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Short Article

Adjusting the volume: Reflections on engagement with autistic young people living in secure care

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Abstract:

In undertaking a doctoral research project looking at the impact of Scottish secure care experience on the identity constructions of autistic young people, I experienced a number of unexpected challenges with engagement. This paper offers reflections on these complexities, in order that others may be informed by my experience. Some of these reflections are specific to engagement with autistic or neurodiverse young people, whilst others are of relevance for research with the secure sector or residential child care more broadly. Throughout the paper I share my learning on each aspect of this experience, with the intention that this learning may be given consideration in future research.

Introduction

In Scotland, residential child care provides accommodation together with personal care or support to young people who are unable to live at home. Secure care is a branch of residential child care that provides a safe, containing, highly controlled environment through restricting the freedom of children and young people, due to the high risk of significant harm they present to themselves or others (Children and Young People's Centre for Justice [CYCJ], 2024; Scottish Government, 2024).

The aim of this research project was to explore the impact of secure care experiences on the identity narratives of autistic young people. This is of current relevance due to the increasing prevalence of autism (Sample, 2024); at least 1% in the UK (Baird et al, 2006; Green et al, 2005), with 0.6% people diagnosed autistic in Scotland (National Records of Scotland, 2011). The variability and complexity of need that autism presents requires careful decision making about suitable placements, with the provision of environments and staff

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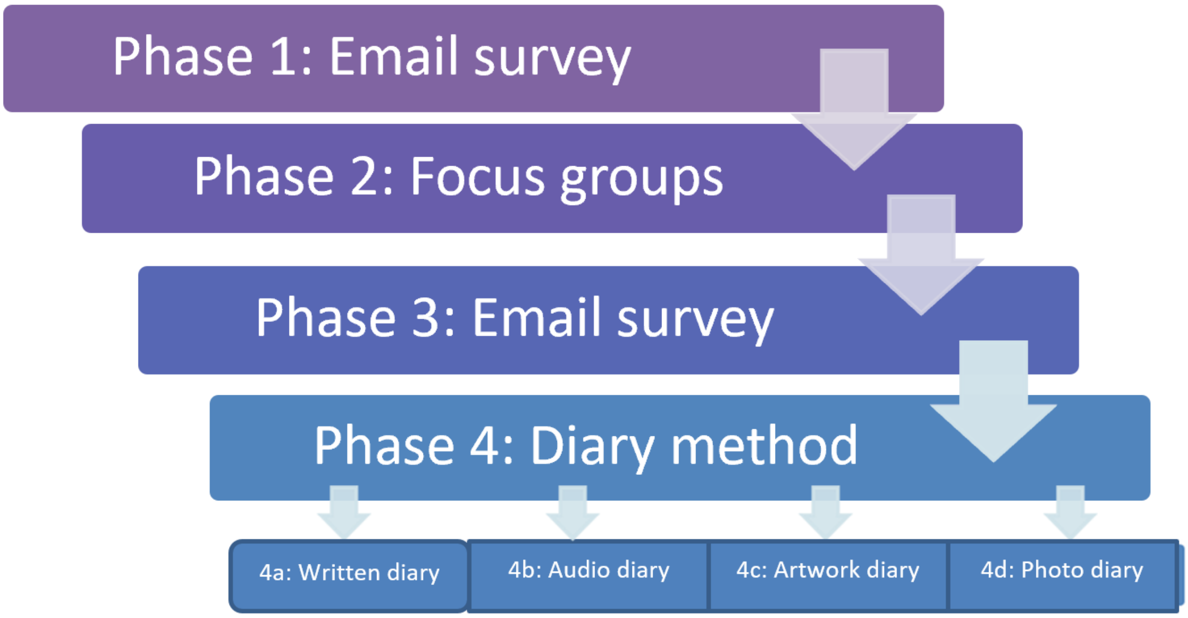
who are equipped to appropriately meet their needs. There is anecdotal evidence that increasing numbers of autistic young people and/or those with learning disabilities are being placed in secure care or 'juvenile correctional facilities' (Jolivette & Swoszowski, 2020; Thompson, 2018), however there is little research or data to support this (Allely, 2018).

The data for this project was collected over four phases between June 2021 and May 2024. The first and third of these were quantitative phases using an email survey to gather statistics on the number of young people who were suspected, self-identified, or diagnosed autistic currently living in secure care in Scotland. As well as providing a reliable measure of data (Bryman, 2008) and offering an opportunity for initial engagement and negotiation with gatekeepers (Blaxter et al., 2001), it informed the later phases of the research in terms of understanding the sample size of participants and which young people to make contact with. The second and fourth phases were delivered using qualitative methods, with meetings taking place at phase 2 to add an element of co-design (Abma et al., 2019) and to inform the developing methodology, and phase 4 offering engagement through four variations of the diary method depending on young people's cognitive style (Grandin, 2009).

