administrative tasks serve to increase parents' knowledge and understanding of Child Protection meetings and therefore to redress power imbalances that are created by unequal access to knowledge. The group also expected that peer parent advocates would be able to support parents emotionally, by showing 'real empathy', being nonjudgmental, and 'fighting their corner'.

Our developing logic model shows how these two aspects can work together. For example, the trust that advocates build with parents allows parents to ask questions without fear of judgement and helps them to 'process' information as well as to understand it. Similarly, the time that advocates invest in getting to know parents allows them to represent them fairly at meetings, including child protection conferences.

These suggestions largely echoed what was happening in our case study sites, except that in one of these, policy advocacy was predominant. For example, advocates at this site had instigated and helped to create a video explaining to parents what would happen at the ICPC and introducing them to the location. When asked about such practices, the group reflected that they had not found any guidance (for example, on the internet) about how to go through the child protection process and what different parts of it, such as the child protection conference, involve. While they recognized that it was the social worker's job to provide this information, they felt that this often did not happen in practice, so the idea of peer parent advocates filling this gap was welcomed. They said that people who have been through the process know which technical aspects do not work well for them, and changing these has the potential to make a big difference.

3.3. *New Ways of Working*

The group felt that social services had generally become more accepting of advocacy and that some social workers saw it as a means of creating a good working relationship with parents. This echoed what we heard as part of data collection, where, at some sites, advocates were involved in the training and recruitment of social workers. This meant that more professionals were aware of the need to build positive working relationships with parents and advocates from the beginning of their careers. Advocates in our study reflected that this had been part of a broader cultural shift whereby newer social workers were more receptive to their involvement than those who had more ingrained ways of working. In a similar vein, one member of the parents' group suggested that the act of offering parents an advocate would demonstrate a social worker's willingness to be challenged and to see things from a parent's perspective. This openness to challenge would, in turn, help them to build trust with parents.

3.4. *Peer vs. 'Professional' Advocacy*

Although the present project focused on peer parent advocacy, the wider research team (including the parents' group) has also worked on projects in which the advocates were predominantly 'professional' advocates. The terms 'peer' and 'professional' were designed to reflect a difference between the advocates for whom prior lived experience was a criterion for carrying out the role (peer parent advocates) and advocates who were professionally trained and paid (professional advocates). This distinction, and particularly

the use of the term ‘professional’, is controversial (see [Evans et al. Forthcoming](#)), because peer advocates often receive training and approach their role with professionalism, and professional advocates may in some cases have had similar experiences (although this is not a requirement). Peer advocates in our study also felt that, despite not being referred to as ‘professional advocates’, they were often ‘equally professional’, if not ‘more professional than the professionals’ with their input. They also described their ways of working using professional language, such as referring to the ‘strategies’ they had developed for dealing with difficult cases.

Across the study sites from England and Wales, we have found that peer advocates tend to be volunteers, at least initially. In many cases, they are recompensed with vouchers and have expenses paid, rather than receiving a regular income, although payments tend to become more formalized over time. They are more often (not always) set up or supported by people employed by the local authority. Professional advocates tend to be paid by an external organization, often an NGO. These differences, although not essential, also have consequences for the degree to which the different types of advocates are perceived as being adequately independent from social services. This theme is addressed under the heading ‘Boundaries Between Advocates and Parents’ below.

The group did not rule out the possibility of professional advocates, but they emphasized the importance of shared experience. They saw the unique advantages of the peer model as follows:

- Providing a positive role model, i.e., someone who has been through the child protection system. Advocates would be those who had not only survived this process but who were making positive contributions. At such a challenging time, knowing someone who had thrived after a similar experience could be inspiring and motivating for parents.
- Reducing isolation by having someone with similar experience by their side throughout the process.
- Building trust, particularly for those with negative experiences of professionals. Some authors with lived experience said that they would only have felt comfortable being supported by someone they knew had had similar experiences.
- Challenging stigma by demonstrating the abilities of parents with experience of child protection involvement.
- Having an understanding of the parents’ perspectives in a way that would make them non-judgmental. The group acknowledged that professional advocates may work hard to see things from the parent’s perspective and may be invested in the idea of supporting them beyond being paid to do this. This was seen as absolutely necessary for professional advocacy to work. However, there was a sense from peer authors that their own experiences would make peer advocates non-judgmental by default. As one parent put it, people who have been in a similar position ‘get it’. This idea was supported by peer advocates who were interviewed for our study on parental advocacy in England. One said, ‘Parent-to-parent is an easier conversation to have. You can get away with saying a lot more than a professional-to-parent, because they see us [and think] “they understand, they get it, they’ve been through it.”’
- Providing a chance for parents to channel their experiences in a positive way, as involvement with children’s social services is often traumatic. Feeling that this could lead to positive change for others may help parents to heal.

