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Chapter 5

Centring the voices of disabled LGBT+ young people in research: Ethical and methodological considerations

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Introduction

Young disabled LGBT+ people often face multi-dimensional discrimination and exclusion in their everyday lives. They are often denied opportunities to express their authentic identities and voices, and face barriers to having their rights met as disabled and as LGBT+ people in a world that still predominately chooses to ‘other’ them or deny, and in some cases outlaw, their existence.

In addition, until very recently, this group have also been denied opportunities to share their experiences, and have not been afforded attention within research agendas. Often falling between gaps in disability, sexuality and youth studies – where majority populations and homogeneity within groups are often the focus. Few studies have sought to centre the voices and experiences of young disabled LGBT+ people in order to better understand their lives and acknowledge their intersectional identities and the impact of this on their everyday family, school and social lives.

We draw upon our work which aimed to address this gap in our understanding. We also sought to develop an approach and methodology which would address multi-dimensional discrimination and exclusion, and try wherever possible to overcome power differentials in the research process. Our approach was under-pinned by the work of Collins and Bilge (2016) in which we sought, through the exploration of the impact of multiple factors, to reveal power imbalances and inequalities. We do not see intersectionality just in terms of how multiple identities contribute to a person’s self. For us, it is important to explore how intersectionality can be used as a tool in understanding how

disabled LGBT+ young people are situated in terms of conceptions, inequality, and power imbalances, based upon age, sexual and gender identities and disability. In this chapter, we explore how these intersections impacted on the research study and how we approached and undertook the research in ways which sought to overcome any inequality or power differentials which might hinder the young people's opportunities to participate in the research or be encouraged to share their experiences and authentic selves. We wish to share an honest account of some of the considerations, challenges and successes of researching alongside young disabled LGBT+ people.

First, we will present the background to this work, exploring the gaps in research and why it is important to recognise this group and give them a research platform for expressing their views and experiences. We will then explain the aims and methods of our study before considering a number of issues which we feel warrant further discussion in this newly emerging field of research. These include:

- Accessing young disabled LGBT+ people.
- Whose voices are we hearing and who is still being silenced?
- Issues of consent and capacity.
- Issues concerning confidentiality and anonymity.
- Language, identity labels and issues of power within the research process.

Finally, we consider the importance of ensuring there is a balance between managing risk and ensuring the protection of this group of young people in the research process, whilst also ensuring their rights to express their views and undertake empowering positions within research and within the emerging research agenda. We conclude by offering some suggestions of how we might overcome some of these issues as an encouragement for further research and debate in this area.

Background

Disabled childhood studies

Watson argues that disability is rarely found in generic childhood research that

would recognise other social markers such as gender or ethnicity (2012). Similarly, Slater states that ‘disability is too often side lined, returned to, added on or omitted altogether from research surrounding youth’ (2013: 180). When disability is the focus, it is predominantly examined through a social, political and/or economic lens, with medicalised and psychiatrised conceptualisations of disability prevailing. This has profoundly influenced the nature of research undertaken with disabled children and young people, whereby they are often viewed within deficit models and problematised. Their childhoods are rarely studied, with little attention paid to the perspectives of disabled children themselves. Although in relative infancy, disabled childhood studies as a distinct discipline has done much to push forward an agenda of inclusion of disabled children and young people in research studies in more empowering ways than as data ‘objects’. Curran describes this as a movement to bring disabled children’s views to the centre and create research space (2013). Due to limitations with funding, much research in this area has been service orientated and of an evaluative or applied focus (Abbott, 2013). However, increasingly studies have sought to explore and understand the lives of disabled children through their own accounts. One of the reflections of some of the earlier disabled childhood studies work has been that in pushing for inclusion of disabled children within scholarly activity, it may have fallen into the trap of treating disabled children as a homogenous group neglecting to see the intersectional nature of identities such as gender, ethnicity or sexuality in disabled children and young people’s lives. Furthermore, the intersectional barriers, oppression and discrimination faced by, for example, disabled children living in poverty, black and ethnic minority disabled children and (in the case of this chapter) disabled children and young people who are LGBT+, have rarely been explored. It is thus important to open up opportunities for their engagement in research so that we can understand the full richness and tapestry of their lives and not view disabled children and young people as one-dimensional, be that just through a disability or child-focused lens.