Figure 1: Methods Map



Whilst the value of co-design and engagement with people with lived experiences cannot be underestimated, there were a number of unexpected challenges experienced during this process. I have employed an autoethnography approach here, with the self-placed in a cultural and social context (Reed-Danahay et al., 2020), to enable reflective learning; something which Curtis et al. (2004) feel is helpful in developing practice around research with 'hard to reach' children.

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Phase 1

The process of seeking formal consent from the units at phase 1 took much longer than anticipated, given that informal agreement and/or ethical approval to participate had already been granted. There was a careful balance to be achieved in pursuing formal consent whilst remaining sensitive to the pressures the units were under as a result of Covid-19 (World Health Organization, 2020). Gatekeepers changed frequently throughout the project, and each stage brought a different layer of gatekeepers (Vaswani, 2018); being able to navigate the complexities of this would have been more complex without having a background in residential child care myself. The exclusion of autistic voice from research (Fletcher-Watson et al., 2019; Raymaker, 2020), and silencing of children's voices more widely is not an unknown phenomenon, despite the Independent Care Review (2020) advising of the importance of listening to the 'quieter voices' of young people. Vulnerability is a dominant construction of childhood (Davis, 2013; Smith, 2010), resulting in the exclusion and oppression of young people (Moss & Petrie, 2002; Smith, 2010). This leads questions to be asked around how well young people are presented with engagement opportunities, and protected from marginalisation (Alderson & Morrow, 2011; Bird & Waters, 1989; Mockler, 2007).

There was confusion around the term 'communication preferences' (of young people) used in the survey, with services leaving this section blank, or referring to the use of English (whereas it was intended to mean verbal, visual, or sign). This seemed indicative of a lack of understanding around speech, language and communication needs. The involvement of the nurse in one service was supportive in this section being completed correctly, but the fact that autism sat under the remit of the nurse (and under the remit of psychology teams in other services) led me to question whether it was being medicalised (Bumiller, 2008).

Engagement

The level of work involved in individualising all initial information letters, participant information sheets and consent forms was extensive, but both important and necessary to meet individual needs. It was important to keep accurate records of what had been sent to whom, and what had been returned, and this was achieved using a colour coded table. It was also apparent that the amount of time required from gatekeepers to support with distribution was significant, due to me being unable to make direct contact with young people and their guardians. Aside from putting additional pressure on gatekeepers, it was difficult to explain what documents should be shared with whom, and to ensure the correct ones were returned, albeit the learning from phase 2 was supportive in enabling a smoother process during phase 4. Curtis et al. (2004, p.169) recognise that 'in leaving the process of invitation to the research in the hands of gatekeepers we are not entirely taking responsibility for ensuring young people's fully informed consent'. Interestingly, when inviting young people to

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complete the consent form in person, both versions of the form were offered (by holding both out) and on every occasion all young people bar one chose the form with the supporting visuals.

Contact with gatekeepers was avidly pursued, ensuring that there were opportunities for young people to meet with the researcher if they chose to do so. All young people expressed a preference for individual (rather than group) meetings, and face-to-face (rather than virtual), which came as a surprise due to the potential benefits of online meetings (McAloon & McLaughlin, 2020; NAS, 2020). Memorising the questions I wanted to ask meant that we could just ‘chat’, and this felt more natural than having to refer to notes. It was difficult to engage with some of the young people, with some of them changing their mind about participating even after they had agreed to take part, or having an unsettled day which meant meetings had to be rescheduled. When they changed their mind on the day of the meeting, an alternative meeting was quickly scheduled. This was always caveated with a reminder that participation in the research was voluntary, and young people could withdraw if they no longer wished to take part. The audio recorder used may have been off-putting for some young people, so this was introduced at the initial meeting simply by being present and not used. One young person commented that it was ‘like what the police use.’

Physical access to the units brought additional complexities, which felt like another layer of gatekeeper approval. The difficulties with engagement appeared to be reflective of the complexities of trying to reach this very vulnerable group of young people (Chapman et al., 2020; Vaswani, 2018). Meeting with young people without staff present felt more natural, although I recognised that individual young people would have specific risks which may require the presence of a staff member. When staff were present, young people often deferred to them for the ‘answers’, which has parallels with others’ findings within research undertaken in children’s homes or schools when adults were present (Pyer & Campbell, 2013).

