PREPARATION OF INTELLECTUALLY DISABLED AND/OR AUTISTIC YOUNG PEOPLE FOR LEAVING CARE IN SOUTH AFRICA

Wendy M. Mupaku

University of Johannesburg, Department of Social Work and Community Development, Johannesburg, South Africa.
 https://orcid.org/0000-0001-7582-8628 *wendympako@gmail.com*

ABSTRACT

Research on the transition of intellectually disabled and/or autistic care-leavers is still in its infancy globally and there have been no studies on this population in South Africa. This article, therefore, aims to illuminate the experiences of this overlooked group in South Africa, with a focus on how well they are prepared for the transition from residential childcare facilities to young adulthood. Semi-structured interviews were conducted with eight intellectually disabled and/or autistic young people who were about to disengage from Child and Youth Care Centres in the Cape Peninsula, and their caregivers. Data were analysed using thematic analysis. Four themes emerged: person-centred planning for care-leaving; opportunities for extended care and gradual exits from care; support for interdependent living aftercare; and addressing loss and anxiety related to moving on during the transition. The study highlights implications for policy and practice, including the need for a clear policy framework to support aftercare provision and improvements in care-leaving preparation with a stronger focus on interdependence.

Keywords: aging out; autism; care-leaving preparation; intellectual disability; leaving care; transition

INTRODUCTION

Children may enter alternative care for various reasons, such as abuse, neglect, orphanhood, parental incarceration, substance abuse and family incapacity to meet their basic needs (Petrowski, Cappa & Gross, 2017). As youths then age out of alternative care, the transition process requires careful planning and preparation that must start well before the young person disengages (Muir & Hand, 2018). Some youths in transition do not have relationships with their family of origin, resulting in limited emotional or financial support from family members, which may impact on

their transition towards adulthood (Mendes, Snow & Baidawi, 2016). Some young people who are placed in foster care may have opportunities to access ongoing support from their foster family. However, transitions from residential care can be sudden, with little preparation, as youths must usually leave care at age 18 (Republic of South Africa [RSA], 2005; Strahl *et al.,* 2021). According to the Children's Act 38 of 2005, a child can extend their stay beyond the age of 18 up to age 21 to complete their schooling in South Africa (RSA, 2005).

For intellectually disabled and/or autistic care-leavers,[1] referred to collectively here as 'disabled care-leavers', the small body of available research indicates that their care-leaving experience is far more complex compared with that of non-disabled care-leavers because of a lack of personalised transition planning and appropriate aftercare support. For disabled young people, the transition process needs to be gradual and well planned, harnessing support from various service systems (Harwick, Lindstrom & Unruh, 2017; Kelly *et al.,* 2016). Poor outcomes are noted for care-leavers in general, and for disabled care-leavers the outcomes can be even more problematic (Bennwik, Oterholm & Kelly, 2023).

Early planning facilitates a gradual transition and addresses any challenges that may arise related to access to disability support (Glasper & Evans, 2014). Effective planning and preparation for leaving care are essential for disabled youths to address barriers to accessing support to meet their ongoing needs; this may require ongoing aftercare support to enhance opportunities for more positive outcomes in young adult life (Cheatham *et al.,* 2020).

However, early planning for disabled youths in care is complicated. Disabled youths are a diverse group with varying types and levels of support needs across different contexts, which means that a person-centred approach is required (Kelly *et al.,* 2016). Service providers' lack of understanding of disability and their limited commitment to a social model perspective often leads to limited preparation for leaving care and insufficient support after leaving care (Harwick *et al.,* 2017). Research globally on preparation for disabled care-leavers is limited and has only recently been growing, while South African research on this group is virtually non-existent. The absence of research on the care-leaving experiences of disabled youths in South Africa (and across Africa) confirms that this is an invisible population.

Therefore, this article aims to describe the preparation of disabled young people leaving care in South Africa, based on interviews with disabled care-leavers and their caregivers. The objective of the study is to describe how South African disabled care-leavers (specifically those with intellectual disability and/or autism) experience and navigate the preparation process in the light of the recognised challenges they face during this transition.

---

[1]Intellectual disability is used as the internationally recognised term for cognitive impairment, also referred to as 'learning disability' in the UK context. Autism, on the other hand, refers to a spectrum of neurodiversity that can impact on how people interact socially and in the world around them (American Psychiatric Association, 2013).

UNDERSTANDING DISABILITY

Definitions of disability are numerous and contentious.[2] The terminology regarding disability can be quite diverse and subject to debate, with different terms being employed in policies and services, and by disabled individuals themselves. However, in this article, I will use the term disabled young person instead of person with a disability. This choice aligns with the social model of disability (Flink, 2021) and helps clarify our perspective.

Clear definitions are important because they enable accurate statistical information on prevalence and identify trends in different geographical locations. However, accurate statistics on the population of disabled young people leaving care are often unavailable. For example, in South Africa, no statistics relating to disabled care-leavers are available.

For many years, the prevailing perspective on disability was rooted in the medical model. This model, often referred to as the individual or personal tragedy model, viewed disability primarily as a medical condition inherent to an individual who needed to be diagnosed and treated (Retief & Letšosa, 2018). From this perspective, services were aimed at the cure or rehabilitation of the individual and the provision of segregated, specialist services for disabled people (Haegele & Hodge, 2016). This approach has traditionally led to institutional and hospital-based care.

By contrast, the social model of disability focuses not on the individual, but on an oppressive society that disables people with impairments (Barnes, 2019). With this approach, the state is responsible for ensuring that policies and legislation promote the inclusion of disabled people in society and uphold the equal rights of disabled people to counteract discrimination. The social model is relevant to disabled care-leavers who experience intersectional oppression based on their status as both a care leaver and a disabled person (MacDonald, Ellem & Wilson, 2016).

Although critics of the social model of disability consider it an outdated model, this study draws on the social model, as its rights-based, political focus is particularly relevant in the South African context, where there are significant gaps in legislation and major barriers to access to services to support disabled care-leavers to ensure that they enjoy full participation.

DISABLED CARE-LEAVERS

International research consistently demonstrates that care-leavers constitute a disadvantaged group because of pre-care abuse and neglect, experiences in the care system, and the abrupt transition to adulthood, all of which render them vulnerable to adverse outcomes (Gilligan, 2019; Munro, Molholt & Hollingworth, 2016). In South Africa, this vulnerability may be exacerbated by high youth unemployment rates (Bond, 2018), a deficiency in aftercare services and the overall socioeconomic status of youths (van Breda, 2020).

---

[2]As defined by the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), disability encompasses long-term physical, mental, intellectual, or sensory impairments. When these impairments intersect with societal and environmental barriers, an individual's opportunity to engage fully and on an equal basis with others in society can be limited (United Nations, 2006, Article 1).