Disability and sexuality

Research on disabled sexual lives also does not have lost history. This is considered to be in part due to sexuality in the lives of disabled people often being denied (see Liddiard, 2018). Over the last couple of decades, the work of

Shakespeare et al. (1996); Goodley et al. (2017), Liddiard (2014, 2018) and Slater (2013) have drawn attention to this area and have addressed gaps in our understanding. However, research regarding non-heterosexual disabled lives is still emerging. The work of Abbott and Howarth (2007) and Blyth (2010) has done much to highlight the experiences of disabled gay men. These important qualitative studies have been undertaken with adults. Even when they have included aspects of retrospection, they do not allow us to have insight into the lives of young disabled LGBT+ people currently, where the world is fast changing, conversations about sexual and gender identities are more common, and social media plays such an important role. It is important that we understand and explore the here and now experiences of disabled LGBT+ youth. Undoubtedly, many experiences of older and younger disabled LGBT+ people will be similar, we can expect that they will face many of the same experiences – positive and negative. But it is unquestionably a different world than even ten years ago for disabled LGBT+ people. Corker (2001) argued that it was really important to explore young lives because they are periods of exploration and getting to know oneself. Similarly, Toft et al. (2019b) have reported how for disabled young people periods of sexuality and gender exploration are often viewed as a ‘phase’ and although it is a period of exploration, this study illustrated that this does not mean that there has to be a specific end-goal. It is just the period in which young people begin to question and understand their own identity – and thus worthy of study in its own right.

Young, disabled LGBT+ studies

There are few studies which have thus far centred on the experiences of disabled LGBT+ young people. These studies are often small qualitative studies providing a rich depth of experiences, often shedding light on societal, structural and cultural factors that impact on the lives of LGBT+ disabled young people (e.g., Dinwoodie et al., 2016; Juvva et al., 2020, Michaels and Gorman, 2020). These studies have offered an insight into the worlds of this group of young people, but rarely have researchers reported the barriers and facilitators that have enabled them to connect with this group – a group whose authentic lives are often hidden, who are often prevented from making their own choices, decisions and/or being able to express themselves, their views and experiences (Toft et al., 2019b).

Despite such strides forward, there has been little reflection on some of the ethical and methodological considerations which have faced researchers striving to ensure that this new and emerging area of research pushes boundaries, involves more representative groups of disabled LGBT+ children and young people; whilst developing research methodologies which place disabled young people in more empowering roles and enables them to express themselves and their views and experiences in multiple ways.

This chapter aims to reflect on the authors' experiences of working in partnership with a group of young disabled LGBT+ people to undertake a small qualitative, exploratory study, and subsequently establish a young disabled LGBT+ researchers' group in order to develop a research proposal, and with future funding undertake their own research. This chapter is intended to be an honest and reflective account of some of the challenges, and to debate potential ways forward of seeking to involve disabled LGBT+ young people in empowering ways within the research process. We do not profess to know the answers, and indeed many of the solutions require wholesale change in how society values, views and treats this group of young people. We also acknowledge our gap in understanding, and experience, of undertaking participatory research with this group of young people in other cultures and contexts. We have sought to find examples, and are seeking collaborations, to address this gap and share learning, especially within the global south, where Western concepts of disability, sexuality, gender and youth might differ. However, research in both the global south and north is still emerging in this field, and we are all on a learning journey.

We also appreciate that some of these issues raised below are not unique to this group – they are barriers often faced by any oppressed group to being involved in research. However, discussion of their application to this specific group of youth appears to be unique, thus it is important to share challenges and successes as we seek to remove the barriers faced by this group to being heard, and empowered within research agendas.

