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Centering vulnerable voices: facilitating the participation of looked after children with learning disabilities in research.

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ABSTRACT

Within the looked after child population, those with a learning disability constitute a significant group, making their distinctive experiences particularly crucial to understand. Despite this, there remains limited attention given to the lives of children with a learning disability in the care of the state (Hill et al., 2017) and there is a noticeable gap in research dedicated to exploring their unique experiences (Baker, 2007). Doctoral study was undertaken with an aim to address this research gap, employing creative methods to engage nine looked after children with learning disabilities as participants. This article presents a case study, focusing on insights gleaned from this research initiative into the ethical considerations and practical challenges faced during recruitment of this 'hard to reach' and 'vulnerable' group. Challenges presented include negotiating ethical approval and addressing safeguarding concerns, which emphasises the need for a rights-based, inclusive approach. Organisational changes and staff turnover posed further challenges, leading to the loss of participants and concerns about potential bias and additional gatekeeping where social workers were assigned the responsibility of identifying and approaching potential participants. This underscores the importance of cultivating relationships and maintaining communication with practitioners. Navigating the complexities of obtaining consent from children with learning disabilities involved enhancing the child's capacity through engaging the support of caregivers and adapting to the diverse communication and learning needs of each child. The article concludes by emphasising the need for researchers and practitioners to find a balance between protection and empowerment to gain critical insight into the needs and experiences of looked after children with learning disabilities.

Introduction

Gaining insight into the involvement of looked after children in decisions regarding their care holds significant implications for shaping policy, training programmes, and best practice guidance while upholding and advocating for children's rights. Nevertheless, research frequently overlooks the perspectives and experiences of children with a learning disability, leaving a notable lack of representation from children with additional learning and communication needs in influential research. This gap in research motivated the present PhD study, which aimed to fill this omission by conducting creative interviews directly with looked after children who have a learning disability. Despite a recent increase in participatory research, several challenges persist in accessing this specific group of children and obtaining consent to participate. This article will engage with ongoing debates related to accessing and obtaining consent from child participants classed as 'vulnerable'.

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These discussions will be informed by the author's experiences during the data collection phase of PhD research.

Looked after children with a learning disability

There are currently more than 82,000 children being looked after by Local Authorities (LAs) in England, the majority of which (70%) are in foster placements (Department for Education, 2023). A child is considered looked after by a LA if they are in their care or provided with accommodation for more than 24-hours by the authority. Whilst the UK Government conduct an annual collection of statistics regarding the number of children who are looked after, these do not accurately record whether a child has a learning disability. Hill et al. (2017) point out that without official statistics we are left to rely on a limited number of research studies which aim to identify the prevalence of such in care, but readers need to be aware of the lack of depth in which these studies sufficiently cover this issue. Children who are looked after are three to four times more likely to have a Special Education Need (SEN) than all children and are almost nine times more likely to have an education, health and care (EHC) plan (HM Government, 2023), suggesting there is a high proportion of looked after children with additional learning needs. However, the available Government data does not include a breakdown of special education need category, making it difficult to know the exact figures of looked after children formally recorded as having a learning disability (Parsons et al., 2019). Irrespective of a lack of clear data, it is evident that children with a learning disability are over-represented in the care system (Baker, 2007), therefore their unique experiences should be explored.

Children become looked after primarily due to significant welfare concerns related to the risk of abuse or neglect, leading to a court order (Department for Education, 2023). Studies indicate that children with a disability are three to four times more likely to be abused than non-disabled children (Jones et al., 2012; Sullivan & Knutston, 2000). Despite existing high figures, the abuse of children with a disability is likely under-reported due to barriers to disclosure (Taylor et al., 2016), as well as inaccurate recording of disabilities (Stalker et al., 2015). Once in care, children with disabilities are more likely to continue to experience poor outcomes and remain vulnerable to abuse in settings like residential schools (Stuart & Baines, 2004) and foster care (Biehal, 2014). Whilst the data does not often differentiate between categories of disability, it is generally revealed that children with learning disabilities experience particularly poor outcomes and a heightened risk of abuse (Sullivan & Knutston, 2000). Cooke and Standen (2002) found that among children who had experienced abuse and had an identified disability, 83% had a learning disability as opposed to 17% with a physical disability. This evidence underscores the heightened vulnerability of looked after children with learning disabilities.