Current research consistently highlights the adverse outcomes experienced by disabled care-leavers, including homelessness, mental health challenges, unemployment and exploitation (Cheatham, Randolph & Boltz, 2020; Harwick *et al.,* 2017; Mendes & Snow, 2014; Roberts *et al.,* 2018). These outcomes underscore the critical importance of effective preparation for the care-leaving process, which identifies aftercare opportunities and addresses barriers to successful transitions (MacDonald *et al.,* 2016). Disabled young people, in particular, face even more formidable challenges when transitioning from alternative care (Harwick, Unruh & Lindstrom, 2020). They encounter additional obstacles in accessing transitional support and aftercare services (Kelly *et al.,* 2016).

Studies consistently reveal inadequacies in preparation for care-leaving, with some individuals being informed of their impending transition mere days before disengagement (Harwick *et al.,* 2017; Mupaku, van Breda & Kelly, 2021). Furthermore, planning is hindered when professionals are uncertain about the destination or next steps for the young person (Snow, Mendes & O'Donohue, 2014). Given the accelerated transition to adulthood for care-leavers, rigorous planning becomes imperative (García-Alba, Gullo & Del Valle, 2023).

The exploration of preparation and transition among disabled care-leavers is a burgeoning field with significant potential (Cheatham *et al.,* 2020; Gauthier-Boudreault, Couture & Gallagher, 2018). While research has exposed the heightened vulnerability of youths with disabilities to maltreatment, including both abuse and neglect (Slayter, 2016), there is a substantial knowledge gap that underscores the need for further investigation and a deeper comprehension of how disabled care-leavers navigate their transition into adulthood (Kelly *et al.,* 2016). Studies also reveal that the transitional process lacks systematic structure and stakeholder collaboration (Gauthier-Boudreault, Gallagher & Couture, 2017).

It is therefore imperative to underscore the critical significance of comprehensive care-leaving preparation to ensure that disabled young individuals receive the necessary leaving-care and aftercare services (MacDonald *et al.,* 2016; Roberts *et al.,* 2018). It must be acknowledged that the path to independent living may not be viable for all disabled care-leavers; some may require long-term interdependence. However, despite this diversity in transition needs, there is a conspicuous dearth of research dedicated to unravelling the nuanced experiences of disabled youths during their transition (Kelly *et al.,* 2016). This marks the urgency for developing a deeper understanding of their unique care-leaving journey.

Furthermore, research emphasises that the transitional process frequently lacks planning and should commence earlier (Broadley, 2015; Harwick *et al.,* 2017; Mupaku *et al.,* 2021). Unfortunately, the transition is often driven by crisis rather than by identified needs. Interventions tend to be deployed only when the situation has deteriorated significantly, such as when the young person has already become homeless (Roberts *et al.,* 2018).

Care-leaving challenges are intensified by a lack of support to meet needs relating to impairment and limited social inclusion in the community (Mendes & Snow, 2014). Disabled care-leavers with

more complex needs are often channelled into long-term dependency on specialist disability services and reliance on welfare benefits (Mendes & Snow, 2014), with limited opportunities for supported living in the community and support to engage in further education or employment (Engelbrecht, Shaw & Van Niekerk, 2017; MacDonald *et al.,* 2016).

Transitional plans for disabled care-leavers should include goals for the future, a managed shift from child to adult disability services, building on strengths and a natural support network, fostering self-determination skills, and promoting inclusion into their communities (Crous, Montserrat & Balaban, 2020).

Traditionally, preparation for leaving care focused on skills required for achieving independence, but the trend now is towards transitioning to interdependence (Storø, 2018). Interdependence is a life course concept acknowledging that we are all socially and relationally embedded and therefore interdependent, in line with the African principle of ubuntu (Van Breda, 2019). For care-leavers, interdependent networks can be a vital source of informal support and connection to the community (Storø, 2018). Interdependence is particularly relevant to disabled young people who may need additional long-term support because of their multiple needs and challenges, interfacing with various service systems, and being vulnerable to isolation and stigma in the community (Kelly *et al.,* 2016; Mendes *et al.,* 2016). Transition means moving from child to adult services, where the professionals are unknown to the young person (Roberts *et al.,* 2018).

LEGISLATIVE FRAMEWORK FOR DISABLED CARE-LEAVERS IN SOUTH AFRICA

South Africa's disability legislation is rooted in its Constitution, international agreements like the UN Convention on the Rights of Persons with Disabilities (UNCRPD), and the African Union's Continental Plan of Action for the African Decade of Persons with Disabilities (African Union, 2002; RSA, 2005; United Nations, 2006). Surprisingly, despite these long-standing documents, prior to this study, no South African research had focused on the transition experiences of disabled youths leaving care.

Children's services in South Africa are governed by the Children's Act 38 of 2005, which stipulates that all children in care must exit the system at the age of 18, but care can be extended for academic completion until 21. Akin to many other countries, aftercare support is neither mandatory nor funded (Kelly *et al.,* 2020; Strahl *et al.,* 2021). The Act also allows for an extension of care to age 21, primarily if the young person is pursuing education or training, and this decision is at the discretion of the residential home (RSA, 2005). Nevertheless, continuing education or training is often neither feasible nor suitable for disabled young people. The absence of legal obligations to support care-leavers is particularly concerning, especially given South Africa's socioeconomic challenges, marked by high unemployment, poverty and homelessness.

Considering the imperative for early preparation for leaving care and the dearth of legislative and policy support for care-leaving services, understanding how disabled young people may be readied for this transition is crucial (MacDonald *et al.,* 2016). This understanding can inform the

development of policies tailored to meet the unique needs and capacities of disabled care-leavers, thereby facilitating their successful transition out of care and toward young adulthood.

METHODOLOGY

Research approach and design

The study followed a qualitative approach (Campbell, Taylor & McGlade, 2016) with a qualitative description research design (Sandelowski, 2010). Qualitative description focuses primarily on the ordinary descriptions of participants about their life experiences; thus it is not as in-depth an approach as phenomenology and broader in the range of experiences of interest. It makes less use of interpretation of the experiences than some other research designs, though the sense that participants make of their experiences is of relevance. It is also not concerned with generating theory, as in grounded theory approaches, but nevertheless does generate themes. We considered qualitative description to be the most suitable research design for this study.

The findings presented here are from the first wave of data collection in a longitudinal study of the transitional experiences of disabled care-leavers. The more extensive study was conducted over 18 months, with five waves of interviews, investigating the transitional journey of disabled care-leavers.

Sampling CYCCs and participants

This study focused on residential care settings known as Child and Youth Care Centres (CYCCs) in South Africa. CYCCs are full-time residential homes that accommodate children who would have been abandoned or removed from their birth families as a result of concerns about neglect or abuse, often in the context of high levels of poverty and deprivation.