Our study

The study reported here challenges notions that disabled, LGBT+ young people are passive research subjects. At the core of this project was the ultimate idea of empowering a group of young disabled LGBT+ people to become equal

partners with academic staff in a research study. Funding was received by the British Academy to undertake a small-scale qualitative study, piloting participatory methods and exploring the lives of disabled LGBT+ young people from their perspectives. We sought to use their experiences and stories to explore their identities. Taking inspiration from the work of scholars exploring sexual and gender identities and sexual storytelling, and framing the study within intersectionality, we explored and analysed how identities interact and inform. It was hoped that through a greater more nuanced understanding of the lives of this group that inequality and exclusion could be better understood and ultimately reduced.

In our study we undertook one-to-one interviews (13 participants) and focus groups (two groups: 10 and 12 participants, respectively). The young people were aged between 17 and 25 and identified as LGBT+ (a term they have chosen to use to define their group). The sample included young people with learning disabilities, autism and/or mental health needs. Interestingly, a number of participants did not identify with a label of ‘disabled’ or consider themselves to be disabled despite being part of a group for disabled LGBT+ young people and/or attending a specialist college for disabled young people. Further in-depth exploration of this is not possible within this chapter; however, the significance of this for the undertaking of the study is explored further below.

The sample was purposive, and due to challenges in recruitment we ultimately worked with gatekeepers with whom we had an existing relationship. As part of their professional roles they worked with disabled LGBT+ young people in an educational and youth group capacity. The young people knew each other and considered focus groups a comfortable, supportive environment for them. The individual interviews complemented the group work as it enabled more in-depth discussion and exploration of personal stories and the sharing of information, which the young people may not have wanted to share or explore in depth in the group setting. A ‘toolbox’ of creative approaches was developed in order to support the young people to express their views in any way they chose, to feel more comfortable and to reduce the intimidation of having to talk directly and intensely with the researcher. The toolbox included vignettes, role-playing exercises and card games. All access needs of the young people were sought prior to the interview to ensure that the

interview or group approach was accessible to all. The tools we developed were all accessible to this group, however, we are aware that they may not have met other disabled young people's access needs and would urge an individual approach to making the research encounter accessible to young people with other impairments. We note that our sample did not include young people with complex communication needs or sensory impairments which would require appropriate adaptation to the approach.

The findings from this study contribute much new knowledge in terms of a more nuanced understanding of sexuality and gender in the lives of LGBT+ disabled young people – including the idea that sexuality is often seen as a phase in their lives and as a result of the misconception and interplay of age, sexuality, gender identity and disability (see Toft et al., 2019b), and the complexity of lives of this group of young people who are constantly negotiating and shifting identities in different spaces and places (Toft et al., 2019a). However, the results of the study are not the focus. This was a pilot project with the aim of testing methods to address power relations and explore how we might examine complex issues of intersectional identity. We aimed to build trust with a group who we could also develop a longer-term relationship, whereby they would set the research agenda moving forward and learn and be supported to become researchers and co-deliver a research project where power imbalances between the young people and academics were equalled as far as possible. This model of empowerment has been previously undertaken by Franklin in studies with disabled young people and reported in detail in Brady and Franklin (2019). The aim of this paper is not to discuss this model in detail but to highlight the additional challenges faced when undertaking this work with disabled LGBT+ young people and where the focus is on gender and sexual identities. It became apparent that the addition of seeking to work alongside disabled young people who identify as LGBT+, and/or seeking to explore issues of sexual and gender identity of disabled young people, presented new considerations to our model of co-led disabled young people research.

There has been little discussion of the involvement of disabled young people as co-researchers or research leaders. Rare exceptions to this include Watson et al.'s (2014) study with children with little or no speech, Liddiard et al.'s (2018) on-line co-researcher collective and Brady and Franklin's (2019)

reflections on power and protection in a co-led disabled young researcher study. We aim to contribute to these debates.

