

The barriers involved in including vulnerable groups in research

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Research, I would suggest, is often a series of successes and failures. Reflecting on my own research, my failure to access one particular group of possible participants has proved to be problematic and will, most definitely, leave a gap in my findings. In my study, exploring the organisational influence of decision making in corporate parenting, this should have included young people, aged 16 years and over, who have had experience of being corporate parented. Their participation was important as, Ward et al (2004) explain that, in order to give best value, users' views must be considered in evaluating the provision of services.

The concept of corporate parenting came into being with the launch of the "Quality Protects" programme in 1998. This was in response to a critical study of the care system by Sir William Utting and was a Department of Health initiative to transform the management of children's social services. The principle of this programme was that the local authority was the corporate parent of children in care, having a legal and moral duty for the provision of support as any good parents would provide for their own children. The intention was not only to keep children safe but also to enhance the quality of their lives (UK Parliament, 1998).

Building on this, The Children (Scotland) Act 1995, introduced legislation providing for those who had left the care system after their school leaving age. While this may have embodied the notion of corporate parenting, it was not until the Children and Young People (Scotland) Act 2014 that, for the first time, those organisations and agencies responsible for corporate parenting were named. The expectation of corporate parenting, as defined in this legislation, is that the agencies named would work in collective collaboration, thus placing responsibility for the wellbeing of young care leavers on all of the partners.

Given the challenging childhoods and traumatic experiences prior to and possibly while in the care systems, the young people who had been corporate parented would be perceived to be a particularly vulnerable group (Jones et al. 2011). This reflects the developmental approach suggesting that children cannot make decisions regarding their future but are in need of protection (Foucault, 1975).

However, Alanen (1988) suggests that children and young people are actors in their own right and have the ability act consciously and make decisions.

Although the proposed sample of young people sought for my research were over 16 years of age, they were considered to be vulnerable and, according to ethical guidance, should be accessed through gatekeepers. Gatekeepers are those individuals or organisations who have the power to grant or withhold access to people or situations for the purpose of research (Burgess, 1984).

When seeking the views of those young people who have been involved in the care system, there can be a succession of gatekeepers. These can include local authorities, parents, carers and other agencies. While they have the responsibility to safeguard the welfare of children and young people, they also have a duty to consider the views of children and young people, taking into account their age and level of understanding.

This duty to consult children in relation to legislation was introduced in the Children Act 1975. This focus on the right of children to be heard increased with the adoption of the United Nations Convention on the Rights of the Child in 1989:

“the right of children to express an opinion and to have that opinion heard”
(Article 12).

These views were reinforced with the introduction of the Children Act in England and Wales in 1995 and subsequently, the Children (Scotland) Act of 1995 and the Children (Northern Ireland) Order 1995. These Acts emphasised the importance of children’s views being heard and taken into account in the legal decision-making process.

This then led to good practice guidelines for research with children, one of those being an online Research Ethics Guidebook by the Economic and Social Research Council. This sets out guidelines, which take into consideration the need to prevent and reduce harm to children and young people while also being aware of the risks of silencing and excluding them from research. By excluding them from research this also discounts their views and experiences. Indeed, Best Value requires that service users’ views should be taken into account in all evaluation of service provision (Ward et. al., 2004).

In seeking informed consent for young people, who had experience of being corporate parented, to participate in my research, I had to identify those agencies in a position to identify the sample group. The best route appeared to be to approach some of those agencies promoting themselves as advocates for young people. The primary focus of these agencies appeared to be giving children and young people a voice. With their vision statements and plans including; using the views of young children to tell the government what is important to them, speaking out for children and families when the

government or society fails to hear them, and ensuring that the voices of care experienced children and young people are heard by the people that have the power to positively influence their lives.

However, in my experience, this method proved to be fruitless resulting in either no response or, perhaps more concerning, refusal to consider identifying young people who might participate. This then begs the question of why are these young people being denied the opportunity of giving their views in independent research, given that some of these agencies appear to include them in government and other funded research.