It is no surprise that the parents in our present study were similarly positive about peer advocates, having received support from them. Indeed, we found that those who worked with or received support from either type of advocate generally spoke positively about whichever form they have experience. In this instance, then, it is particularly interesting to

have the views of parents who are considering what kind of service they would most like to receive, given the choice of either.

3.5. Boundaries Between Advocates and Parents

The group highlighted the balance that would need to be struck by peer advocates, between being emotionally close to parents and being appropriately professional and independent. While the group expected peer advocates to be able to deeply empathize with and understand parents, they also recognized that advocates would need to be able to remain calm in situations in which parents might experience heightened emotions. This would require advocates to center the experiences of the families they were tasked with helping over their own experiences, avoiding making the work ‘all about them’.

This maintenance of boundaries between parents and advocates was also seen as essential from the advocates’ point of view, in that involvement in other parents’ cases could also risk re-traumatizing them. The group suggested that separation in both time and space from the advocates’ own cases would be helpful for managing this. Firstly, where possible, peer advocates should support parents in a different local authority to their own. This would limit the chances of them having to work with professionals who were involved in their own cases, either as a child or as a parent. It would also mean that social workers would be less likely to have preconceptions about the advocates with whom they are working. The group acknowledged that working in a different local authority might make things more difficult for the advocate. They also said that, as social workers and IROs sometimes move between authorities, working with professionals who had worked on the advocates’ own cases could not be completely avoided anyway. However, their identification of physical locations as triggers echoes data from one of our study sites, where advocates reported that the physical environment of the local authority triggered difficult memories:

I think if you’ve been through child services and gone through the whole lot of where you’ve had child removals and things like that, you’ve always got the fear of going back into that, and with that comes a lot of triggers. So I know that, at first, some of us felt really uncomfortable being over the road at [a local council building], because that’s the building of memories and, like, the reminders. And that took a lot of. . . even now, there’s still triggers, fears, but we’ve built up to going into there. (Advocate, England)

As well as space, the parents suggested that advocates should have time away from their own cases to rebuild their lives before attempting to help others through a similar process. This would enable potential advocates to reflect on their experiences and to ‘work it through’ so they would be able to understand why social services had taken some of the actions that they had, even if they ultimately disagreed with these decisions. The group saw this process as essential for advocates to be able to work constructively with professionals on other cases.

At the point at which advocates were ready to take on cases, the group suggested practical ways that they could protect both themselves and parents. They suggested the following:

- Advocates being given access to a separate phone or means for parents to contact them that is not linked to their personal phone number or social media accounts. Without this, advocates may be unable to ‘switch off’ from their cases. Training should include models that put the focus on whoever the advocate was trying to support, enabling them to find their own solutions where possible. The group suggested models in which they had been trained as part of support groups they had attended, which had worked well. These include ‘Clean Language’ (a set of questions developed by a psychologist and used in coaching to help people to understand themselves and their

situation better using their own words) and ‘Systemic Modelling’ (an approach to group work related to Clean Language that clarifies the group dynamic and sometimes suggests altering it to make the most of each member). It was suggested that this type of training would also be useful for professionals.

- Advocates should not face difficulties with their benefits or finances in general because of their roles. Services relying on their support should ensure this, including developing guidance, making sure they paid advocates’ travel expenses (especially when working away from their local authority), and rewarding time with vouchers when this was preferred by the advocates. Training should also be arranged in a way that would not limit the advocates’ availability for other work (which would also affect their benefits). Advice should be sought on how best to achieve this.
- There should be adequate support for advocates to maintain their emotional wellbeing, particularly when faced with triggers that may be re-traumatizing. Some of the group members had very positive experiences of receiving and giving peer support, and they suggested that similar models of support could be included in this (for example, the model used by Barnardo’s ‘Reflect’ service).

Many of these concerns echoed what advocates reported in our study sites. In particular, the provision of psychological support was seen as fundamental and was highly valued by advocates when it was provided regularly, responsively, and by people who understood them and their triggers well.

