6

Methodological issues when interviewing disabled care-leavers: lessons learned from South Africa, Norway and Northern Ireland

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Introduction

Research on care-leaving is growing globally. However, for disabled young people,[1] this is still an emerging field of study (Cheatham et al, 2020). Disability prevalence within the care-leaving population varies from 11 per cent (Gundersen et al, 2011) to 50 per cent (Slayter, 2016) depending on inclusion criteria and national context. Existing research indicates that the most common impairment types within the care-leaving population are intellectual disability and autistic spectrum disorder, often co-existing with mental health needs (Lee et al, 2018; Kelly et al, 2022) with varying outcomes reported across disability types (Cheatham et al, 2020). Care-leavers may also experience others forms of impairment including physical, sensory or speech impairments.

As disabled care-leavers reach the age of 18, they often have a dual experience of ageing out of both child welfare services and children's disability services. A small body of research has begun to highlight the complexity of these transitions and the range of challenges facing disabled care-leavers including lack of appropriate housing, restricted post-care education or employment opportunities, limited informal support networks, high risk of mental ill health and vulnerability to exploitation (Mendes and Snow, 2014; MacDonald et al, 2016; Crous et al, 2020; Kelly et al, 2022). However, the evidence base on the transitional experiences of disabled care-leavers is limited with calls for further research to advance knowledge of the experiences of disabled young people leaving care and, in particular, studies that seek to ascertain the views of disabled young people (Harwick et al, 2017).

Given the limited focus of research on disability and care-leaving, little is known about how to design studies to recruit and involve disabled care-leavers or how to negotiate the complexities of interviewing care-leavers who use alternative communication styles or who may need support to participate in research (MacDonald et al, 2016). There is a strong body of work on participatory disability research more generally (Curran et al, 2021; McNeilly et al, 2021) and also a range of care-leaver studies that have employed participatory methods (Dadswell and O'Brien, 2022). However, the inclusive approaches adopted in these separate bodies of participatory research have not been widely integrated to support the development of inclusive research with disabled young people leaving care. Indeed, much of the research on care-leaving has ignored disability issues or excluded disabled care-leavers (Kelly et al, 2016; Dadswell and O'Brien, 2022). There is an onus, therefore, on academics who have conducted research with disabled care-leavers to share their experiences and offer guidance and encouragement to other scholars interested in researching the transitions of disabled care-leavers.

This chapter, therefore, aims to highlight the methodological issues encountered by the authors as they engaged disabled care-leavers in qualitative research in Norway, South Africa and Northern Ireland (NI). Rather than providing a descriptive comparison of each study (details of each study have been published elsewhere: Kelly et al, 2016; Bennwik and Oterholm, 2021; Mupaku et al, 2021), the chapter will present a thematic discussion of the common challenges and methodological issues identified across all three studies and offer guidance to inform future care-leaving research that is more inclusive of disabled youth. While the primary focus is on research with disabled care-leavers, the discussion will also have relevance to the ongoing advancement of leaving-care research more widely to ensure it is inclusive of the heterogeneous experiences of youth leaving care. Before we consider the methodological challenges and issues, it is important to consider the positioning of disability and the country context for each study as these both have implications for research with disabled care-leavers.

Positioning disability

Many disability policies globally are now informed by the social model of disability which, since the 1970s, has challenged the dominant medical model's main focus on individual incapacity. The social model highlights how people with impairments are disabled by societal barriers that hinder the fulfilment of their rights and their full inclusion in society and seeks to eradicate these disabling barriers (Oliver, 2013). The social relational model expanded on the social model's focus on disabling structural barriers to further consider the bodily experience of impairment and the impact of oppressive social relations on the psycho-emotional wellbeing of people with impairments (Thomas, 2007). Contemporary critical disability studies, however, has further advanced thinking about disability. Although still grounded in a commitment to human rights, critical disability studies shifts away from the dichotomous view of disabled and non-disabled people upheld by both the social model and the social relational model to place greater emphasis on fluid interpretations of disability, exposing and resisting normative ideas that stigmatise and produce disability (Campbell, 2009). From this perspective, disability is not a fixed biological condition and traditional dichotomous positions of disabled or non-disabled are challenged and disrupted (Goodley et al, 2018). This perspective bears particular relevance to this chapter on research with disabled care-leavers given the complex identities of disabled youth leaving care and the struggle for care-leavers as they seek a sense of belonging in a society where they experience much stigma and social exclusion (van Breda, 2018). In alignment with contemporary disability theory, advancing the field of leaving-care research requires more proactive efforts to develop participatory methods that engage disabled care-leavers and greater attention to addressing intersectional, disabling barriers and discourses that limit their participation in research and hinder their full inclusion in society.