Purposive sampling was used to select participants (Rubin & Babbie, 2016). We developed inclusion criteria for the young people, which included they had to be between 17 and 21 years old, with an intellectual disability and/or autism, and had been living at a registered CYCC in the Western Cape province for at least 12 months before the interviews and were due to leave care. Given the timeframe for the study and the practicalities of recruiting participants, the study was conducted in the Western Cape close to where I live. The young person's primary care giver was also included in the sampling criteria.

Recruitment took place in two phases: first CYCCs and then young people and their caregivers. I compiled a list of 67 CYCCs registered with the Western Cape Department of Social Development from the government website. After initial contact via email and a study leaflet, I followed up with phone calls. Out of these 67 CYCCs, 20 declined and 43 did not respond. Only four expressed interest, so I collaborated with them to advertise the study and identify prospective participants. Most CYCCs offer mainstream care and do not provide specialised support for disabled youths, making it challenging to determine the number of disabled young people in their care. Of the four CYCCs who agreed to facilitate access to study participants, three offered general care and

protection for children and only one specialised in care for intellectually disabled young people and employed professionals trained to work with disabled youths.

We shared the inclusion criteria with the social workers at the CYCCs, who identified disabled young people who met the criteria; they also facilitated the distribution of the study information sheet, which included my contact details, to their primary caregivers. The eight young people who met the sampling criteria and their caregivers were invited to participate. All consented or assented and comprised the study sample.

A brief profile of each young person is provided in Table 1., with pseudonyms used to protect the confidentiality of the participants. Eight young people, including two females and six males, entered care between the ages of 3 and 17 and aged out between 18 and 20. Among them, seven had intellectual disabilities, four had foetal alcohol syndrome (FAS), and two had autism. The caregivers, all women, included two biological mothers (Avery for Sue and Gary, and Cathy for Lee), two adult disability caregivers (Dorothy, who cared for Sihle, and Ellen, the director of a CYCC that specialised in dealing with disability, who also managed a disability adult facility and cared for Ann, Buhle, Peter and Clive). In addition to these young people and their caregivers, I interviewed Tia, Lee's occupational therapist, at Lee's request, as he considered her an ally.

Table 1: **Demographic profile of participants**

Young person (gender)	Diagnosis	Type of CYCC (ages in care)	Transitioned to	Caregiver
Ann (female)	Mild intellectual disability and FAS	ID specialised CYCC (10-18 years)	Adult care facility	Ellen
Buhle (male)	Severe intellectual disability and Foetal Alcohol Syndrome (FAS)	ID specialised CYCC (11-18 years)	Adult care facility	Ellen
Clive (male)	Mild intellectual disability and FAS	ID specialised CYCC (5-19 years)	Adult care facility	Ellen
Gary (male)	Severe intellectual disability and autism	General CYCC (17-18 years)	Birth family	Avery
Lee (male)	Moderate intellectual disability	General CYCC (13-18 years)	Birth family	Cathy and Tia
Peter (male)	Moderate intellectual disability and FAS	ID specialised CYCC (3-18 years)	Adult care facility	Ellen
Sihle (male)	Moderate intellectual disability	General CYCC (13-20 years)	Former foster care family	Dorothy

Sue (female)	Autism	General CYCC (16-20 years)	Birth family	Avery

Data-collection methods

I collected data using semi-structured interviews guided by open-ended questions. Once consent was obtained, interviews took place in October and November 2019. Data-collection tools were pilot tested before use to ensure the questions were pitched at an accessible level for intellectually disabled participants. Two disabled youths, who were recruited through a centre not directly involved with the study, provided guidance and assisted in piloting the data-collection tools.

A picture exchange communication system (PECS) was an alternative communication tool for young people with limited verbal skills (Frost, 2002). Interview questions focused on the following core themes: feelings about leaving care; preparation for leaving the CYCC; adequate transition supports; and linkages with community-based services.

The study's trustworthiness was strengthened by prolonged engagement with the participants. In certain instances, the interview required two separate sessions to be completed. Confirmability and credibility were enhanced by triangulating data gathered from the young people with data from their caregivers.

Data analysis

To analyse the data, I followed the six-phase thematic analysis method described by Braun and Clarke (2012): familiarisation with data; generation of initial codes; sorting codes into possible themes; refining of potential themes; defining and naming themes; and writing up of findings. Throughout this manuscript, pseudonyms are used to protect the identity of the participants.

Ethics

Ethical clearance was granted by the University of [omitted to ensure blind review] Research Ethics Committee (REC-01-079-2019). I met with the participants before the study to explain the nature and purpose of the study and to obtain consent and assent. For adult participants who could give consent, informed consent was obtained. For adults deemed to lack the capacity to give consent and those aged 17 assented to participate, while their caregiver consented by proxy (Strode, Slack & Essack, 2010). As per the recommendations of Ho *et al.* (2018), the assent process was simplified so that it was not dependent on verbal and memory ability. Pictorial instructions were used to improve participants' understanding when required. All participants consented to the audio recording of interviews.

FINDINGS

The study identified four primary themes relevant to preparing disabled youths for leaving care: person-centred planning for care-leaving; opportunities for extended care and gradual exits from care; support for interdependent living post-care; and addressing loss and anxiety during the

transition. The article's overarching goal is to delineate the prerequisites for adequately preparing disabled youths leaving care. Rather than focusing on existing practices, I have chosen to frame these themes in terms of what appears imperative for the wellbeing and successful transition of disabled care-leavers. This approach enables a clearer focus on identifying and addressing the core needs of this vulnerable population during their transition to independence.

Theme 1: Person-centred planning for care-leaving

The approach to care-leaving preparation varied significantly across the CYCCs. While each CYCC had its unique care-leaving preparation plan, most adopted a uniform approach that did not account for the specific needs of disabled youths. This standardised method typically involved conducting review panels and periodically reminding young people about their impending departure from care.

In contrast, the CYCC specialising in care for intellectually disabled youths embraced a person-centred approach. Their staff possessed a deeper understanding of the unique needs of disabled young people, resulting in a highly individualised care-planning process. Notably, the preparation planning at this specialised CYCC was tailored to the developmental needs of each young person. Moreover, they carefully considered both abrupt and gradual transitions, with the transition process commencing well before the youth reached the age of majority.

For example, Buhle, one of the young people, initiated his transition process early, using a picture exchange communication system (PECS) to express his desire to visit the adult facility he would transition to on weekends. He explained that this approach familiarised him with his future living environment. This person-centred approach starkly contrasted with the more generalised and less adaptive approach in other CYCCs.