Ethical and methodological issues raised

Accessing young disabled LGBT+ young people

One of our initial challenges was how to access a sample of disabled LGBT+ young people aged 17 to 25 years in order to approach them to invite to take part in the research study. Our study was focused on this age group due to this period being a time of identity exploration but also due in part due to a short time frame and limited funding. However, there was an awareness that we would face considerable challenges in accessing an under 16-year-old group of disabled LGBT+ young people. Experience of undertaking many studies with disabled children and young people has indicated extremely high levels of gatekeeping and denial of access to disabled young people through over-protection (although often well-meaning). It is also well established that research within the fields of youth sexuality are also subjected to high levels of ethical scrutiny and a risk averse bias over the rights of young people to participate in research about their sexuality (Whittington, 2019). This is explored further below.

Accessing children and young people through schools and colleges is often a successful route for researchers. Children spend vast amounts of their time in education settings, and often education providers can see the benefit of their pupils' participation in research as both a learning experience and opportunity to take part in an activity which might benefit others – and thus grant access. However, in the UK it is still the case that there exists much prejudice and misunderstanding concerning discussion around sexuality and specifically non-heterosexuality. This is a legacy of the ideology of Section 28 (Local Government Act). Although this was repealed 18 years ago, Section 28 created an atmosphere of uncertainty and confusion regarding what is included in teaching concerning sex and relationship education. Equating teaching with promotion, it legitimised phobia based upon sexuality and gender identity, mainly through the absence of discussion regarding LGBT+ relationships and identities (Toft and Franklin, forthcoming). The legacy of this continues as

LGBT+ identities are still positioned as non-normative and mostly erased within a heteronormative education system. Simultaneously, disabled young people are often excluded from any discussion and lessons on sex and relationships due to ableism which denies disabled people sexuality or gender identities. This often creates an atmosphere of fear, anxiety or denial in educational settings and thus limited opportunities to research sexuality and related topics in school settings. A personal example of this occurred when one of the authors was escorted from a residential college following a very innocent conversation with an 18-year-old female who wanted to share that she had a boyfriend – it was said by a senior tutor that ‘we do not discuss those sorts of things here; our pupils do not have boyfriends and girlfriends’. The infantilisation and denial of the sexuality of disabled young people was a further barrier to overcome in recruitment for research.

In the UK there are very few youth services or voluntary sector organisations working with this specific group of young people, and as such young disabled LGBT+ people do not have a defined, well-established ‘voice’, advocacy or lobbying movement through which to access them. This group of young people are often hidden (although often in plain sight), falling between gaps in support – their intersectional identities not necessarily a focus for LGBT+, disability or children’s policy and practice attention. Of course, young disabled LGBT+ people will be accessing youth services (either mainstream youth provision or specialist disability services), but described research in this area may be seen as a taboo subject and not a topic area services want to open up for discussion. We also learnt following our data collection that many young disabled LBGT+ people may camouflage and hide a disability or choose to keep their sexuality a secret, and thus services may be unaware of young people’s identities. Our experience in under-taking disabled child-centred research has also taught us that mainstream services have a very narrow definition of disability, and thus if asked if they support the disabled, young people will often say no as they presume this means a physical disability. With further conversations, where possible, it becomes apparent that they support many disabled children with a whole spectrum of needs. Thus access to this group via educational settings and youth services is wholly reliant on gatekeepers’ understanding and knowing who they support, being willing, not prejudiced, not over-protective and valuing a young person’s right to

participate. It is important that we continue to challenge some practice to recognise the rights of this group to be involved in research opportunities and to have a voice.

Accessing young disabled LGBT+ people via online spaces would be a possible avenue as these are not so reliant on gatekeepers and in many ways are spaces which are independently accessed and determined by young people themselves. Cuthbert's (2017) recent work with asexual identified disabled persons is one such example of successful use of online spaces. However, online spaces are not accessible to all disabled young people, and this method raises important ethical issues for accessing younger disabled children and ensuring children and vulnerable young adults are properly protected. We decided against online spaces for our study as we wanted to explore identities in depth and build longer-term relationships – for example, if the young person was interested in future opportunities to become a research leader. Face-to-face interaction was thus important. Recruiting via social media may be considered a useful approach, however, we were concerned that we were potentially raising difficult issues and personal experiences in an online space, where it would be difficult to ensure that the young person had access to ongoing support.