Methodological approach: bringing three studies together

This chapter draws on the authors' experiences of conducting qualitative interviews with disabled care-leavers across three studies conducted in South Africa, Norway and NI. Each study had a qualitative design and sought to recruit a small sample for in-depth exploration of transitions from care. Table 6.1 summarises the approach taken in each study, including the aims, sample and interview methods used. Across each study, purposive sampling was used to recruit participants with a range of experiences across both leaving care and disability. In all studies, parents/guardians and/or social workers were also interviewed.

The authors have collaborated in different ways over the past few years, and have all participated in the International Research Network on Transitions to Adulthood from Care's Disability and Leaving Care Interest Group. In addition, one author (Kelly) had an overview of the issues relating to all three studies as lead for the NI study and co-supervisor for the doctoral studies in Norway and South Africa. Through this collaboration, the authors have reflected upon methodological issues in their research which led to an interest in synthesising their experiences of carrying out qualitative interviews with disabled care-leavers. The authors began this process by holding a series of meetings focused on the methodological issues relevant to each study to identify common issues and challenges. This process began with each author presenting the key issues for their study followed by a discussion with the co-authors in relation to how these challenges related

Table 6.1: Overview of studies

Country	Norway	South Africa	Northern Ireland (NI)
Study aim	To explore how ruling understandings of aftercare and disability shaped support for care-leavers with disabilities in Norway	To investigate the transition from alternative care for youth with intellectual disabilities in South Africa	To investigate the transitions of care-leavers with mental health and/or intellectual disabilities in NI
Timeframe	2019–2020	2019–2021	2012–2016
Number of care-leaver participants	Eight young people aged 19–27 years old (two males and six females) leaving a range of care settings including residential care and foster care	Six young people aged 17–21 years old (two females and four males) leaving residential Child and Youth Care Centres (CYCC)	31 young people aged 16–23 years old (14 males and 17 females) leaving a range of alternative care settings including family-based foster care and residential care
Recruitment	Recruited via aftercare service providers and social media groups for child welfare professionals or forums for care-experienced youths and/or their biological parents in Norway	Recruited via CYCC in Cape Peninsula region, South Africa	Purposively sampled from the population of all disabled care-leavers in NI to reflect a range of experiences (larger sample frame was based on an earlier survey of the population facilitated by the Health and Social Care Trusts across the region)
Types of impairment	Mental ill health, learning difficulties, autism, physical disability, chronic illness and behavioural disorders	Intellectual disability, autism, mental ill health	Intellectual disability, autism, mental ill health often co-existing with other health conditions (for example, epilepsy) and challenging behaviours
Interview methods	Semi-structured interviews with young people who had dual experiences of care-leaving and disability	Semi-structured interviews were conducted with the young people, some professionals that worked with the young person and their caregivers were interviewed twice at baseline and follow-up interviews	Case studies involved case file reading and interviews with care-leavers, their social worker, carer and, where appropriate, birth parent. Semi-structured interviews with care-leavers were conducted by peer researchers (care-experienced young people) with support from academic researcher when needed
Number of interviews with each young person	One interview (no withdrawals from the study)	Five interviews over an 18-month period as they left care (two left the study during the second wave of interviews)	Three interviews over an 18-month period as they left care (six left the study after the first or second interview)

Table 6.1: Overview of studies (continued)