3.6. Boundaries Between Advocates and Social Services

While boundaries between advocates and parents were seen as essential, so were boundaries between advocates and professionals. The group reflected that a balance would need to be struck by advocates between being able to work cooperatively with social services and to remain sufficiently independent from them. While they recognized that advocates could support social workers, who may not have the time to explain things in a way that the parent needed them to, they also felt strongly that advocates should not become too close to professionals. In particular, they felt that if advocates and social workers began to consider each other as ‘colleagues’, the advocates would be less likely to challenge social workers in the way that they should.

Where possible, they felt that services providing advocacy should be independent of the local authority (for example, by an independent charity), although this was recognized as challenging for some practical reasons. At the case study sites, advocacy services were often set up, or at least supported, by their local authorities. As indicated above, when peer advocacy services became more established, local authorities often began to pay advocates for their work, in some cases after advocates had lobbied for this.

The parents’ group agreed that advocates needed to be paid for their time (while being responsive to the needs of some advocates to avoid their benefits being affected) but felt that the source of payment was important. They felt that being paid by an independent charity would be less likely to compromise the advocates’ independence. However, they recognized that being situated in a local authority would also have advantages, such as providing access to data for cases, training, consistency in terms of pay, and enabling easier working relationships with other local authority staff. In such cases, they argued that there needed to be independence or separation in the following circumstances:

- The recruitment process for advocates: Advocates should be involved in the recruitment of other advocates. They should not be chosen by social workers who have worked on their cases. The group expressed concern that if this were to happen, some parents could be put forward partly because they were nonconfrontational. Similarly, if social workers were involved in reviewing applications and interviewing for peer

advocacy roles, there would be a risk that they would choose people they thought would be easier to work with. This might mean that people who were more critical of social services would be less likely to be hired.

- The referral process (for parents to be referred for advocacy): the group anticipated that parents would be less likely to trust an advocate who was referred to them by a social worker. They cautioned that social workers who did not want their practices to be challenged would be less likely to promote advocacy to parents. Suggestions included being referred via healthcare professionals, such as midwives and sexual health clinics, as well as community childcare services, such as Flying Start groups.
- The location of the different roles: Where advocacy services were part of the local authority, the group suggested that they should be placed in a separate building. This would help to foster a sense of independence from social services for the advocates and help parents to trust that the advocates would be impartial.

They felt that it would be up to the advocates to continue to challenge things that were wrong, whether or not they were being paid by the local authority. As well as relying on advocates to do what was right, they suggested that this would require the thoughtful recruitment of advocates, selecting candidates who would be able to maintain their independence from social services.

At our study sites, advocacy referrals were sometimes made via social workers, and some of our interviewees highlighted the positive impact of this practice. However, it is worth noting that social workers who are less enthusiastic about advocacy might not refer parents to advocates as frequently, and that these cases will not have been captured in these interviews.

3.7. The Role of PPI in Research on Parent Advocacy

While the data from our studies on parental advocacy in England and Wales for the most part aligned with what parents in the participation group said, there were some points of divergence. The differences, in most cases, refer to balances that need to be struck between different elements. For example, an effective advocacy service must both support parents and work cooperatively with social services. Depending on their experiences and the topic being discussed, different people emphasized the importance of one of these elements. In other cases, points of contrast reflected the difference between imagining how such a service could be set up and discussing what had happened in practice, where services had sometimes started more organically.

The discussions slightly shifted the researchers' overall understanding of peer parent advocacy. Much of the literature and our own data view advocates as mediators between parents and professionals (social workers in particular), facilitating a better working relationship between them. In other words, advocates can be pictured as a channel between parents and professionals: perhaps not the only one, but one that helps information to flow more freely in both directions. The authors with lived experience, on the other hand, repeatedly emphasized the boundaries that should be in place between advocates and both parents and professionals (even if the same boundaries need not be in place between parents and professionals). In this way, they have two separate relationships to manage, with firm boundaries between themselves and both parents and professionals, and can be thought of as partners who have separate interactions with each of the other parties.

The issue of independence from social services also represents a substantial shift in our conceptualization. During data collection, some of our interviewees raised the issue of independence in relation to the paperwork they were asked to encourage parents to complete, but issues of pay were generally not seen by advocates as compromising their impartiality. Although we did not specifically ask advocates whether they felt independent

enough from social workers, when asked about instances where they had challenged social workers, advocates often recalled these easily. They felt that their previous experiences had a strong influence on their motivation to perform the role, and this is unlikely to be compromised by being paid by the local authority.