Fortunately, the authors connections with a college and specific support group working with a group of disabled LGBT+ young people enabled us to access our sample. Although this was not a large or representative sample (we did not seek this), it does raise concerns about how you might achieve a larger, more diverse sample in the future and how we enable more young people to share their experiences. This highlights the importance of working in partnership with young disabled LGBT+ people to help identify approaches which might open up avenues of access. Young people can become positive ambassadors in teaching gatekeepers and professionals about the positive experiences, and the importance of research participation and this could be an important method to facilitate change in attitudes. Equally of importance is the building of relationships with practitioners who support young people so that they can begin to trust researchers, understand the research process and provisions made to support young people and your motivations so that they can become less risk averse and support the development of this area of work. This lack of recognised avenues for recruitment also raised another dilemma

for the research team. This concerned our duty to support the young people should issues be raised in the interview which required signposting to support services. We were conscious that participation in the study may trigger difficult or even traumatic past experiences and/or bring issues to the fore which highlight oppression and exclusion. On a more positive note, talking about these issues may also heighten a desire to explore their sexuality and gender identities, seek out community engagement or a desire to make a difference – we wanted to be able to point the group in the direction of good quality support, information and opportunities. However, despite much consultation and searching, we were unable to find appropriate support available to meet the specific needs of this group. This was a concern, but one which we were able to address because we worked in close partnership with the gatekeepers who were undertaking pioneering support work in this area.

A finding from our research has also indicated the need to carefully consider the location of data collection with this group of young people. The young people we interviewed spoke at considerable length about the lack of ‘safe spaces’ for them. Some had a perception that they would be unwelcome in the community and within social spaces because of their disability, their sexual or gender identity or the intersection of these. Others had experienced homophobia, ableism, and in some case hate crimes and violent assaults. Thus the need to consider safe spaces for data collection is vital. The home, school or youth club, for example, might also not be considered safe either. Some of the young people we interviewed were afraid of being ‘outed’ and had hidden their identity. Therefore, the need for flexibility in the research approach and empowering young people to choose their own safe space cannot be underestimated. Limited accessible venues and accessible transport also creates additional barriers and considerations for this group. We were fortunate enough to access young people who felt safe in their college and support group; however, it should be noted that the support group met in an undisclosed location to avoid incidences of homophobia.

Who are we reaching?

As indicated earlier, gatekeeping and access restricts who we are able to recruit for research. However, we also reflected on how we ‘advertised’ and informed young disabled LGBT+ people about the study. The development of accessible

information sheets and consent forms was part of the initial ethical approval process and is further discussed below. Yet, initial contact, or the first impressions we made with this group of young people, took on a significant importance – written information may not be enough, even if accessible and inviting.

Our research findings have indicated that many of the young people in our study had experienced high levels of discrimination, prejudice and lack of understanding often from adults in their lives whose task it is to support them. Not surprisingly, trust and authenticity is important to them. In some cases, the young people in our study had hidden their identities because of the reactions of others and prejudice. Our good relationships with their support workers and their endorsement of us was vital in terms of the young people seeing the value in taking part and trusting us. Trust was also identified as an important issue by other disabled young people taking part in co-led research. In this case, trust developed when the young people saw the researchers as ‘human’, meaning that they shared something of themselves with them and made a human connection by being interested in them (Brady and Franklin, 2019).

Accessing young disabled LGBT+ people in the few studies thus far undertaken in this field have predominantly been through support services. However, this does mean that in these studies we are only hearing the voices of those who have accessed support or who are maybe more open with their sexuality or gender identity, as they will have confided or been open with support workers. This raises the question of how do we reach those with communication needs, those questioning their gender/sexuality or those living in residential settings or institutions where outside access is limited. Of equal importance is those young people living in cultures/religions and spaces where their identities have to remain hidden. It is important that we seek to understand the multitude of lives this group of young people live and to challenge when young people are silenced, particularly if our motives are to highlight issues such as oppression and inequality.