Country	Norway	South Africa	Northern Ireland (NI)
Adaptations to interview approach	Participants could choose to use Photovoice and life-mode interviews. None chose Photovoice (though several showed photographs when sharing their experiences), but all interviews employed life-mode methods to explore everyday-life experiences	An interview schedule with pictorial support was used. A visual 'life map' was also used to show the transition as well as an ecomap to illustrate significant people in the young person's life. Feelings cards were also to illustrate the young person's emotions about certain aspects interviewed	A shorter, 'All About Me' pictorial version of the interview schedule was provided. Feelings cards were used to illustrate a range of emotions. A visual 'life map' to show the transition from care supported discussions of phases of transition and an ecomap was used to identify key people in their lives

to their own studies. The authors then moved into thematic analysis of these issues to identify three overarching methodological themes. For each of these themes, the authors also collated concrete examples from each study that could be used to illustrate the complexities of researching the transitions of disabled care-leavers in each country and the various strategies used to respond to these challenges to work towards a more inclusive and reflexive research approach. It should be noted that ethical concerns were also discussed including issues relating to consent, confidentiality, capacity and risk of harm. The authors decided that these ethical challenges required separate, in-depth consideration elsewhere and, within the scope and limited space of this chapter, the primary focus would be on methodological issues. The chapter will now provide an overview of the country context for each study followed by discussion of the three core methodological themes that emerged across each of the studies: categorising disabled care-leavers and the effect on recruitment; designing inclusive research tools; and responding to fieldwork challenges.

The impact of country context

It is important to be mindful of the impact of varying country contexts on researching the experiences of disabled care-leavers. How disability is understood within each country's sociocultural context and how disability is categorised within and across child and adult service systems has a significant impact on the experiences of disabled care-leavers but also the approach to researching their transitional experiences. The policy and service structure for aftercare support for youth leaving care is also important when seeking to recruit research participants within these service systems.

In NI, under the Children (Leaving Care) Act (NI) (2002) and Children (Leaving Care) Regulations (NI) (2005), health and social care service providers have clear duties to maintain contact with youth leaving care and provide aftercare until age 21 or 24 if they are still in further education and training. A regional strategy also outlines the role of the state as a Corporate Parent for children in its care with responsibility for promoting their wellbeing and welfare as any parent would be reasonably expected to act (Department of Health and Department of Education, 2021). However, as disabled youth age out of children's services and seek support from adult services there is a shift from a focus on parental models of care to services with eligibility criteria based on type and severity of impairment that is more aligned with the medical model (Kelly et al, 2016). A disabled care-leaver, therefore, is entitled to leaving and aftercare support until at least the age of 21 but may not be able to access adult disability or mental health services (Kelly et al, 2022).

In Norway, a similar division between child and adult disability or mental health services is reported (Bennwik and Oterholm, 2021). Under the Child Welfare Act (1992), aftercare can be offered from the age of majority until the young person reaches 25 years old with the aim of supporting their transition to independence in adulthood. Aftercare consists of the same services that are offered before these young people reach the age of majority, including foster care, financial support, counselling and housing services. The Norwegian welfare system does not have a strong, targeted, legislative framework for the transition to adulthood, neither for care-leavers from the child welfare system nor for disabled young people. There are no national aftercare programmes, but there seems to be an expectation that child welfare services, in combination with high-quality universal support and services for adults, should be sufficient to meet individual care-leavers' needs in the transition to adulthood (Munro et al, 2016). If a care-leaver needs disability-related support, child welfare services are responsible for assisting the young person to connect with relevant services and coordinating support. However, Norwegian studies show that care-leavers facing more complex challenges are often transferred to adult services instead of receiving aftercare from child welfare services (Oterholm, 2009).

In South Africa, care-leaving is referenced in the Children's Act (2005), however, aftercare support is not mandatory and there is no funding for aftercare programmes (Kelly et al, 2020a; Strahl et al, 2021). The absence of a legal duty to support young people leaving care is concerning, particularly as the socioeconomic context in South Africa is characterised by high youth unemployment rates, poverty, homelessness and poor quality education that further exacerbates the challenges facing care-leavers (van Breda and Dickens, 2016). In South Africa the *White paper on the rights of people with disabilities* (Department of Social Development, 2016) is explicitly grounded in a commitment to the social model of disability. However, disabled young people leaving care face significant barriers to accessing adult disability services and transitional support for care-leavers is unregulated, often managed by the Child and Youth Care Centres (CYCCs) providing care. Several providers have noted the absence of support for care-leavers and are developing transitional supports, however, these do not specialise in transition support for disabled care-leavers (Tanur, 2012).