Looked after children are often regarded as highly vulnerable, particularly because of their past adverse experiences and the additional needs arising from being separated from their family. Among this population, children with a learning disability are perceived as especially vulnerable, given their heightened risk of experiencing continued abuse and facing poorer outcomes in the care system. Due to these perceptions, adults often view these children as in need of protection, which can inadvertently result in their exclusion from research studies (Heptinstall, 2000).

Research with looked after children with a learning disability

Historically, research on disability and childhood experiences has been carried out without the active involvement of those affected, due to concerns over vulnerability and negative assumptions and stereotypes. Often, children were considered as objects of study, with adults interpreting their experience without considering their subjective viewpoints (Hogan, 2005). A common approach was 'research by proxy' where adults, such as parents or professionals, spoke on behalf of children, further silencing children's voices (Watson et al., 1999).

This perspective, rooted in 'adultism', perpetuated the notion that children lack the capability to provide accurate and constructive accounts of their own lived experiences (Prout, 2001; Sinclair, 2004). Moreover, children with a learning disability have been excluded from research or subject to research by proxy due to ableist assumptions that they cannot effectively communicate (Stafford, 2017). Within research, adultism (the discrimination and oppression of children by adults) combined with ableism (the discrimination and oppression of people with disabilities in favor of non-disabled people) has resulted in children with a learning disability being excluded from the opportunity to participate actively and contribute their unique insights.

Historical understandings of disability (such as the medical model) pathologised individuals and came from a deficit approach, this was challenged by disability activists and through the introduction of social models of disability, which recognises that children with a disability encounter disabling barriers in society which serve to exclude them and minimise participation (Thomas, 1999). These socio-political interpretations of disability developed during the 1970s and 1980s, led to a shift towards greater empowerment of people with disabilities in the research process (Jenkin et al., 2015). As a result, more emancipatory research emerged, whereby the research aimed to empower disabled people through generating meaningful and accessible knowledge, with a direct benefit to people with a disability (Barnes, 2003). Concurrently, there was a move to seeing children as actors in their own right, rather than passive recipients of adult socialisation (Christiensen & Prout, 2005), highlighting the importance in the research community of seeking direct views of children.

There has since been a growing body of research with children with learning disabilities, with researchers successfully using creative means of in-depth data collection which seeks the direct viewpoints of those whom the research is regarding. Regardless of this progress, Stafford (2017) argues there remains perpetual negative assumptions about capacity and perceived worth of involving children with learning disabilities in research. These constructs result in the voices of children with disabilities continuing to be largely unheard in mainstream research. Additionally, looked after children are often perceived as particularly vulnerable and in need of protection. As Steckley and Smith (2011) point out Corporate Parenting hinges on safeguarding and risk management; if social workers, acting as corporate parent, are concerned that involving children in research will potentially jeopardise this, they may decide to exclude the children in their care from the process. Vis et al. (2012) label this as 'protectionism', whereby what is done in the name of protection goes at the expense of the child's participatory rights. For looked after children, their participation in research can be impacted upon by the priorities and attitudes of their social worker and their respective agency, rather than the needs of the individual child and the potential benefits of the research.

Described as a 'hard to reach' group, looked after children with a learning disability have been largely excluded from contributing to the academic evidence base (Alderson et al., 2019), potentially perpetuating their invisibility and reinforcing stereotypes. Efforts to protect these vulnerable groups from harm through preventing involvement in research can paradoxically be harmful through further excluding their voices and perspectives, which denies researchers and policymakers critical insight and meaningful data necessary to better address their needs and ensure their well-being. As Atkinson (2007) argues, research needs to find a balance between protection and empowerment.