Three CYCCs had only a few disabled young people residing with mostly non-disabled young people, resulting in more generic preparation that did not fully meet the needs of disabled young people, as explained by Tia the occupational therapist at Lee's CYCC:

> *We do not specialise in disability, we had to learn firstly how to provide care to Lee first. Honestly, I am worried about his departure from us. I think that the process is not clear on who has what responsibilities regarding preparing him to leave. His exit plan is constantly changing, almost with every review panel. People around here do not understand intellectual disability and actually think that he is just behaving badly when things do not go his way. Applications to several adult facilities were made by the external social worker, but he was not accepted in any. He has multiple conditions, and no single agency wants to admit him. They all give feedback on how they will not be able to handle either his intellectual disability or epilepsy and poor self-care skill. The system is not adequately equipped for children like Lee. He will leave here, but he might become homeless because the same house he was unable to stay previously is where he must now go to and not much has changed.*

Tia acknowledged their limitations in creating a person-centred plan for Lee, leading to the implementation of a generic plan. She was fully aware that this generic plan would not adequately address or meet Lee's transitional needs.

Sihle's caregiver, Dorothy, also alluded to limited person-centred transition planning in his mainstream CYCC:

> I am not sure what will happen to him, the social worker has not said anything to me, I think he will come back to me. He doesn't have anyone else. He does not speak properly. I am not sure if I will have to take him for his hospital check-ups if he comes to me. He is diabetic also, so he will need someone to always watch what he eats because he don't understand why he cannot eat everything…a lot of things do not make sense to him, so he will never be able to live alone. Someone has to be there to help him. The CYCCs only take them up to a certain age, then after, no one really knows what's next. It feels like it becomes someone else's problem.

Sue highlights that her care-leaving preparation was basic and did not consider her needs as a disabled young person:

> I know when I am leaving, I have learned some skills to help me, but there are a lot of things I am not sure of. I don't know who will provide counselling when I need it. I also don't know how to apply for the disability grant; perhaps my mother will help me with that. I am still not sure of how to use public transport or get medical help. These things make me feel anxious and sometimes, people do not understand me.

By contrast, Ellen, the director of the CYCC specialised for intellectually disabled youth, where Buhle, Clive, Peter and Ann lived, said:

> In my experience of running this home, I have come across many professionals who do not understand these invisible disabilities. Some are uninterested in educating themselves in order to provide better care. I employ my own social workers, so I am able to screen their knowledge of intellectual disability. Our preparation starts when the child is admitted– when we are drafting their care plans. We read and learn best practices from other international organisations, and then we adapt our services to fit our South African context. So, when we admit children, we teach them various skills, put them in special schools where necessary so that we can develop skills to help them after they leave. There aren't a lot of options where they can go to, especially if they are severe or profound. We have developed our own adult facility for those who are likely to be faced with homelessness when they leave. In their case, transition starts months before they finally leave. We conduct reviews, agency meetings to get some stakeholders on board and gather resources to assist with the exit, but it is very difficult. The support on adult services in South Africa is extremely limited.

Theme 2: Opportunities for extended care and gradual exits from care

Although young people might have reached the age to transition out of care, many still require ongoing support after their 18th birthday. The South African Children's Act (section 176) allows extended care but only to complete education and training (Republic of South Africa, 2005). Unfortunately, extension based on completion of education excludes disabled young people with complex needs who are not continuing in formal education, but may require extended care which is often not available unless the CYCC can generate private funding to cover care costs. Ellen explained:

> *When they reach 18 years, they have to leave, even though they might not be ready. The difficulty is getting an extension order for them to stay. … Their external social worker falls away, and their stay affects our bed capacity and funding. This is the reason why I started an adult care facility so that I can phase their transition since this is not available in Western Cape right now…*

Tia (occupational therapist) at Lee's CYCC also highlighted the lack of aftercare provision:

> *There are long waiting lists for places that can provide the support he needs. So even though we have many review panels and meetings to plan, we can't start the actual transition without a destination. This is a big challenge!*

Lee described the lack of certainty about where he was going to transition to, which could have been alleviated by a gradual transition:

> *I know I have to leave on my birthday, but I do not know where I am going. The social worker changes it all the time. Sometimes they say I will go to my mommy. Then they change and say I will stay in a place with others like me.*

By contrast, Sue, who was one of the young people who remained in care past her 18th birthday, showed greater calm about her transition:

> *The planning was okay, I knew when I will be leaving. I still needed to finish school, so I stayed after my 18th birthday. I also knew I was going to go home and go to college after leaving.*

Gradual transitioning and acknowledging the developmental needs of disabled young people helps enhance the transition and achievement of positive outcomes.

Theme 3: Support for interdependent living post-care

Traditionally, care-leaving focused on transitioning young people towards independent living. Some young people in this study reflected this goal to achieve independence. For example, Sue had high expectations for her future, including learning how to drive:

When I leave care, I want to try and get a driver's licence. I will maybe learn on the farm roads because it is not too busy than in the city. My mum is willing to teach me once I leave.

Clive, who was aiming to live independently, said:

I am going to stay on the farm for a little bit. Then I am going to move out once I save enough money. I want to live by myself. I am not sure about cooking though; I do not really know how to make real food. I can make a sandwich and braai [barbeque] *meat; that's about it. I have to learn, otherwise, I will starve.*

Ann also said,

I have learned to use public transport when I went home for holidays and I will be going to work at a charity shop and will use a taxi [public transport] *to go to work.*

These young people emphasised that self-determination and striving to achieve independence as much as possible were vital to them. The above comments reveal a desire to achieve independent living, but with some degree of support from others, especially caregivers.

There is, however, increasing recognition of the need to support interdependent living after leaving care (Buitt, 2017). Disabled young people, in particular, may require different types and levels of ongoing support in their young adult lives (Kelly, 2013). Interdependence focuses on circles of informal and formal support (family, service providers, peers, community members and other relationships) and community connectedness (Storø, 2018). Post-care support is necessary, given the various kinds of support required by disabled young people in transition.

This focus on interdependence is particularly relevant to disabled care-leavers. For example, Gary's mother, Avery, explained that, because of his complex needs, he would require ongoing post-care support:

What has always been difficult for us was being in public with him. He can get overly stimulated by certain sounds, and he experiences a meltdown in public. Sometimes the meltdowns are really bad; he bangs his head sometimes, and people stare at you. Coupled with his size, if you do not know how to handle him, he can hurt you. You have seen how big he is.

Lee's mother, Cathy, echoed the same view and also had fears for his safety if he returned home to live in their local community:

Lee will always need lifelong care; he can never live alone. His self-care is poor, sometimes he does not go to the toilet alone; he is still bedwetting at night.