Across all three country contexts, therefore, disabled care-leavers are vulnerable to being unsupported due to significant gaps in policy and service provision. The varying policy and country contexts outlined reflect the complex challenges disabled care-leavers are likely to encounter as they navigate their way from care into young adult life and underline the importance of addressing the experiences of disabled young people in care-leaver research. These issues also indicate that the categorisation of disabled care-leavers within these complex and often inadequate service systems is likely to impact on researchers' efforts to identify and recruit disabled care-leavers as research participants.

Categorisation of disabled care-leavers and the impact on recruitment

The implications of these varied country contexts for recruitment and sampling of disabled care-leavers in each of our studies were multiple. Each study sought to recruit disabled care-leavers via the main child welfare or care/aftercare service providers. However, these service providers in each country initially indicated that disabled young people would not be within their service remit. On the other hand, disability and mental health service providers indicated that disabled care-leavers would not be within their services as they should be located within services for youth leaving care. This dual lack of recognition for disabled care-leavers highlights how this population can fall between the gaps in services with no service taking lead responsibility for their welfare.

The researchers in all three countries, therefore, had to spend considerable time working with service providers to help them to identify disabled care-leavers within their services. At times, this required use of medical model language that service providers used, including clarity about types and levels of impairment. Across the studies, researchers were asked by gatekeepers to stipulate the range of conditions/disorders that could be included in the study, often with a narrow focus on a clearly diagnosed medical condition or severe impairment. While this may help to guide gatekeepers with their identification of study participants, it may also serve to exclude those with unspecified conditions, those not yet formally diagnosed and those with less severe levels of impairment. This use of medical language also evoked theoretical and methodological challenges that required ongoing, sensitive negotiation with gatekeepers.

Opportunities to discuss study inclusion criteria and the complexities of defining disability with individual gatekeepers usually helped to address these issues and identify disabled care-leavers within the service system, however, researchers were also often told that the potential participant was 'too impaired' or 'vulnerable' to participate in research, indicating an over-protectionist stance. This required further negotiation with service providers. For example, sometimes the social worker's concern about the vulnerability of the young person could be allayed when the researcher explained more about the participatory approach being used or if the timing of the invitation to participate was delayed to avoid current issues (for example, the young person was recovering from an illness or had recently moved to new housing).

A further issue impacting on recruitment was the extent to which young people who were approached to participate in the study self-identified as disabled. Across our studies, we were aware of this issue and ensured that study recruitment materials did not place an over-emphasis on disability or impairment. Many young people contacted to participate in the three studies did not use the term disability to describe their own identity or identify as being disabled, even if they could describe many disabling experiences. As an example, one care-leaver who did not consider themselves to be disabled and did not wish to use disability services was denied access to generic job-training and the regular housing market and found that they had no choice but to receive support from disability services. This presented a clash between the research and service categories of disabled youth leaving care and the young people's own self-identities. In some instances, young people were happy to confirm they were in receipt of disability services which helped to confirm eligibility for the study but did not self-identify as disabled. This disassociation with categories of disablement is unsurprising given the dominance of the medical model focus on impairment-related deficits, the social oppression of disabled people and the cultural stigma associated with disability (Rohwerder, 2018). However, it should be noted that there may be multiple other reasons for this disassociation including lack of knowledge of disability-related terminology or own diagnosis or, indeed, integration of disability-related experiences as a normative part of the young person's identity/daily experience that does not require a label or identification as disabled (Kelly, 2005). In parallel to this disassociation with disability, young people leaving care can also be keen to shed their identity as a care-leaver due to the stigma of being a former child in care (Frimpong-Manso, 2018). For disabled care-leavers rejecting these intersecting social identity categories is understandable as young people are keen to minimise the risk of further stigma and marginalisation (Kelly et al, 2020a).