Children's right to participate in research

The participation of children is enshrined within the United Nations Convention on the Rights of the Child (UNCRC) (UNICEF, 1989). Here, participation relates to the rights of children to express their views freely in all matters impacting on their lives (Article 12). Considerable advances have been made since the ratification of the UNCRC in the United Kingdom, including greater inclusion of children's voices in research, which has led to genuine improvements in the way they are treated and understood (Aldridge, 2017). The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (United Nations, 2006) sets out the rights of all disabled persons, including children, to live free from discrimination and requires appropriate measures to ensure that their human rights are upheld. The UNCRPD is built on a foundation of ensuring participation for all people with a disability and article 7 focuses specifically on the rights of disabled children to be heard and have their views taken into account. This further enhances the participatory rights of children with a disability.

Despite the advances in the participation of children and those with a learning disability in research, the experiences of children with a learning disability in the context of being looked after by the state remain underrepresented (Mannay et al., 2019). This study addresses this gap by adopting a rights- based approach, viewing looked after children with a learning disability not as objects of concern, but as active citizens who are capable of and entitled to a voice in their own lives (Rogers, 2015). Embracing this perspective requires challenging processes and individuals who may undervalue their contribution. This approach upholds the child's right to protection, necessitating thoughtful consideration of ethical dilemmas and the use of appropriate data collection methods. The study recognises that children have both a right to participation and a right to protection, emphasising that these rights are not mutually exclusive.

Case study

The current study proposed to fill a gap in research by gaining the direct views of children with a learning disability who are looked after, via creative interviews with children. The purpose of the study was to explore how participation in decision making is experienced, understood and promoted, in the context of looked after children with learning disabilities. Nine children participated in semi-structured interviews, where creative methods were used to support memory recall, to promote communication and to improve a shared understanding, as guided by research literature on how best to promote their authentic participation (Chan, 2012; Jenkin et al., 2015; Kelly, 2007; Stafford, 2017; Underwood et al., 2015). Methods used included 'getting to know you' activities to build relationships and develop a shared understanding of communication needs, development of a life story map which identified significant changes in the child's life and explored important people to the child, use of emojis to reflect on emotions and feelings and a magic wand activity which allowed the child to share changes they would like to make. Children were given the opportunity to choose between a variety of communication methods with each activity, with some choosing to communicate verbally, others using drawing or writing to explore these activities and others using pre-developed visual representations.

Children ranged from eight to 17 years old, with mild to complex learning disabilities. Six were cis males, two cis females and one identified as male and hopes to transition from his birth sex of female to male once he turns 18. The children were invited to reflect on how they feel about decisions that have been made in their lives, how involved they are in these decisions and how they may like professional practice to improve in the arena of children's participation.

The purpose of this article is to present this research with children as a case study to explore the issues associated with gaining access to and recruiting participants and obtaining consent to undertake each individual interview.

Gaining access and consent

Ethics

Navigating the ethical landscape while conducting research with this group of children poses a challenge. On one hand, researchers must respect and uphold the participatory rights of these children. On the other hand, these children are labelled as 'vulnerable' within research governance and ethics protocols which researchers must work within, necessitating a delicate balance to ensure their protection during the research process (Aldridge, 2017). To proceed with the research, ethical approval was sought from the University of Huddersfield. In preparation for this I reviewed literature pertaining to research in this field, which highlights several potential ethical dilemmas. As each child is unique with individual needs and circumstances, there are no universally applied solutions available to address these ethical dilemmas (Wiles et al, 2007). Therefore, planning involved consideration of the wellbeing, comfort, and safety of each child throughout the research process and how this might impact the information gathered. One example relates to the presence of an adult during the interview, which can aid with interpreting information where there are specific communication needs and could provide support where the experiences shared by the child may cause them pain or anxiety. However, the presence of a guardian can inhibit participants from discussing issues most significant to them (Mutua and Swadener, 2015) and can challenge confidentiality. Ultimately, the broad principle used when considering the ethics of this study was to take an individualised approach, which respects each child's unique circumstances and most importantly, their choices.

It is worth noting that many researchers in this field find their work restricted or prevented by risk-averse ethics committees (Stalford & Lundy, 2022), however through meticulous preparation, the research proposal for this study received ethical approval without constraints, providing confidence to proceed with the next stage of recruiting participants.