Terminology

Due to the presentation of some of the young people involved in phase 2, and the fact that autistic people are less likely to comply with gender norms (LGBT Youth Scotland, 2022), I was careful to ask about pronouns as we moved into phase 4. This required an explanation of what pronouns were, which I had not anticipated, with young people expressing bemusement that I was asking the question. This was evidenced by one young person who responded, ‘well I’m a lassie aren’t I, so she/her!’ Gender data was not included in the surveys, which I felt was supportive of gender fluidity given that young people were not able to self-describe in the survey responses (Watts, 2021). Eight out of the 12 young people who engaged in the phase 4 cohort identified as female, which was surprising as this is not reflective of the wider autism population (Green et al.,

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2005). It is possible that this is indicative of the picture of autistic young people who are placed in secure, perhaps due to concerns about them being ‘at risk’ and vulnerable (Roesch-Marsh, 2014).

There was very little preference during phase 4 expressed by young people around terminology (for example ‘autistic’, ‘person with autism’, or ‘on the spectrum’), with the exception of one young person (with an autistic parent) who expressed a clear preference for ‘autistic’. This is the language used here to reflect the majority of participants’ preferences. Others during phase 2 expressed a preference for ‘on the spectrum’, which is not reflective of the wider autism community (Belek, 2019). This difference could be accounted for by these young people’s potential lack of engagement with the wider autism community, and it is of interest to consider whether there is any correlation here between young people’s autistic identity and their being placed in secure. Whilst identifying positively with an autistic identity (Cooper et al., 2017), and participating in autistic community (Bagatell, 2010) can act as a protective factor, the converse is also true. Identity management behaviours such as masking or camouflaging (Lai et al., 2017; Pearson & Rose, 2021) increase in correlation to autism-related stigma with a resulting impact on identity (Perry et al., 2021).

Posters were provided to allow young people who were perhaps ‘under the radar’ to make contact. There were almost no young people who self-identified as autistic, which was surprising given recent developments around this (Russell, 2020), and only one who took part in the research. However, this may have been due to the age and developmental stage of young people, and their developing identities (Erikson, 1963; Marcia, 1980; Stangor & Walinga, 2016), with self-identification perhaps being more prominent in adulthood. A parallel example of this is teenagers’ rejection of neurobiological definitions (Ortega & Choudhury, 2011). Theories around developing identities (Stangor & Walinga, 2016) may also provide an explanation for young people’s lack of concern about terminology and pronouns. However, LGBT Youth Scotland’s ‘Life in Scotland’ survey (2022) of 1279 LGBT young people aged 13-25 makes repeated reference to pronouns, showing that this is of importance for some young people. It is also reflective of the differences between adults’ and children’s concerns (James & Prout, 1997; Powell et al., 2021).

Codesign

The views of the seven young people who took part in phase 2 were used to inform the methodology of phase 4. All of the young people were happy with a flexible diary method. Some young people described how they couldn’t read or write but liked taking photographs or drawing. Other young people told me that they liked writing or creating artwork. They were all comfortable with the suggested timeframe of ‘up to one year’ (this was later extended due to delays with engagement), although some were concerned that they would not be

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resident for a year. For that reason, and to really attend to what they told me, the methodology was amended to include young people who participated in phase 2 but may since have left the service, or to allow for young people to continue to take part once they had left secure care. Unfortunately, the difficulties with making contact were insurmountable. Some young people were particularly keen to meet with me to discuss their data, with most young people feeling that prompt questions would be helpful to support their reflection. Without exception, all young people thought that compensation was a good idea, with the primary preference being for financial compensation. There were also more creative suggestions for compensation such as art supplies, a certificate, and even a hamster or a dog. To manage potential risks associated with financial compensation, Amazon vouchers were used rather than cash.

Phase 4

Written questions were posted weekly to each participant on a hand decorated postcard. During the data construction at phase 4, one young person advised that receiving weekly written questions was ‘fine’, however found it difficult when staff did not give them the mail every week (this was in part due to Covid-19 outbreaks, and postal strikes which had not been anticipated), meaning they would receive several weeks’ worth of questions at once. One young person advised:

> The first question I got I freaked out a little bit coz I wasn't sure who that was from, but um, yeah I get my questions out, I read them, I have a think about them, try and remember them for when I come in for our meetings.

But when asked how they felt about getting questions through the post, they responded, ‘em I don’t mind, it gives me a good idea of what we're gonna be talking about when we meet’.