For some disabled youths, the complexity of their support needs, often coupled with a lack of attention to building their independence skills whilst in care, meant they were not ready to move into independent living on leaving care. However, with the right support and preparation grounded

in a social model perspective, many disabled young people could develop their daily living skills and enjoy more self-determined lives. Ellen said:

> [Buhle] *has achieved so much now. It took us many years to teach him how to eat independently. He used to drool, but now he chews his food and swallows it. Toilet training was the hardest! He can go now without much help, but he needs visual prompts so that he remembers the steps to follow.*

The goals of disabled care-leavers vary, reflecting the heterogeneous experiences of the group. For example, some disabled young people aim for independent life after leaving care, others striving for independent life after leaving care, and others strive for interdependence with ongoing practical and psychosocial support from informal and formal networks in their young adult lives. These findings underline the importance of person-centred planning, preparation and support for their successful transitions to adult life.

Theme 4: Loss and anxiety related to moving on

Leaving care, like all transitions, involves significant environmental and relational changes, which can evoke feelings of loss and anxiety. Youths had concerns about acceptance in a disabling society and how they will cope with reduced support from welfare services. For example, Ann said:

> *It's going to be hard not to see my friends daily, not walking into the social worker's office when I need to talk. I am not sure yet who I will be able to talk to when I need help. Not knowing makes me worry. I do not know what I will do when I leave the home. I have known the aunties and uncles* [care workers] *here for a long time and I do not know if I will ever see them again. They all help me here. I am a bit scared that it will be too difficult to go back to the community.*

The lack of planning for the disengagement from care and limited options for ongoing support post-care accentuated these fears and anxieties, leaving disabled young people very unsure about their future. For example, Lee was worried about leaving and about who would take care of him:

> *I don't know where I am going to go, and I am worried. I don't know who will take me to the clinic and give me my tablets when I have a seizure. Mr.* [care worker] *always checks on me. Sometimes he also brings me extra socks and clothes.*

Uncertainty about their future and the reality of disengagement from the CYCC caused great anxiety. Some of these emotions could be better addressed with more careful involvement in planning, where the transitional process could be explained in a more accessible way rather than as a once-off event. In addition, some felt abandoned by the CYCC staff that had supported them for many years and would no longer be involved in their lives, as Peter explained:

> *I am not really sure how everything will work out. But here at* [CYCC] *I knew where I was supposed to be and if I got confused, I could always ask the social worker. People*

are friendly here; they know us and what we struggle with. When I leave, I have to make new friends and I am worried about that.

Young people consistently expressed sadness about terminating relationships as a result of the transition and anxiety about social isolation and being exposed to discriminatory public attitudes and behaviour. Clive said:

People out there are not always understanding of my needs. When they look at me, I look normal, but I struggle to remember information. I think that it will be difficult to make new friends like I have here. People can be mean also. So, I am scared that sometimes I have to speak up for myself and I might not be taken seriously.

Sue will be furthering her education after disengagement and expressed concerns similar to Clive and Peter:

It's college I am worried about. I am worried about the other children. Everyone will have their own way, but there is too much pressure to fit. I don't know if I will make friends. I guess I will have to keep on explaining that I am autistic because I can be socially awkward.

Anxiety about leaving care was apparent in all participants, regardless of their level or type of impairment. They all wondered if they would be understood and accepted, and safety was a concern, and who would help them if they were at risk in the community. They were also concerned about disruptions to their established sense of belonging. Handling care-leaving as a process would allow the young person adequate time to process the stage of development. If not, considerable distress can result, as Lee said:

They lie for me! Sometimes they tell me I am going to place for people like me. Then they tell me they did not get a place and I am going to my mother's house. It's not safe there. They are shooting. I tear my clothes and hit my head against the wall when I am upset. Why they lie for me?

Sudden changes trigger anxiety and mixed messages may lead to confusion. A gradual process and frequent updates on any changes can help the young person understand their future and reduce being overwhelmed.

One CYCC prepared the young person for transition through enrolment in mentoring programmes and conducted review panels and multi-agency meetings to ensure a gradual and inclusive transitional process. Clive had his skills enhanced through enrolment in such a programme:

I've been enrolled in the mentoring programme since I was 14 years and I know where I am going to live after leaving the children's home. I know people that I can ask for help, so I am not too worried. My only fear is that people might see that I am not like them because I forget stuff a lot. I am going to stay at a farm in [a rural community].

Sue explained how she was actively involved in the process to prepare her for transition, which generated positive feelings about the upcoming transition out of care:

> *I sat with the social worker at the Centre several times and I also sat with them and my mother and discussed what will happen. They helped me apply at a college to work with animals because that's what I love. I know that when I leave, I am going to stay in* [another community] *close to the college and work…daily. I am so excited!*

DISCUSSION

This study highlights four significant themes derived from our research: person-centred planning for care-leaving; opportunities for extended care and gradual exits; support for post-care interdependent living; and addressing loss and anxiety during the transition. These findings underscore the vital importance of preparation for care-leaving, particularly for disabled youths.

A person-centred approach to transition planning for disabled care-leavers is essential, aligning with the imperative of facilitating a gradual transition process (Mupaku *et al.,* 2021). The complexity of transitioning out of care for disabled youths is well documented (Bennwik, Oterholm & Kelly, 2023; Biggs & Carter, 2016; Cheatham *et al.,* 2020, Harwick *et al.,* 2020). Research consistently underscores the substantial benefits of actively involving disabled youths in crafting and executing their transition plans as they prepare to exit care systems (Hagner *et al.,* 2014).

Research on support for disabled young people transitioning out of care is a slowly growing field, with studies highlighting a multitude of obstacles hampering their move from care (Geenen & Powers, 2007; Kelly *et al.,* 2016; Snow *et al.,* 2014). These challenges include unstable housing situations, inadequate pathways for education and employment, financial hardships, and a dearth of informal support networks; such challenges are exacerbated by inadequate care-leaving preparation (Harwick *et al.,* 2020; Kelly *et al.,* 2016).

Moreover, the findings emphasise that disabled youths leaving care frequently have to deal with inadequate exit planning and face challenges accessing post-care support. These hurdles arise from restrictive eligibility criteria and a pervasive lack of disability awareness across service systems (Duncalf, 2010; Geenen & Powers, 2007; Harwick *et al.,* 2017; Hutton *et al.,* 2019; Roberts *et al.,* 2018; Snow *et al.,* 2014).

The lack of recognition of the unique needs of disabled youths during the transition process is concerning. It underscores the critical necessity for comprehensive care-leaving preparation that addresses not only practical aspects but also youths' emotional wellbeing. The transition phase for disabled youths is a period of heightened vulnerability (Young-Southward, 2018), marked by various challenges, including the potential loss of support networks and anxiety about moving forward (Adley & Jupp Kina, 2015).

Furthermore, it is crucial to acknowledge that not all youths transition to independent living and, for many disabled youths, the focus on interdependence is critical (Mupaku *et al.,* 2021). Therefore, strengthening interdependent networks as part of the broader care-leaving process is imperative to cater for the diverse needs of this population.