Adult gatekeepers

In research involving children there are generally gatekeepers, often a hierarchy of gatekeepers (Hood et al., 1996), resulting in access to children for research purposes encompassing a complex negotiation process with a variety of adults (Kelly, 2007). This generally involves additional stages of providing them with information regarding the study and requesting that they suggest or contact potential participants. This may call for the building of rapport and trust with the gatekeeper and convincing them of the benefits for the people they will often see as in need of their protection (Nind, 2008). Gatekeepers can be any number of relevant adults, in this research, due to the 'looked after' status of the children, Parental Responsibility (PR) is generally shared between the LA and parent(s), therefore, consent was required from both parent and LA. Carers are also involved in the day-to-day care and protection of the child, therefore will want to be assured the research process will be suitable for the child before the child is approached for their consent. This meant there were several steps involved in gaining access and consent for a child to participate in this research, which proved to be a lengthy and at times, challenging process.

Gaining consent from adult gatekeepers is considered good practice, however adult gatekeepers can restrict opportunities for children to participate in research through refusing consent and obstructing access to the child. Many researchers have indeed found gatekeepers blocking access (Stalker, 1998; Tuffrey-Wijne et al., 2008). This can lead to a situation where a child may have consented to take part but cannot do so as the adult gatekeepers refuse access (Kelly, 2007). I attempted to reduce these barriers through developing relationships with a variety of adult gatekeepers, providing clear information regarding the research and its potential benefit to children, engaging in frequent communication to follow up on potential participants and ensuring minimal burden to those adults who could aid in accessing and recruiting suitable children.

Typically, researchers in the field of children's welfare recruit participants through social services, this is because knowledge of the population of children in the area who are looked after is only generally held by the LA themselves, additionally they share PR with parents therefore both LAs and parents must provide consent prior to any research being conducted with children in their care. Across the duration of the research connections were made with decision makers in four LAs and whilst the key people in each LA approached showed an interest in the research, child participants were eventually recruited from just two. All parents approached provided consent for their child to participate, however in one case only verbal consent could be gained and attempts to gain written consent from this parent were not successful. Advice was sought from a senior manager who confirmed they required written consent from each person with PR, therefore following some further unsuccessful attempts, this child was not able to participate. In all other cases, parents provided written consent for their child to participate.

Over a period of 18 months of attempted recruitment, a total of nine children participated in the research. Four children were recruited from various teams across one LA; here the team managers were supportive of the research in theory, but relied on the individual social workers to put children forward and there was no clear route for following up with the teams when recruitment slowed down and information about the research and enthusiasm for securing participants seemed to wane. The most successful approach was with the 'Children with a disability team' from the other participating LA, largely due to the enthusiastic support of the team manager. She actively encouraged her team's social workers to respond to participant requests, identifying children who met the criteria and were in a suitable position to participate. Five children were recruited within this team, with more identified as suitable once their circumstances had settled, however this was unfortunately out of the timescales of data collection for this research.

The primary barriers to access and recruitment related to safeguarding concerns, organisational changes and staff turnover and the requirement to rely on individual social workers to aid in the identification of suitable participants.

Safeguarding concerns

To address concerns about protecting the children involved in the research project, LAs requested I demonstrate a clear understanding of the procedures to be followed in case a child disclosed any concerning information during the interview, therefore, I created a safeguarding referral map for each LA. Drawing on publicly available information gathered from the LA safeguarding websites, I mapped out the steps I would take in various circumstances if an allocation or disclosure was made, this included contact phone numbers and email addresses as well as internet links to further guidance from the LA if I was unclear on which steps to take. I also demonstrated an understanding of the thresholds for harm, linking relevant legislation and providing an overview of how I will use my judgement as a registered social worker. It is important for the LAs to feel confident in a researcher's abilities to adequately promote the safeguarding of children and not to miss any significant concerns. However, early career researchers may not be experienced in identifying safeguarding concerns or have an awareness of how to produce a safeguarding referral map, which could deter researchers from conducting studies in this field if adequate support and guidance is not provided.