The researchers, therefore, were acutely aware of how the categories 'disabled' and 'care-leaver' are embedded in discourses of oppression and the potential risk and, by relying on such categories, researchers can inadvertently reproduce dominant understandings of disability and care that are not beneficial to the young people participating in research (Stone and Priestley, 1996). In contrast, we have learnt that the onus is on the researcher to use this insight to enable socially marginalised young people to transform oppressive categories and open new understandings of the intersections of disability and leaving care. This encourages the researcher to reflect critically upon how they work with these categories in research and how research can potentially counteract disabling effects. A positive experience from the researchers' dialogue with professionals was that new understandings of disability could emerge that challenged practice grounded in the medical model and encouraged a deconstructed understanding of disability that recognised the political processes of classification and drew attention to social structures rather than the individual attributes. Likewise, it was fruitful to discuss how these 'disabled' and 'care-leaver' identities may intersect and/or obscure other forms of social and personal difference.

In summary, therefore, several stages of the recruitment process developed into a negotiation with service providers and potential participants about what it means to be disabled, what terms could be used to describe disability and leaving care, and how self-identification can be promoted within the research rather than used as a strategy to exclude young people. These conversations led to an enhanced understanding of both disability and care-leaving among the research teams, but also within the professional community facilitating each study. This ongoing process of critical reflection and negotiation of categories informed the theoretical approach to the research, drawing on ideas from critical disability studies to stay close to the language used by study participants while maintaining a commitment to understanding disability as a matter of social justice (McNeilly et al, 2021). While inclusive and open understandings of disability was helpful in the recruitment stage, as it both avoided imposing categories on young people and helped include those with borderline/undiagnosed disability, the researchers recognise the need to approach this carefully to ensure participants have relevant experiences to address research questions. For example, in the Norwegian study young people who did not self-identify as disabled were only included in the study if they had experiences relevant to the study's core research questions and gave clear accounts of experiences relevant to disability issues, such as experience of disablism, use of disability services or categorisation as disabled by service providers.

Designing an inclusive research approach

Various strategies may need to be employed to enable an inclusive and reflexive approach to involving disabled care-leavers in research. Researchers will need to consider adaptations to their usual interviewing methods and make refinements to interview guides and communication tools to accommodate a range of participants (Teachman, 2019). Such adaptations and preparatory work are aimed at equipping the researcher with a range of skills and tools that can be used reflexively to meet individual participant needs/preferences rather than a disablist focus on individual levels of incapacity or lack of cognition. The emphasis is on how the researcher can facilitate the engagement of disabled care-leavers in the interview process rather than the participant's individual limitations (McNeilly et al, 2021).

In our studies, a range of adaptations and communication aids were utilised to facilitate the inclusion of disabled care-leavers in interviews. Carefully piloting of interview guides and communication tools with disabled young people was essential to test out the range of options available and different levels of interview schedules. Such piloting exercises also provide an opportunity for disabled young people to assist with the design and development of the research tools. For example, in the Northern Irish study a Young People's Advisory group with members who had experience of disability and leaving care guided the development of the research tools and assisted with the piloting of interview schedules (Kelly et al, 2016). This helped to create a more inclusive approach that enabled participation, but avoided a paternalistic or age inappropriate approach.

We also found that it was important to have at least two different versions of the interview schedule to reflect a range of literacy, comprehension and concentration abilities, but still enable the collection of useful data relevant to the study's aims and objectives. For example, in the Northern Irish study, a longer interview schedule was shortened to produce a more accessible version that still addressed the same core themes but used shorter question styles and more accessible language. Across our studies, visual representations of transitions or interview themes also helped to introduce more creative ways for disabled young people to engage with the interview. Graphics, ecomaps, sentence completion and drawing or writing activities also prompted further discussion to enable disabled young people to share their perspectives (Teachman, 2019). For example, on the South African study, visual life-maps aligned with the interview questions about how they envisioned their lives after care helped to identify hopes and goals for the future (Mupaku et al, 2021). Similar pictorial techniques were used in the NI study which used an 'All About Me' booklet that had a page for each theme on the semi-structured interview schedule that was visually presented to invite discussion, inclusion of photographs and writing or drawing activities (Kelly et al, 2016). This study also found it helpful to use visual cards to depict like/dislike, yes/no and a range of feelings were used to illustrate emotions. These alternative interview approaches and aids helped to provide a 'communication toolbox' offering a range of ways to participate that could be used by young people with different levels of capacity. In introductory visits, young people were shown these tools and could decide with the researcher which approaches would be most helpful to facilitate their interview.