The importance of consulting with children and young people on legislation and decisions being made about their future cannot be ignored. According to the Scottish Government figures, *Children's Social Work Statistics Scotland, 2016-17*, figures gathered up to July 2017, showed 5653 young people who were eligible for After Care services (Corporate Parenting). The figures recorded as receiving a service were, however, less than 3000 (53%) which suggests that over 2500 had no apparent support through the corporate parenting route. How can these young people not receiving services voice their opinions and, in doing so, influence legislation and the provision of services that might impact on their future if they are a hidden, unheard, population. It could be argued that an example of this is the Continuing Care provision which entitles young people to remain within their care placement until the age of 21. This provision introduced by the Children and Young People (Scotland) Act 2014, was informed by young people's views, and were likely to be influenced by the experience they had in care system. Those not accepting support and services are unlikely to have had the opportunity to give their views.

With the introduction of Children and Young People (Scotland) Act 2014, these figures will increase. Under this legislation, since April 2015, eligibility for aftercare services has been extended to include those young people up to the day before their 26th birthday as opposed to the previous age of 21. This raising of the age group by 5 years will have an impact on the resources and levels of support available should even 50% of care leavers accept the services to which they are entitled.

It seems that I am not alone in my unsuccessful efforts to include children and young people in my research. Through discussion and some exploration of the literature on this issue, it has become clear that several researchers have planned but struggled to gain informed consent from children and young people for participation in research that may have some relevance to their current, and future situations and circumstances. This prompted me to explore some of the literature on gatekeepers, their motivation and the importance of considering and including the views of vulnerable groups in research that may influence their current or future circumstances.

In a qualitative study on substance use communication between looked after young people and their carers, similar difficulties arose in accessing young people (Carver, 2017). Due to the restrictions of

the university, local authorities and other ethical regulations, access to young people had to be sought through gatekeepers. Carver suggests that some of the gatekeepers chose not to pass information onto young people as they may have considered them to be too vulnerable. Should this have been the case, it is possible that some young people who might have been willing to participate were excluded from the study.

This perceived vulnerability of children and young people and the adult gatekeeper's need to protect could be one reason for this reluctance to identify young people. Another might be the perception that they lack the cognitive ability to understand the research and the concept of informed consent.

Murray (2005), explored young people's participation and non-participation in research, based on a review of the 2004 Quality Protects database which comprised of 182 studies, since 1991, of which 72 were relevant to adoption and fostering. Of these studies, only 38 involved children and young people. She found that in most of the studies the target sample number of participants of children and young people were not achieved. The indications were not that this was due to a poor response rate from possible participants but rather that there were several other factors, one of the most fundamental to emerge was that of gatekeepers.

This then led to some exploration of the concept of gendered gatekeeping as, in the studies that identified gender of participants the indications were that more females than males participated. This may have been because less males chose to participate. However, Thomas and Beckford (1999) in their study of adoptive children, suggest that this could have been the result of some form of gender filtering by the gatekeepers. Murray (2005) suggests that this is an area that should be further explored as it could include filtering of other groups including those with disabilities and young people with black, Asian, and minority ethnic heritage. I would question that, while we may claim to listen to the voice of those deemed to be vulnerable, whose voice are we actually hearing?

In their evaluation of mentoring schemes for care leavers, Clayden and Stein (2002) achieved only half of their target sample of interviews. This appeared to be due to the reluctance to participate in their study by a number of the projects they approached who would have identified possible participants. Harwin et al (2003), had a similar experience when trying to interview children in relation to care orders. They found that, in the majority of cases, it was the carers who refused to allow the children to participate.

Neuman (2000), suggests that those who initially identify possible participants are gatekeepers and, as such, can influence the course of the research path. Therefore, the role of the gatekeeper can be a powerful one as they are representing vulnerable populations. Bound (2012) suggests that vulnerable includes any individual whose condition, status, or circumstances, make them susceptible to the

negative influence of others. This includes those who may be economically, socially, culturally and physically or mentally vulnerable.

While gatekeepers have a positive function and should protect the vulnerable from participating in damaging research, they are also in a position to suppress their views. This was similar to a conclusion reached by Masson (2000) who suggested that gatekeepers may censor the opinions of children and young people participating in research.