To ensure appropriate participant recruitment, both LAs decided that children meeting the criteria (looked after children with a learning disability) would be identified by and approached through their allocated social workers. This approach would allow social workers to obtain consent from parents, children, and carers without sharing confidential contact details of those who chose not to participate. Assigning responsibility of identifying potential participants to their social workers also assured the LAs the safeguarding of each child would be a priority. They felt social workers were in the best position to assess whether a child is in a suitable position to take part in the research, ensuring that their involvement would not lead to any undue harm that might outweigh the research benefits.

Whilst there was no need for individual consent from social workers as this had already been provided by the LA, this method inadvertently introduced an additional layer of adult gatekeeping. This recruitment process also raises concerns about potential bias, as social workers might favour children who speak positively about their experiences with social care (Diaz et al., 2018). However, it is important to recognise this method was chosen to prioritise the protection of children and balancing the need for safeguarding with the potential limitations of this recruitment approach is a crucial consideration. Ultimately, the decision to involve allocated workers in the participant selection process aimed to safeguard the children while allowing them to have a voice in the research. Safeguarding concerns did ultimately lead to the loss of potential participants, where some social workers expressed reservations about discussing sensitive topics with vulnerable children which they felt may potentially cause upset or distress. The topic of the interview was around important decisions made in the child's life since being in care, so whilst these may be considered 'sensitive' they all relate to occurrences in the child's own life, therefore are events that the children are aware of and will likely have an opinion on. Whilst some children may feel distress at reflecting on these events, if done in a sensitive way they can be supported to understand their journey in care and express their opinions regarding this without undue distress. The discourse of 'protectionism' which sees childhood only as a time of innocence and vulnerability can result in children being denied opportunities to participate in research, to protect them from any discussions which may potentially be disturbing, upsetting or destabilising (Toros, 2021). Whilst safeguarding is essential, it should be assessed on an individual basis, considering each child's unique circumstances and resilience to prevent the potential wider harm of having this population of children's voices missing from the field.

Organisational changes and staff turnover

Whilst legitimate safeguarding concerns warranted the exclusion of several children, there were other reasons which challenged the participatory rights of this group of children, including organisational changes and staff turnover. Four LAs originally provided consent to recruit participants from their population of children, but one was going through a period of significant instability involving multiple changes to senior management, which resulted in a loss of knowledge regarding the research and a lack of prioritisation of team manager attendance at information sharing meetings regarding the research. Another LA had shown initial interest at several levels of management, however recruitment coincided with Ofsted inspection of their children's services and a phase of high turnover of case working staff, resulting in a lengthy process of attempted recruitment with no success. Therefore, the recruitment strategy was revised to recruit only from the other two LAs who were in more stable positions at the time.

Numerous children were excluded by their social worker as they had recently experienced a placement move or change in social worker, leading to concerns about introducing another new person or further changes. Whilst this decision was identified as being made in the best interests of the child, it poses a notable challenge for researchers in the field of social care. The Department of Education (2022) statistics revealed a high turnover rate of social workers in children's social care, with 15.4% turnover in 2021, the highest in the past five years. Additionally, 33.1% of full-time equivalent leavers left their positions within two years of service, and around 60% of the social care workforce had been in service for less than five years. Consequently, looked after children often have multiple social workers supporting them over their time in care, making continuity unlikely. As a result, this prevalent yet concerning practice of staff changes would automatically exclude a significant proportion of looked after children from participating in research.

These children by the very nature of being looked after have had disruption to long term stability in their lives and are likely to have experienced disrupted relationships with family, carers and social workers, insecure attachment, loss, and separation (Cocker & Allain, 2019). The children themselves are best placed to identify how a placement move or change in worker has impacted them, as each child will respond differently. Therefore, this needs to be considered when assessing whether changes justify looked after children not having their voices represented in research moving forward, so as not to automatically exclude all children who have recently experienced disruption. Furthermore, the disruption and frequent changes in these children's lives is a result of decisions made or implemented by LAs via social workers, with often no choice or power given to the children, as was found in the results from this study. Yet, the same system holds responsibility for deciding whether children can participate in research, highlighting the wider systemic issues involved in supporting the participatory rights of children in research within a system where children's rights to participate in their own life decisions are often not present.