In the Norwegian study, user organisations for care-leavers and disabled youth were consulted in order to identify potential communication challenges and to seek advice on how best to design an inclusive interview guide. Similar to the other two studies, the Norwegian researcher held an initial meeting with each young person to develop rapport and explore how best to approach each interview including the timing of the interview, where it would be conducted and how to address any potential communication challenges. At this early stage, the researcher tried out different types and levels of questions and adjusted the interview approach according to the needs and preferences of each young person. In this study, the interviews adopted a life-mode interview approach (Haavind, 2014). Here, the young person was encouraged to openly describe their daily everyday lives rather than being asked direct questions about impairment or disability which was particularly helpful when participants did not identify with disability or impairment. This approach enabled the researcher to learn from the young person and use language they preferred to describe bodily experiences or disabling encounters at later stages of the interview process. Reflecting critical disability studies, such experiences highlight how researchers need to adopt an individualised and fluid approach to language that is responsive to the preferences of participants rather than imposing terminology routinely used by service providers.

Responding to fieldwork challenges

Despite all efforts to prepare for interviews and design a range of accessible and inclusive research tools, challenges were encountered during each of our studies, highlighting the need for a reflexive approach as the research progresses. Across all three studies, a key challenge was the need to adapt the interview approach in response to the individual needs of the young person while avoiding the risk of a paternalistic, disablist or age-inappropriate approach.

In most cases researchers had access to information about the young person before the interview, including their impairment type, communication style and any potential issues relating to literacy, concentration, memory or sensory issues. This information was sometimes presented by carers or professionals as a barrier to the young person's participation in the study with a focus on deficits, traditionally aligned with medical model thinking. While it is helpful to have access to information about the young person's support needs or communication preferences, across our studies we found it was important to only use this information as guidance and to still make every effort to overcome barriers to the young person's participation in interviews. In accordance with critical disability studies, the researchers focused on establishing rapport with each young person and developing an effective communication approach that could facilitate their participation in an interview. In South Africa and NI, this involved offering the young person options, showing them the range of visual aids and communication tools available and trying out different levels of question styles or communication methods (including those more familiar to the young person that the research may not have considered) to establish which level of interview schedule might work best. These studies also involved multiple interviews over time which gave the participant and researcher more time to develop their relationship and an opportunity to further refine research tools in advance of follow-up interviews with each participant.

During fieldwork, the researchers also had to be responsive to the everyday context of care-leavers' lives and ensure that interviews were carefully scheduled at times that best suited the young person. For example, avoiding times of the day when they were likely to be busy with other demands or be feeling tired. For some participants, it was also important to remember to offer frequent breaks or shorter, multiple interviews over several visits rather than one lengthy interview. These findings indicate that, at the stage of planning and costing a study involving disabled care-leavers, research teams need to factor in additional time and resources to facilitate their meaningful involvement.

In most cases, across our studies, the researcher was able to proceed with an interview. However, in a very small number of cases, an interview was not possible. These young people had multiple and complex impairments and often exhibited high levels of distress when meeting a researcher who was unfamiliar and not part of their daily routine. In these cases, rather than exclude the young person and their unique experience of leaving care, information was gathered by spending time with the young person, observing their experiences, and collecting information about their transition from those who cared for them and knew them well (often carers/parents or key professionals). While gathering information from other sources by proxy is not ideal, it is important for the researcher to uphold an ethical and sensitive response to individual needs that may mean an interview is not always possible or appropriate (indeed it could be disabling) and alternative methods are needed to more meaningfully capture the experiences of some disabled young people (Kelly, 2007; Teachman, 2019).

The involvement of parents/carers was another key challenge across our studies. Parents/carers usually know the young person well and can provide helpful information about their support needs and communication styles. They can also be a useful source of support for the young person during initial visits and can sometimes help with interpreting sign systems or expressions used by the young person. However, parents/carers may be inclined to speak for the young person and young people may expect their parent/carer to be present during the interview and speak on their behalf. This can be a well-established practice for both the young person and their parent/carer when engaging with professionals over the years (McNeilly et al, 2021). It is important, therefore, for the researcher to explain the boundaries of the parent/carer role in the interview from the outset. If the young person would like their parent/carer to be present, the researcher needs to emphasise that the focus is on the young person's views and experiences rather than the parent/carer perspective. In several cases, following interviews with disabled young people, parents/carers asked the researcher what the young person had said, usually due to a genuine interest in their expressed views that they may not have previously known. However, in these situations, the researcher should explain the boundaries of confidentiality and reassure the young person that their right to confidentiality will be respected.