So, what motivates the gatekeeper? In discussing this issue, Bound (2012) explores how ethical violations by gatekeepers including manipulation of access to participants and possible coercion could, in turn, influence and bias data gathered. This could then affect not only direct participants (those who engage directly with the researcher) but also indirect parties as the findings of the research may inform legislation or funding and have an impact on their welfare. This reflects a much earlier suggestion that gatekeepers, by only identifying and including particular participants in research who are in agreement with their own or organisation's views, can direct the findings and recommendations of studies (Lee, 1993). I would suggest that, for research either commissioned or undertaken by the organisations they represent, gatekeepers have no difficulty identifying possible participants. Unless recruitment of research participants were a representative group with a range of views and experiences, it might call into question the validity of the findings of some of these studies and have implications for any funding or legislation informed by them.

We return to Ward et al (2004), who explain that, in order to give best value, users views must be considered in evaluating the provision of services. In my research this should have included young people who had experience of being corporate parented. While some of the professionals involved in the decision-making processes for young people who have been Corporate Parented have participated, it has not been possible to gather the views of these young people. It would appear that, not only in my research but also other studies, children and young people may have been denied the opportunity to make informed decisions as to whether they participate or not. There is no doubt that vulnerable people have to be protected, however, they also have a right to have their views and opinions listened to. Whether denying them that right is a result of the possible over protectiveness of gatekeepers or some other motivation is unclear. This is surely an issue that must be discussed and debated further and, I ask again, when the only way to reach vulnerable groups is through gatekeepers, whose views and voices are actually being heard?

References

- Alanen, L, (1988) Rethinking childhood, *Acta Sociologica*, 31(1): 53-67.
Bound, M., G, (2012) *Ethical Considerations with Gatekeepers*, Nova Southeastern University.

- Burgess, R, (1984) *In the Field: An introduction to field research*, London: Allen & Unwin.
- Carver, H, (2017) *Substance use communication between looked after young people and formal carers: A qualitative study*, Edinburgh Napier University.
- Clayden, J and Stein, M, (2002) *Mentoring for Care Leavers*, London: The Prince's Trust.
Economic and Social Research Council.
(ethicsguidebook.ac.uk/Research-with-children-105).
- Foucault, M, (1975) *The Birth of the Clinic: An Archaeology of Medical Perception*. TR. A.M. Sheridan Smith. New York: Random House.
- Harwin, J., Owev, M., Locke, R and Forrester, D, (2003) *Making Care Orders Work*, London: The Stationery Office.
- Jones, R., Everson-Hock, E.S., Papaioannou, D., Guillaume, L., Goyder, E., Chilcott, J., Cooke, J., Payne, N., Duenas, A., Sheppard, L.M., & Swann, C, (2011) factors associated with outcomes for looked-after children and young people: a correlated review of the literature. *Child: Care Health and Development*, 37(5).
- Lee, R. M, (1993) *Doing Research on Sensitive Topics*, London, Sage.
- Masson, J, (2000) Researching children's perspectives: legal issues, *Researching Children's Perspectives* (eds A. Lewis & G. Lindsay), Open University, Buckingham.
- Murray, C, (2005) Children and young people's participation and non-participation in research, *Adoption & Fostering Vol 29 Number 1*.
- Neuman, W. L, (2000) *Social research methods: Qualitative and quantitative approaches* (4th ed.), Boston, Allyn and Bacon.
- Scottish Government (2018) *Children's Social Work Statistics Scotland 2016-17*. Edinburgh.
- Thomas, C., Beckford, V., Lowe, N., Murch, M, (1999) *Adopted Children Speaking*, London: BAAF.
- Ward, H., Holmes, L., Soper, J. & Olsen, R. (2004) *Costs and Consequences of Different Types of Child Care Provision*, Centre for Child and Family Research, Loughborough University.

Acts and Statutes

- Children Act (England and Wales) 1975.
- Children (Scotland) Act 1995
- Children (Northern Ireland) Order 1995
- United Nations Convention on the Rights of the Child, (1989), Article 12.
- Children and Young People (Scotland) Act 2014