There was a further challenge to participant identification due to the lack of response and engagement from individual professionals. Repeated attempts were made to contact team managers and social workers, with some never responding or engagement trailing off before participants were secured. As I researcher I maintained commitment by keeping the child's rights at the forefront of my approach, using resilience, commitment and tenacity, yet I also needed to acknowledge the current climate of social work practice. Social workers are busy professionals, with high workloads and at the time of requesting support from social workers to identify participants the full-time equivalent vacancy rate was 16.7% (Department of Education, 2022), meaning higher workloads for the remaining staff. This presented obstacles to recruitment, as engaging with the research requests presented an additional piece of work. In hindsight, a more direct approach to meet with each social worker individually, in person, and discuss potential participants could have been beneficial, as recommended by Diaz et al. (2018).

Recruitment through social workers

In addition to the potential loss of participants via social workers due to organisational changes and staff turnover, there are further considerations regarding the use of social workers for recruitment. In response to recruitment requests for this study some social workers expressed concerns regarding a child's ability to effectively engage in the research given their learning need. In seeking to identify potential participants other researchers have frequently reported encountering negative attitudes from gatekeepers regarding the child's communication abilities and capacity (Rabiee et al., 2005). However, it is essential to also acknowledge that social workers regularly work with children with a diverse range of abilities, especially within specialist children with disability teams. Therefore, the concerns raised may have been particularly relevant to children with non-purposeful communication. To prevent unnecessary loss of those able to engage in the research, even where this may be potentially challenging, I shared examples of the adaptations I would make to interview techniques and communication methods which would meet the needs of different children and gave reassurances regarding my abilities to engage effectively with children with a diverse range of needs.

At the request of the LAs, social workers in this study were also responsible for seeking consent from each child's parent(s), to prevent unnecessary sharing of confidential contact details. However, parents of looked after children could have a negative relationship with the social worker or social work involvement in general due to their personal experiences, therefore it is important to be aware that the child's social worker may not always be the most appropriate person to seek consent from parents. Considering this, other means of contact could be recommended such as seeking support from school or carers to engage parents, although in this study all parents who were approached for consent via their social worker did agree to their child's participation.

Using social workers as intermediaries involves entrusting social workers to pass on information regarding the purpose of the study and the requirements of participants. If a social worker is unclear on this information or is not fully committed to recognising the child's rights to participate in the study, this could lead to further loss of potential participants. This was mitigated as far as possible through sharing detailed participant information sheets to be passed on to parents, as well as child-friendly, accessible information sheets which could be adapted to meet the communication needs of individual children.

Consent of the child

Research with looked after children requires the consent of their legal guardians, however, the approach taken within this research placed equal importance on the child agreeing to take part, so afforded the opportunity to decline, even where legal guardians provide consent. Therefore, following consent from those with PR, consent was sought from the child. Whilst adult gatekeepers can be potential obstacles to access, they can also be useful facilitators for participant understanding in research (Munford et al., 2008). Communication and learning needs varied among the children who participated, highlighting the importance of recognising the expertise of those who interact daily with the child, such as caregivers, who are best positioned to enhance the child's comprehension of the research requirements and objectives. Therefore, ensuring the child's main caregiver understood the research was a vital first step to obtaining appropriate consent from the child.

To initiate the process, the parent information sheet was shared with each child's caregiver before my first visit, providing contact details for any concerns or questions the social worker had been unable to address when introducing the research initially. Subsequently, a phone call was conducted to give an overview of the interview's content, confirm the child's agreement for the visit, seek advice on communication strategies and level of likely engagement. Each caregiver was receptive to the research and did not pose any barriers at this stage. They acknowledged that communication with the child might be complex but expressed confidence in the child's ability to engage with the research if adapted to meet their specific needs. Moreover, many caregivers believed that the research topic would be beneficial for the child to engage with.