Other young people also noted that having the questions in advance helped them to prepare for our face-to-face meetings. Moyse (2023) noted similar benefits to providing questions in advance of interviews in her research with autistic girls. Some young people agreed to take part in my research, but then found it difficult to engage. Twelve young people (around 80% of autistic young people who were living in secure accommodation in Scotland at that time) expressed an interest in participating, and data was received from seven of these. This resulted in data being collected from 58% of young people who showed an interest in engaging in the project. Only one young person chose to draw responses, which was surprising given the feedback provided by young people during the co-design element in phase 2 of the research project but aligns with the experience of Moyse (2023) during her research with autistic girls.

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Alternatives such as meeting online (with camera off if preferred) were offered. It was important to be flexible in approach, with a variety of methods of engagement available to cater to individual young people's preferences (as included in the research design). A variety of times were also offered, such as evenings or weekends, which may have suited some young people better. Curtis et al. (2004), in considering research engagement with 'hard to reach' children, similarly advise on the importance of flexibility, both from their own research experience and that of other researchers. The timing of meetings in relation to what else young people had going on in their lives was important to consider. Some young people declined to meet as they were having an unsettled day or week. One young person, whilst keen to engage (and able to offer some data) had to withdraw from participation due to being hospitalised for an extended period. One young person was noted to be significantly less focused during the final interview, five days prior to moving on from the service. Another was able to verbalise their preference not to have an interview within days of their court date, as this would be the focus of their attention at that time.

When carrying out the semi-structured interviews it was important to allow sufficient response time. Smith et al. (2022, p. 63) advise that 'richer, fuller answers will be cut short if the interviewer jumps in too quickly'. This is particularly true for autistic participants who may require a longer processing time. It was found that young people having access to the questions in advance, even where they hadn't provided a response to these, was supportive in allowing their consideration of responses. Differences in how young people supported their own need for additional processing time were observed. These included verbally advising that they required additional processing time, repeating the question back to the researcher, or using unnecessary 'filler' words in their responses, such as 'basically' or 'obviously', to afford themselves additional time to respond.

The flexible diary methodology was supportive in allowing access to aspects of experience that were perhaps more difficult to express verbally (Smith et al., 2022). It is possible that exploration of the themes may have furthered some young people's understanding of their self, or their constructions of secure care. To ensure sufficient depth and richness of data Smith et al., (2022) advise using follow up questions to probe responses. For young people engaged in this project, the 'probing' was carried out over an extended timeframe; often over the course of more than one meeting. For some young people, the same question was asked on more than one occasion. It was noted that this elicited varying responses. This may have been due to the variation in presence of staff from the service; young people becoming more familiar with the researcher; or perhaps just being in a different frame of mind. Some young people found it difficult to respond to some of the questions, or to recall certain events, particularly those related to the day of admission when they may have been under increased stress. This included difficulty with reflections on search

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procedures, which are carried out when a young person is admitted to secure care to ensure they are not bringing in any unauthorised items and are usually carried out manually by staff doing a physical search, or electronically using a wand (unit dependant). Interestingly, although more than one young person referred to blanket restrictions, nobody mentioned physical restraint or seclusion.

Conclusion

The need for a researcher to be able to maintain resilience during periods of limited engagement such as those described here is critical. There are parallels to be drawn with resilience practices in residential child care and child and youth care studies, which Garfat (1999a) describes as 'hanging-in'. There is a careful balance to be maintained between being available to young people and recognising that they may not be able to engage at this time; akin to Garfat's (1999b) description of 'hanging-out'. For young people who were able to engage with the researcher on multiple occasions, the relational impact of ongoing engagement on a one-to-one basis, and the opportunity to both take part in research and have the space to talk about what felt important, may have had a positive impact on young people's developing sense of self. When reflecting on how it had felt to take part, one young person advised:

> Oh. It hasn't been stressful or anything, I mean I'm used to talking to people about how things are going, what's happening, all the environments I've been in I'm used to doing that and er, happy to contribute to any positive outcomes for future young people that come in to secure.

In exploring the 'balance' that is required in residential child care, Anglin (2002) describes the struggle for congruence, which he defines as a combination of consistency, reciprocity, and coherence. With the researcher's previous experience in residential child care it was possible to draw on these concepts in an attempt to present a relational model of research. The ability to triangulate the concepts of knowing, being and doing required by residential child care practitioners (White, 2007) is similarly beneficial to researchers. This is particularly so when engaging with 'hard to reach' children such as those invited to take part in this research project, and echoes Steckley's (2020) explorations of praxis in developing a parallel between educators' and practitioners' knowledge gaps between theory and practice. In this instance the researcher was able to draw on their residential child care experience when attempting to align their practice in a relational manner, in an ongoing search for congruence.

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