However, parents' views of this are underrepresented in our data, because our initial interviews were only with parents who had received advocacy services and those who had successfully become advocates, as well as the professionals with whom they had worked. This is to some degree inevitable, because those who are skeptical of advocates are unlikely to respond to requests to take part in research on parental advocacy. However, discussions with the parents' group caused the researchers to consider the view of advocacy services that parents who chose *not* to accept advocacy may have (i.e., whether they may feel that it is not independent of social services). We asked about instances in which parents turned down support, and these have been reported as being infrequent and often for specific reasons relating to their cases. Because advocacy services are currently being trialed and expanded in these areas, there is often a lack of supply rather than a lack of demand. However, our logic model has been adjusted to account for the idea that some who need advocacy services to be independent of the local authority may never access local authority-led advocacy services.

4. Discussion

PPI can offer a distinct perspective on services for which those who are consulted do not have direct experience of receiving advocacy, in that it can offer the opportunity to consider the types of services one would like to receive rather than to reflect on whether one that was received was helpful or not. However, rather than considering unrealistic idealized scenarios, the parents' group often tended to provide concrete practical solutions to the problems they discussed. For example, while academics have highlighted the risks of re-traumatization (Lalayants 2021; Diaz et al. 2023), the parents were able to identify specific aspects of this work that parents in this position might struggle with and therefore offer some practical suggestions to minimize these risks

While study participants were unlikely to suggest alternative means for achieving these aims, the PI group was more likely to see advocacy as just one potential solution. However, their support for the idea was not weaker. This suggests that advocacy is not only better than nothing, it is seen as an ideal means of addressing a range of needs by parents with experience of the system.

It is important, however, that these findings are placed in the context of the underrepresentation of fathers in the PPI group. It is difficult to estimate what impact this may have had on discussions between researchers and parents in the group. So far, our data with fathers has involved observing their interactions with advocates as part of support groups rather than discussing their views of these services. Some international research on parent advocacy has examined fathers' advocacy services and indicated that similar barriers exist in relation to building trusting relationships with them in the context of previous negative experiences and the transformative effect of mentoring from those with lived experience (Tobis 2013). However, we are not relying solely on these reflections to inform our understanding of the intervention: our ongoing data collection will incorporate fathers' perspectives, and our analysis will examine the extent to which these perspectives can be incorporated into our developing understanding or whether they require the development of a separate model.

5. Conclusions

As discussed in the background, most of the research and standards on PPI come from medical or large-scale research in which there is a clear distinction between advice received from PPI boards and data collected from the study's participants. The similarity between the conversations which formed part of a focus group, for example, are harder to distinguish from those had with experts by experience, particularly when these conversations are not limited to making decisions about the research.. In the case presented here, the authors' own thoughts on the topic prompted the researchers to take into account perspectives that the data may have missed and to reflect on the differences between discussing services received and services as they might be designed by parents.

While some of the recommendations made by parents in the group may not be taken up in practice, they act as a reminder of what could happen. For example, the call for advocates to support parents for the entire time they are involved with social services may be seen as impractical while services struggle to recruit experienced advocates. While services may be forced to target these resources at the times where there is most need, this risks replicating the crisis-oriented model that is often seen in children's social services (MacAlister 2022).

The fact that the idea of advocacy was uniformly welcomed in both contexts also strengthens the case for advocacy, both to support parents and to challenge a system that often does not work well for them and their families. The implications of this are not limited to changing the experiences of parents, but making them more likely to engage in positive changes that impact their children and stand to benefit the system. It underlines the idea that advocates, as well as the parents they support, stand to benefit from using their experiences in a positive way and that advocacy can both pave the way for and indicate the existence of broader systemic change.

Author Contributions: Conceptualization, C.H., L.C., J.W., L.R. and Z.P.; writing—original draft preparation, review and editing, H.L.; project administration, C.D. All authors have read and agreed to the published version of the manuscript.

Funding: This research was funded by [Nuffield Foundation] grant number [JUS/FR-000024044] and Health and Care Research Wales grant number HCRW SCG-21-1844. The APC was funded by [Nuffield Foundation].

Institutional Review Board Statement: The study was conducted in accordance with the Declaration of Helsinki, and approved by the School of Social Sciences ethics committee at Cardiff University (SREC reference: 485, date: 13th September 2023).

Informed Consent Statement: Informed consent was obtained from all subjects involved in the study.

Acknowledgments: We would like to thank the Public Involvement team at CASCADE, Cardiff University (most notably Rachael Vaughan) for their help in facilitating the meetings and corresponding with lived-experience authors and for their invaluable advice.

Conflicts of Interest: The authors declare no conflicts of interest.

Abbreviation

The following abbreviations are used in this manuscript:

PPA	Peer Parent Advocacy
PPI	Patient and Public Involvement

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