Within child research literature 'assent' and 'consent' are often used interchangeably. Jenkin et al. (2015) define assent as the child wanting to and agreeing to participate, whereas consent relates to the adult with legal authority or responsibility for the child approving and authorising their participation in the research. There is an argument that 'assent' is difficult to define and is used in diverse ways (Health Research Authority, 2020), which could in turn be harmful to children. Some researchers take this argument further claiming that children should provide their own consent where 'competent' to do so, whereas for 'incompetent' children this should continue to be provided by their parents (Baines, 2011). This argument goes against the value underpinnings of this current research, which does not see children as either 'competent' or 'incompetent', but rather as all having a right to make decisions for themselves. Taking a rights-based approach places a duty on the researcher to promote the child's competence as far as possible via accessible means of communication. Here, all children are seen as being able to provide some form of agreement, with this agreement being of equal importance to that given by those with legal responsibility. Therefore, the child's agreement to take part in this research was identified as 'consent'.

It should be noted that children often do not get the opportunity to consent in their daily life, yet they are being asked to provide consent here, therefore it may be an unfamiliar concept. The paradox of having children consent to taking part in research where they will reflect on decisions made in their lives where they had no opportunity to consent is a wider debate that is beyond the scope of the current paper, however it does raise important considerations for researchers to be mindful of the power relations between adult and child and their confidence to refuse consent when they may be unused to doing this.

Scott et al. (2006) outlines three key issues with gaining informed consent; competence to give consent, the extent to which the research is in the person's own best interests and the balance with public interest. In this research those with PR and adult caregivers are first tasked with identifying whether it is within the child's best interest to take part and it is the researchers, ethics committees and participating LAs responsibility to ensure the research is in the public's interest. The child was therefore not tasked with weighing up these decisions. Instead, the focus was on ensuring the child understood what would be involved during the interviews, what questions would be asked and the activities they will be asked to complete, so they could make an informed decision as to whether they would like to take part or not.

People with learning disabilities may have difficulties with problem solving and expressing their views, which can impair their capacity to give truly informed consent. However, researchers can take action to increase decision-making capacity, such as providing sufficient information to make the decision voluntarily and designing that information to be accessible for those who may struggle with the content (University of Sheffield, 2015). Bessell (2009) recognises that whilst some children may not understand the overall concept of the research, most will be capable of making informed decisions if necessary steps are taken to present the information in an accessible manner, with sufficient time for full explanation, to digest information and to ask questions.

To enable each child to exercise their rights and make informed decisions the consent process needs to be meaningful and active. This started with the use of accessible, child-friendly information about the research and the consent process, which was adapted in a format suitable for each child's communication and comprehension levels and shared in advance to allow time to digest the information. To ensure that consent was obtained directly from the child, the consent form was also thoroughly explained during the initial research visit. To accommodate the diverse communication and learning needs of each child, various methods were employed for consenting to the different aspects of the research, including the use of a thumbs up or down card, emoji stickers, marking boxes, or with the assistance of the caregiver present. Through these adapted approaches, each child was able to provide their own consent, and there were no instances of participant loss at this stage.

A concern when gaining consent from children with a learning disability is the potential for the child to feel coerced or obliged to participate. Ingrained adultism and ableism in society perpetuates the view that children with a disability are not able to appropriately articulate their own views, resulting in disempowerment. The children may be accustomed to agreeing with more powerful adults in their daily lives where they are not given genuine opportunities to make choices for themselves on a regular basis (Adams & Leshone, 2016). Thus, extra measures are required to be taken with 'vulnerable' participants to promote authentic consent and to address power relations. One way this was addressed within the current study was to follow guidance from other researchers in treating obtaining consent as an ongoing process that should be revisited throughout the research project rather than a one-time activity (Gray & Winter, 2011).

An equally important approach is to provide continuous opportunities to dissent, with respect and support given if a child indicates they wish to withdraw from the research at any point. Identifying a child's wish to withdraw can be challenging, especially for those with a learning disability who may not verbalise this request (Beresford, 2012), to address this, close attention was paid to non-verbal cues. Kelly (2007) also recommends the use of activities which allow the child to set boundaries, in turn providing more control for the child and allowing them to feel confident in withdrawing if they desire. This led to the creation of a 'stop card' for this study, which was implemented to provide a tangible and accessible means for the child to indicate their desire to discontinue participation, as well as opportunities for the child to make choices during introduction and throughout the interview. Additionally, consent was regularly reassessed during the research process. Whilst the stop card was not employed in any interview, an instance arose during one interview where the child communicated their dissent through distractive language and showed disinterest in engaging with the remaining research questions and activities. In response to this clear indication, the interview was promptly concluded to respect the child's wish to withdraw. This example highlights the need to be responsive to and respectful of children's verbal and non-verbal cues for dissent.