Consent and capacity

Issues of consent, especially with children, are always contentious and difficult to negotiate. It is still the case in the UK that many ethics committees within statutory, academic and voluntary sectors will not permit research studies with

children under the age of 16 without parental or guardian consent – research with children is often considered high risk. Our own experiences in undertaking research with disabled children has often seen that age range be extended to 18 years and beyond because of concerns ethics committees have expressed regarding capacity to consent by disabled young people (further discussion of this is beyond the scope of this chapter). However, seeking and gaining parental consent in this context can be problematic for disabled LGBT+ young people. A number of the young people we spoke to (albeit it over the age of 16 and not requiring parental consent) had not discussed their sexuality or ‘come out’ to their parents/carers, or they had experienced painful and devastating breakdowns in their relationships with their families as a result of such conversations. Seeking consent from parents in these cases would be highly inappropriate, so this poses real challenges and barriers to enabling this group to be able to be heard. This renders many young voices silent and particularly disempowers disabled children and young people because of disablist approaches, as detailed earlier.

It is therefore important to examine the tensions between this group’s right to participate and to expression of identity versus over-protection and risk-averse structures which deny them choice to take part in research. Interestingly, informed consent is considered to be the key element to ethical research, and researchers are expected to gain informed consent from all child participants – which by definition means that they have been given accessible and full information on the research and its process and potential outcomes. So, seeking parental consent in effect suggests that a child does not have the capacity to make a decision, or that parental rights outweigh those of a child. Consent is seen as particularly controversial when the subject of the research is deemed ‘sensitive’. Talking to young people about sexual identity or sexual relationships seems to create particular anxiety with concerns, similar to those identified previously regarding Section 28, that participation in research about this subject equates to promotion.

We would suggest, as have others, that given the challenges that disabled LGBT+ young people face in being able to express their views and share their experiences, that in studies of this nature ethics committees adopt a position of Gillick competence. This is a term now highly used in the UK, although it is still a debated concept. Gillick competent follows a legal ruling

in 1982, *Gillick v West Norfolk*, which placed children's rights, parental rights, medical duty and the state against each other concerning decisions regarding medical treatment and consent. The case ruled in favour of the recognition that young people under 16 years are capable of making a reasonable assessment of the advantages and disadvantages of medical treatment proposed (*Gillick v West Norfolk*, 1984). This has resulted in the term 'Gillick competent', meaning a child can consent if they have been able to assess the situation. This has led to calls and debate concerning young people under 16 years being able to consent to take part in research in their own right, without the need for parental consent (Coyne, 2010; Pickles, 2019). It is not unprecedented to rely in children's consent without parents' consent (Alderson, 2005; Morris et al., 2012; Pickles, 2019). This is rarely discussed, and would possibly not be familiar to the often generic ethics committees, which are predominantly not used to research with children. Whittington, in a study with young people concerning sexual consent, was allowed to use a Gillick approach to research consent in youth-based settings (2019). Examples of this approach being undertaken within more structured, formal settings such as schools are difficult to locate. Pickles (2019) specifically highlighted the dangers of seeking parental consent with young LGBT+ participants. We would argue that the additional barriers placed on disabled young people to expressing their LGBT+ identities increase these dangers.

It is important to note that the young people in our study (albeit slightly over 16 years) demonstrated competences and capacity to understand and navigate their often very complex identities. Learning to adapt, hide, reveal parts or all of their authentic self-based on an assessment, often of whether they would be safe, accepted or liked. They are experts in their own lives and could make informed, ongoing decisions about their lives, and about their involvement in research when they had been given full information and had been given the opportunity to ask questions and discuss. The necessity of parental consent for an arbitrary biological age creates a significant power imbalance for this group of young people.

Issues of confidentiality and anonymity

Within our study we gave considered attention to the reporting of the data

collected. The depth of information which the young people freely shared with us created detailed rich stories and a web of unique identities which, if reported in their entirety, could easily identify individual young people. The combination of disability and sexual orientation or gender identity, alongside contextual information could be very specific. It was not enough to just use pseudonyms for names. This is an important aspect to consider when examining the intersection of identities, and the combination of identity markers can easily compromise anonymity and confidentiality.