South African policy and legislation lack clear guidelines for youth transitioning from care, creating concerns for aftercare support, regardless of disability status (Department of Social Development 2019; RSA, 2005). Reintegration and aftercare support are necessary to sustain care-leavers in the community (Bond, 2018; Mamelani, 2013; Marx & Dickens, 2016).

This study's findings highlight the need for South African policy that directs and supports a person-centred approach to transition for disabled youths leaving CYCCs, including early preparation, comprehensive support and continuous evaluation. This entails customising transition plans, initiating planning well in advance with phased exits, extending support beyond CYCCs and providing mentorship programmes for youths in transition (Tanur, 2012). These pillars collectively ensure an effective approach to care-leaving for disabled youths in South Africa. Furthermore, South African policies and legislation must mandate organisations to implement these directives, aligning with the South African Constitution's goals of improving access for all and fostering a non-discriminatory society (RSA, 1996).

For those who have reached 18 years and must exit care, but are still awaiting an adult placement, opportunities for extended care may be beneficial to allow them to remain in a familiar environment until suitable accommodation has been secured. A gradual transition is also beneficial for disabled youths who require more time to learn new information and comprehend the implications of leaving care.

This study emphasises the critical importance of comprehensive preparation for and during the transition phase for disabled young people, who are vulnerable to poorer outcomes in adult life (Kelly *et al.,* 2016; MacDonald *et al.,* 2016; Roberts *et al.,* 2018; Roos & Søndenaa, 2020; Young-Southward, Cooper & Philo, 2017). Effective preparation addresses issues that have been consistently highlighted in previous research, such as the disconnect between child and adult disability services. Unlike some countries with well-coordinated child to adult disability services, in South Africa there is a need to shift away from an emphasis on the individual responsibility of the youths towards integrated multidisciplinary service approaches (Cvejic & Trollor, 2018). Recognising the diversity within the disability community, it is crucial that each disabled care-leaver has access to the support they need as they prepare to leave care and that appropriate care pathways are established for their post-care lives.

These findings also support international research which indicates that disabled care-leavers experience the same challenges as other youths leaving care, but these are compounded for disabled young people who do not have access to adequate person-centred planning and preparation for their transition out of care (MacDonald *et al.,* 2016; Mendes & Snow, 2014). Acknowledging the multifaceted interactions between the young person and their environment and

preparing them adequately is vital to support better outcomes for disabled youths leaving care (Stewart *et al.*, 2014).

LIMITATIONS

There are limitations to consider when interpreting these findings. First, the study was comprised of eight disabled young people who were drawn from only four CYCCs in the Cape Peninsula area of South Africa, not the whole of South Africa. Therefore, it is not certain how transferable these findings are to other CYCCs in South Africa. Second, the four CYCCs were diverse: one provided specialised disability childcare services, while the other three provided generic childcare. Understanding of intellectual disabilities and/or autism and the tailoring of services to disabled youths consequently varied between the CYCCs.

IMPLICATIONS FOR POLICY AND PRACTICE

This study emphasises a significant gap in South African policy concerning the transition of children out of care, with a particular focus on disabled youths. The care-leaving process lacks consistency because of the insufficient prioritisation of this aspect in the South African Children's Act (RSA, 2005). To address this gap, early planning and service coordination are crucial, adopting a person-centred approach that actively engages young people to understand and accommodate their perspectives (Jamieson, 2016). Moreover, the literature highlights the importance of adaptable services that consider the diverse characteristics of care leavers with mental health needs, including factors such as ethnicity, culture and gender (Daining & DePanfilis, 2007; Garcia *et al.,* 2012; McMillen & Raghavan, 2009; Yates & Grey, 2012).

As part of person-centred planning, there is a need for extended care that supports gradual transitions, investment in adult care placements, and supported living options to avoid dependency on specialist segregated or institutional adult care. Extended aftercare support should not be offered just to those engaged in education, but also to those vulnerable to poor outcomes, including disabled youths. Aftercare support would require a change to current legislation as the current one only accommodates extension in care until age 21 on the basis that the individual is completing their education or a training programme.

Additionally, there is a need for support for interdependence alongside fostering the development of daily living skills whilst in care. Promoting interdependence is in line with the social model's tenets, as enabling networks of support can promote inclusion and mitigate against isolation and the impact of disabling barriers in society (Keyes, Webber & Beveridge, 2015).

Efforts are also needed to reduce the feelings of anxiety and loss that disabled youths experience in transition. These could include: making the moves in gradual steps, with opportunities to stay in touch with familiar staff; building networks and community connectedness whilst they are in care; developing safety plans to reassure care-leavers about their safety in the community; and addressing stigma and oppression of disabled people in the community to promote social inclusion.

The study shows the diverse needs of disabled youths leaving care and underlines the need for individualised planning and preparation for optimal post-care outcomes. Preparation for care-leaving is crucial and, as such, there needs to be a mandatory process for transition. Achieving this requires a national standard for preparation for leaving care and the provision of aftercare support for all care-leavers, including disabled care-leavers. Current legislation on disabled care is not directive (Republic of South Africa, 2005). The Children's Act needs to be amended to include a care-leaving section stipulating mandatory steps that CYCCs and their professionals should take before the young person's exit from care, during the actual disengagement, and over an obligatory 6-12-months post-care follow-up period.

CONCLUSION

This study highlights that the appropriate preparation of disabled youths for the transition from care is absent across various CYCCs in South Africa. There is a lack of individualised, specialised support, inadequate time to address feelings of loss and anxiety related to moving on, inconsistent participation by young people about ageing out of care, and insufficient interdependent aftercare structures that cover the varied needs of this population. The lack of interdependent post-care networks undermines the social model of disability adopted in South African policies, emphasising the social ecology of disabled people's lives. This study is one of a few on the transitional process for disabled youth globally and the only one in South Africa. While further evidence is required, this study emphasises the importance of person-centred planning, opportunities for extended care, support for interdependent living after leaving care, and greater attention to the emotional needs of disabled care-leavers.

REFERENCES

Adley, N. & Jupp Kina, V. 2015. Getting behind the closed door of care leavers: Understanding the role of emotional support for young people leaving care. *Child & Family Social Work*, 22(1): 97-105.

African Union 2002. *Continental plan of action for the African decade of persons with disabilities: 1999-2009*. African Union.

American Psychiatric Association. 2013. *Diagnostic and statistical manual of mental disorders.* 5th ed. APA: Washington, DC.

Barnes, C. 2019. Understanding the social model of disability: Past, present and future. In: Watson, N., Roulstone, A. & Thomas, C. (eds). *Routledge handbook of disability studies*. London: Routledge.