Key considerations and recommendations

Previous literature coupled with the insights provided by this case example, underscores the intricate challenges associated with obtaining access to vulnerable participants and securing their consent. Nevertheless, there exists a clear need for further research involving individuals who are often marginalised, and whose perspectives remain absent from both policy and existing literature. To foster inclusivity and representation in data collection, researchers must commit to engaging with groups that are traditionally considered 'hard to reach'. Achieving this object will undoubtedly demand persistence and active engagement with the ongoing debates surrounding access and consent.

In cases where a participant is deemed 'vulnerable', many researchers have found their work constrained due to the cautious stance of ethics committees within Higher Education Institutes. This hesitancy often stems from the perception that the level of vulnerability may surpass what can be safely managed within a research setting (Powell et al., 2020). Stalford and Lundy (2022) assert that this predicament leads to many researchers to opt for a more indirect approach to research, as they shy away from directly engaging with vulnerable children. They argue this is especially the case for PhD researchers who may not have the confidence, experience, or support to push back. Whilst this was not the case within this study, the anecdotal experiences and literature on the topic of ethics rejections did initially cause concern and sparked reflection on the method of data collection. Nonetheless, the pursuit of such research remains imperative, and aspiring researchers focusing on vulnerable participants should not be discouraged, particularly if their work aims to illuminate the perspectives of marginalised groups. Meticulous planning and preparation for the ethics panel proved to be successful in this case.

The experiences gleaned from the present research underscore the importance of early preparation and proactive communication with relevant agencies well ahead of the designated data collection period. Within this field of research, there are structural barriers to recruitment and consent, relating to the high turnover of staff and management, as well as the pressures on social work staff and services more broadly. As a result, the recruitment of participants can prove time-consuming, necessitating careful consideration of research timelines. Despite the obstacles faced in recruiting participants, the support and dedication of the children with a disability team manager played a pivotal role in achieving some success in securing participants for the research. There were also several social workers who maintained regular contact regarding their attempts to identify suitable participants and made significant effort to secure consent and support this research. This highlights the importance of creating and building relationships and connections with professionals who may be in a gatekeeping role when it comes to recruiting participants, as well as ensuring that professionals understand the importance of the research. This case study further emphasises the need for transparent and persistent communication with professionals, addressing concerns and fostering a shared understanding of research objectives.

On a broader scale, there is a pressing need for training that enhances professionals' comprehension of children's rights to participate in research within their organisations. While safeguarding of vulnerable participants remains paramount, there must be a balanced approach that safeguards children from harm whilst simultaneously upholding their participatory rights.

To foster inclusive research and enhance the capabilities of participants with a learning disability, consent methods need to be tailored to children's comprehension levels and adapted to suit their individual communication needs. There should also be opportunities provided for dissent while addressing the inherent power dynamics between researchers and vulnerable participants. By acknowledging the communication and comprehension abilities of children with learning disabilities, adapting information, and designing accessible consent processes, research can genuinely facilitate their meaningful participation.

The research presented a case study that sheds light on the experiences of looked after children with learning disabilities and the complexities of obtaining their direct participation. Moving forward, it is essential to continue exploring ways to empower and include this often-overlooked group in research, which will require the challenging of prejudices and a recognition of these children as legitimate research participants. Researchers should adopt a rights-based approach and acknowledge the capabilities of those with a learning disability, to facilitate more inclusive and empowering research. Their voices and insights are vital for developing policies and interventions that address their needs and well-being effectively. It is incumbent upon researchers, policymakers, and practitioners to work collaboratively to ensure that looked after children with learning disabilities are no longer excluded but instead heard, understood, and supported in research and in their everyday lives.

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