However, ‘hiding’ the young people’s details raised other considerations. We had been privileged to hear often very personal, intimate details of a young person’s life, which they often reported that they have told few people about. Their identities and intimate lives had often remained hidden. The young people’s motivations in sharing their stories was that they wanted to be heard and/or they wanted to make a difference to other young people’s lives through generating understanding. This is a constant question in all social research, but it is important as researchers that we do not underestimate this and the responsibility this places on us to ensure that findings are shared. However, this led us to consider the balance between protecting the young people through anonymity but still enabling them to see themselves and their contributions in publications. In order to combat this, we spent time going back to the college and support group to feed back our findings and share what we had done with their stories. Although this should be a matter of good practice, this seemed especially important given the depth of personal information, commitment and trust they had enlisted in us. We wanted to ensure that they knew we had listened to them.

Language, identity labels and issues of power within the research process. As is traditional, we advertised the study through accessible information sheets – stating we wished to invite disabled LGBT+ young people aged 16–25 years to take part in the research. Although this was successful and we recruited our sample, we came to reflect on the language and labels we had used in our recruitment. We wondered how this may have affected who came forward and conversely who was excluded because of the language used; who identified with a different label; or who did not wish to be labelled. As already mentioned, a number of the young people who took part did not consider themselves disabled. Although we were wanting to explore intersectional

identities, we reflected how we were already in some ways predefining these, which was not the intention. We wanted to address this power imbalance and enable the young people to define themselves in the interviews. This also presented a dilemma as we sought to create the right balance between asking questions to understand identities – which were often complex, but then being seen to be questioning their identity. This was especially important to many of them who had struggled to understand their identity as a result of frequently being bombarded with messages of heterosexuality and gender conformity, or had not had their identities accepted. Important care and attention was required to ensure questions were framed appropriately, delivered in ways which are accessible and did not appear to question identities, whilst allowing young people to speak freely. We did not want to define or pre-label the identities of the young people; we also did not want to put pressure on them to have to define themselves. In order to support the conversation, we used cards with identity labels on them (e.g., bisexual, gay, autistic, learning disabled, physical disability), we read them out and allowed the young people to choose any they associated with, none if they did not want to, or use some blank ones to add new words. This worked well to open up the conversation and to indicate to the young people that we did not want to label or in some way prejudge. Many did not choose to identify with any card which had words associated with a disability. Furthermore, some rejected all labels, and some added words (e.g., pansexual, non-binary, gender fluid).

What this also indicated is the importance of getting information right when recruiting and to be considered in the wording of the schedule. It is vital to be led by the descriptors young people used to describe themselves, particularly in relation to sexuality and gender identity, especially with regard to the use of personal pronouns. We benefited from our group having access to well-informed specialist LGBT+ youth workers, who they trusted. The youth workers were able to explain the study and because of good relationships developed by the research team, reassure the young people of our trustworthiness. The investment in building the relationships should not be under-estimated in securing our sample. As we move forward in our partnership with this group of young people, they will define their group and determine a common language. The research they will undertake will be important.

Concluding comments

In this chapter we have presented learning from our research with this under-represented group of young people whose voices in research are rarely heard. We faced barriers to their involvement and were required to think carefully about how we empower, but also protect, this group through undertaking ethical research. We have presented some considerations for moving forward this agenda. In conclusion, we would suggest that there requires a shift in researchers approaches to working with this group. This will require flexibility, careful consideration of power dynamics and barriers to participation, and a willingness to work in partnership with both those who support this group of young people and with young disabled LGBT+ people themselves. Beyond the researcher, there also needs to be a shift in the attitudes of gatekeepers and ethics committees to be confident in managing any perceived risks in involving this group in research, seeing the young people's rights to participate and the importance of this work. Routinely over protection, and ageist, disabledist and heteronormative structures, policies and attitudes silence this group. Preoccupation with concerns around risk and safety needs to be challenged in a balanced way. Our work, and those of the other scholars mentioned, has shown the strength and power of learning directly from young people as experts in their own lives who have much to say about how their lives could be improved. It is important that adults do not entirely set and own the agenda concerning the voice of this group.

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