Bennwik, I. H. B., Oterholm, I. & Kelly, B. 2023. 'My disability was my own responsibility': An institutional ethnography of the transitional experiences of disabled young people leaving care. *Children and Youth Services Review*, 146: 106813.

Biggs, E. E. & Carter, E. W. 2016. Quality of life for transition-age youth with autism or intellectual disability. *Journal of Autism and Developmental Disorders,* 46: 190-204.

Bond, S. 2018. Care leaving in South Africa: An international and social justice perspective. *Journal of International and Comparative Social Policy*, 34(1): 76-90.

Braun, V. & Clarke, V. 2012. Thematic analysis. In: Cooper, H., Camic, P. M., Long, D. L., Panter, A. T., Rindskopf, D. & Sher, K. J. (eds.). *APA handbook of research methods in psychology, Vol 2: Research designs: Quantitative, qualitative, neuropsychological, and biological.* Washington: American Psychological Association.

Broadley, K. 2015. Is there a role for adult protection services in the lives of young people with disabilities transitioning from out-of-home care? *Australian Social Work*, 68(1): 84-98. https://doi.org/10.1080/0312407X.2014.932400

Buitt, L. 2017. *Use of change management tools for interdependent living skills during the transition to adulthood for aged-out foster care alumni*. Doctoral thesis. Pepperdine University, United States of America.

Campbell, A., Taylor, B. J. & McGlade, A. 2016. *Research design in social work: Qualitative and quantitative methods*. London, UK: Learning Matters.

Cheatham, L. P., Randolph, K. A. & Boltz, L. D. 2020. Youth with disabilities transitioning from foster care: Examining prevalence and predicting positive outcomes. *Children and Youth Services Review*, 110: 104777.

Crous, G., Montserrat, C. & Balaban, A. 2020. Young people leaving care with intellectual disabilities or mental health problems: Strengths and weaknesses in their transitions. *Social Work & Society*, 18(3): 1-19.

Cvejic, R. C. & Trollor, J. N. 2018. Transition to adult mental health services for young people with an intellectual disability. *Journal of Paediatrics and Child Health,* 54(10): 1127-1130.

Daining, C. & DePanfilis, D. 2007. Resilience of youth in transition from out-of-home care to adulthood. *Children and Youth Services Review,* 29(9): 1158-1178.

Department of Social Development. 2019. National Child Care and Protection Policy. [Online] Available: https://www.gov.za/sites/default/files/gcis_document/202102/national-child-care-and-protection-policy.pdf [Accessed: 17/09/2023].

Duncalf, Z. 2010. *Adult care-leavers speak out: The views of 310 care-leavers aged 17-78.* Manchester, UK: Care Leavers' Association.

Engelbrecht, M., Shaw, L. & Van Niekerk, L. 2017. A literature review on work transitioning of youth with disabilities into competitive employment. *African Journal of Disability*, 6(1): 1-7.

Flink, P. 2021. Person-first & identity-first language: Supporting students with disabilities on campus. *Community College Journal of Research and Practice*, 45(2): 79-85.

Frost, L. 2002. The picture exchange communication system. *Perspectives on Language Learning and Education,* 9(2): 13-16.

Garcia, A. R., Pecora, P. J., Harachi, T. & Aisenberg, E. 2012. Institutional predictors of developmental outcomes among racially diverse foster care alumni. *American Journal of Orthopsychiatry,* 82(4): 573–584.

García-Alba, L., Gullo, F. & Del Valle, J. F. 2023. Readiness for independent living of youth in residential childcare: A comparative study. *Child & Family Social Work*, 28(1): 171-183.

Gauthier-Boudreault, C., Couture, M. & Gallagher, F. 2018. How to facilitate transition to adulthood? Innovative solutions from parents of young adults with profound intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 31: 215-223.

Gauthier-Boudreault, C., Gallagher, F. & Couture, M. 2017. Specific needs of families of young adults with profound intellectual disability during and after transition to adulthood: What are we missing? *Research in Developmental Disabilities*, 66: 16-22.

Gilligan, R. (2019). Resilience, Transitions, and Youth Leaving Care. In V. R. Mann-Feder & M. Goyette (Eds.), Leaving care and the transition to adulthood: International contributions to theory, research, and practice. Oxford, UK: Oxford University Press. https://doi.org/10.1093/oso/9780190630485.003.0004

Glasper, A. & Evans, K. 2014. Improving services for disabled children and their families. *British Journal of Nursing*, 23(11): 600-601.

Haegele, J. A. & Hodge, S. 2016. Disability discourse: Overview and critiques of the medical and social models. *Quest*, 68(2): 193-206.

Hagner, D., Kurtz, A., May, J. & Cloutier, H. 2014. Person-centered planning for transition-aged youth with autism spectrum disorders. *Journal of Rehabilitation,* 80(1): 4-10.

Harwick, R. M., Lindstrom, L. & Unruh, D. 2017. In their own words: Overcoming barriers during the transition to adulthood for youth with disabilities who experienced foster care. *Children and Youth Services Review*, 73: 338-346.

Harwick, R. M., Unruh, D. & Lindstrom, L. 2020. Transition to adulthood for youth with disabilities who experienced foster care: An ecological approach. *Child Abuse & Neglect*, 99: 104310.

Ho, P., Downs, J., Bulsara, C., Patman, S. & Hill, A. M. 2018. Addressing challenges in gaining informed consent for a research study investigating falls in people with intellectual disability. *British Journal of Learning Disabilities*, 46(2): 92-100.

Hutton, S., Head, K. J., Lyttle, S., Kenneally, N. & Rehou, M. 2019. System kids: Transition-aged youth from foster care to developmental services. *Journal on Developmental Disabilities*, 24(1): 49-65.

Jamieson, L. 2016. Children and young people's right to participate in residential care in South Africa. *The International Journal of Human Rights*, 21(1): 89-102.

Kelly, B. 2013. *Don't box me in: Disability, identity and transitions to young adult life.* Northen Ireland & Queen's University Belfast: Belfast.

Kelly, B., Mcshane, T., Davidson, G., Pinkerton, J., Gilligan, E. & Webb, P. 2016. *Transitions and outcomes for care leavers with mental health and/or intellectual disabilities: Final report*. Belfast, UK: Queen's University Belfast.

Kelly, B., Van Breda, A. D., Santin, O., Bekoe, J., Bukuluki, P., Chereni, A., Frimpong- Manso, K., Jacobs, D., Luwangula, R., Maanyi, M., Makadho, B., Muchiendza, T., Pinkerton, J. & Ringson, J. 2020. *Building Positive Futures: Exploring a peer research approach to study leaving care in Africa.* Queen's University Belfast.