A further challenge particularly relevant to longitudinal research with disabled young people is the retention of participants. Researchers working on longitudinal studies with care-leavers during their transitions from care are familiar with this challenge (van Breda, 2020). However, for disabled care-leavers there can be additional, often unexpected challenges affecting retention. Across our studies some disabled young people experienced periods of ill health, hospital admissions, adjustments to medication or treatment and changes to their daily routines that significantly disrupted their availability to continue with their participation in the research. In these circumstances, researchers must provide flexible choices for participants about how and when they wish to be interviewed and offer all possible opportunities for participation for those keen to continue their engagement in the study. In our studies, the researchers were flexible and arranged alternative, later dates for interviews. However, delays in follow-up interviews also made it difficult for some disabled young people to recall earlier interviews or details of the study. This could mean spending more time with participants to re-explain the purpose of the research and the nature of their ongoing involvement in the study. Previous studies have used a range of strategies to assist with recall and to maintain a connection with participants during delays in data collection that could also be usefully applied, including: timelines of the research stages; photographs of research activities; pictorial bookmarks depicting the seasons and time span between data collection points; and postcard or web-based updates (Kelly, 2007; Weller, 2012). Across our studies, we have found that staying in regular contact with participants in the time lapse between interviews helps to maintain this rapport over time and encourages retention. We kept in contact with participants by telephone, text or email and found that this ongoing contact: demonstrated a commitment on behalf of the research team to facilitate their involvement of the participant; provided opportunities to update participants on the study's progress; and also gave the researcher further insight into the young person's transitional journey and any changes in their circumstances.

Conclusion

Disabled young people are a significant, marginalised sub-group within the population of youth leaving care across the globe but have been under-represented in the field of care-leaver research (Slayter, 2016; Harwick et al, 2017). This chapter has reflected on the experiences of three studies involving disabled care-leavers in research to inform and encourage others working in this field to engage disabled youth in their future studies of care-leaving. From the outset, how disability is recognised and understood has a profound impact on the attitudes and approaches of service providers, researchers and young people themselves. Researching the experiences of disabled care-leavers requires an understanding of: the misrecognition of disabled youth leaving care within and across service systems; and the impact of stigma and oppression associated with both disability and leaving care on the identities of disabled youth leaving care. These insights underline the need for researchers to commit to inclusive research approaches that challenge and address barriers to the participation of disabled care-leavers. Fundamentally, researchers in the field of leaving care should actively seek to recruit disabled care-leavers and be tenacious in their negotiations with gatekeepers to broaden and deepen opportunities for disabled youth to participate not only as but also potentially as advisors and co-researchers (Kelly et al, 2020b; Curran et al, 2021). Researchers are encouraged to develop inclusive research methods and tools but also to engage in reciprocal dialogue with professionals, parents/carers and young people to push the boundaries of traditional, often paternalistic, approaches to disability and leaving care. Across our studies, participants had diverse experiences of both disability and care-leaving and a wide range of cognitive, social, and communication abilities and preferences. These variances demand a reflexive research approach that is person-centred to facilitate the inclusion of each participant. Our studies also highlight that disabled youth leaving care are not a homogeneous group and we have much to learn from the intersectional and varied experiences of disabled care-leavers in different national contexts across the Global North/South. Informed by a critical disability studies perspective, we encourage others researching in the field of leaving care to learn from the messages from our research to meaningfully engage disabled youth in their research and continue the journey towards a more inclusive care-leaver research agenda that enhances our understanding of the views and experiences of disabled youth leaving care.

Note

[1] In alignment with the social model of disability, this chapter uses the terms: 'disabled young people' (rather than young people with disabilities) to recognise disability as a form of social oppression experienced by people with impairments; and 'impairment' to refer to the bodily lived experience of participants and to reflect impairment-related labels used by service providers. The authors recognise, however, that varied terminology is used across service contexts and by disabled people.

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