Keyes, S. E., Webber, S. H. & Beveridge, K. 2015. Empowerment through care: Using dialogue between the social model of disability and an ethic of care to redraw boundaries of independence and partnership between disabled people and services. *Alter*, 9(3): 236-248.

MacDonald, S., Ellem, K. & Wilson, J. 2016. Supporting young people with an intellectual disability transitioning from out-of-home care to adult life in Queensland, Australia. In: Mendes, P. & Snow, P. (eds.) *Young people transitioning from out-of-home care: International research, policy and practice*. London: Palgrave.

Mamelani 2013. *Transitional support: The experiences and challenges facing youth transitioning out of state care in the Western Cape*. Cape Town, RSA: Mamelani Projects. [Online] Available: http://www.mamelani.org.za [Accessed: 18/09/2023].

Marx, P. & Dickens, L. F. 2016. *Five years on: Practice recommendations from the Growth Beyond the Town research project.* Cape Town, RSA: Girls and Boys Town South Africa.

McMillen, J. C. & Raghavan, R. 2009. Paediatric to adult mental health service use of young people leaving the foster care system. *Journal of Adolescent Health,* 44(1): 7-13.

Mendes, P. & Snow, P. 2014. The needs and experiences of young people with a disability transitioning from out-of-home care: The views of practitioners in Victoria, Australia. *Children and Youth Services Review*, 36: 115-123.

Mendes, P., Snow, P. & Baidawi, S. 2016. Young people transitioning from out-of-home care in Victoria, Australia: Strengthening support services for dual clients of child protection and youth justice. In: Mendes, P. & Snow, P. (eds.). *Young people transitioning from out-of-home care: International research, policy and practice*. London: Palgrave.

Muir, S. & Hand, K. 2018. *Beyond 18: The longitudinal study on leaving care: Wave 1 research report: Transition planning and preparation*. Melbourne, Australia: Australian Institute of Family Studies.

Munro, E., Molholt, A. & Hollingworth, K. 2016. Leaving care in the UK and Scandinavia: Is it all that different in contrasting welfare regimes? In: Mendes, P. & Snow, P. (eds.) *Young people transitioning from care: International research, policy and practice*. London: Palgrave.

Mupaku, W. M., Van Breda, A. D. & Kelly, B. 2021. Transitioning to adulthood from residential childcare during COVID-19: Experiences of young people with intellectual disabilities and/or autism spectrum disorder in South Africa. *British Journal of Learning Disabilities*, 49(3): 341-351.

Petrowski, N., Cappa, C. & Gross, P. 2017. Estimating the number of children in formal alternative care: Challenges and results. *Child Abuse & Neglect,* 70: 388-398.

Republic of South Africa (RSA). 1996. *Constitution of the Republic of South Africa*. Government Gazette**,** Vol. 378, No. 17678 (8 May 1996) Pretoria: Government Printer.

Republic of South Africa (RSA). 2005. *Children's Act,* 38 of 2005. Government Gazette, Vol. 492, No. 28944. (19 June 2006). Pretoria: Government Printer.

Retief, M. &Letšosa, R. 2018. Models of disability: A brief overview. *HTS Teologiese Studies/Theological Studies*, 74(1): 1-8.

Roberts, H., Ingold, A., Liabo, K., Manzotti, G., Reeves, D. & Bradby, H. 2018. Moving on: Transitions out of care for young people with learning disabilities in England and Sweden. *British Journal of Learning Disabilities*, 46(1): 54-63.

Roos, E. & Søndenaa, E. 2020. Improving the transition process to independent living for adolescents with profound intellectual disabilities. Experiences of parents and employees. *BMC Health Services Research*, 20(1): 1-12.

Rubin, A. & Babbie, E. R. 2016. *Empowerment series: Research methods for social work*. Boston, USA: Cengage Learning.

Sandelowski, M. 2010. What's in a name? Qualitative description revisited. *Research in Nursing & Health*, 33(1): 77-84.

Slayter, E. 2016. Youth with disabilities in the United States child welfare system. *Children and Youth Services Review*, 64: 155-165.

Snow, P., Mendes, P. & O'Donohue, D. 2014. *Young people with a disability leaving state care: Phase two report.* Melbourne: Monash University.

Stewart, D., Law, M., Young, N. L., Forhan, M., Healy, H., Burke-Gaffney, J. & Freeman, M. 2014. Complexities during transitions to adulthood for youth with disabilities: Person–environment interactions. *Disability & Rehabilitation*, 36(23): 1998-2004.

Storø, J. 2018. To manage on one's own after leaving care? A discussion of the concepts independence versus interdependence. *Nordic Social Work Research*, 8(1): 1-12.

Strahl, B., Van Breda, A. D. P., Mann-Feder, V. & Schröer, W. 2021. A multinational comparison of care-leaving policy and legislation. *Journal of International and Comparative Social Policy*, 37(1): 34-49.

Strode, A., Slack, C. & Essack, Z. 2010. Child consent in South African law: Implications for researchers, service providers and policy-makers. *SAMJ: South African Medical Journal*, 100: 247-249.

Tanur, C. 2012. Project Lungisela: Supporting young people leaving state care in South Africa. *Child Care in Practice,* 18(4): 325-340.

United Nations 2006. *Convention on the rights of persons with disabilities*. General Assembly United Nations, New York.

Van Breda, A. D. 2018. *Care-leaving research in South Africa*. Paper presented at the Open INTRAC (International Research Network on Transitions to Adulthood from Care) Meeting, Porto, Portugal.

Van Breda, A. D. 2019. Developing the concept of ubuntu as African theory for social work practice. *Social Work /Maatskaplike Werk*, 55(4): 439-450.

Van Breda, A. D. 2020. Patterns of criminal activity among residential care-leavers in South Africa. *Children and Youth Services Review*, 109: 104706.

Yates, T. M. & Grey, I. K. 2012. Adapting to aging out: Profiles of risk and resilience among emancipated foster youth. *Development and Psychopathology,* 24(2): 475-492.

Young-Southward, G. 2018. *The impact of transition to adulthood on health and wellbeing in young people with intellectual disabilities.* Doctoral thesis. University of Glasgow, Scotland.

Young-Southward, G., Cooper, S. A. & Philo, C. 2017. Health and wellbeing during transition to adulthood for young people with intellectual disabilities: A qualitative study. *Research in Developmental Disabilities,* 70: 94-103.

AUTHOR BIOGRAPHY

Wendy M. Mupaku is a PhD student at the University of Johannesburg and a clinical social worker in private practice in the Cayman Islands. Her field of specialisation is child mental health,

disability and care-leaving. The article was part of a larger longitudinal study conducted from October 2019 to May 2021. She conceptualised the study, conducted fieldwork, and interpreted the findings, with guidance and editing support from Prof. A. D. Van Breda and Prof. B. Kelly.