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# Caregivers' Perspectives and Experiences on the Transition of Youth with Intellectual Disabilities or Autism Out of Residential Care

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## Abstract

This paper presents the findings of a longitudinal study conducted in South Africa that investigated the perspectives and experiences of informal caregivers in assisting youth with intellectual disabilities and/or autism as they transitioned from residential care towards young adulthood. This was a component of a larger study that examined the transition of six care-leavers. This paper focuses only on the interviews conducted with caregivers. The study utilised a qualitative research design to uncover participants' experiences and perceptions. The three informal caregivers of youth with intellectual disabilities and/or autism were each interviewed thrice over 18 months. Five core themes emerged from the thematic analysis of caregiver interview data: inadequate transitional planning and preparation; limited aftercare opportunities; barriers to accessing formal support; caregiver unmet support needs; and the value of informal relational support. Caregivers play a crucial role in the lives of care-leavers with intellectual disabilities and/or autism as they transition towards young adulthood. However, they often report insufficient support, compounded by challenges in transitional planning and gaps in aftercare support for the young person in their care.

**Keywords** Caregiver · intellectual disabilities · autism · care leaving · transitions

## Introduction

The transition from adolescence to young adulthood is a critical period for all youth. But for youth with intellectual disabilities and/or autism[1], this can be particularly challenging, due partly to discrimination and marginalisation in society (Mitter et al., 2019). These challenges are further complicated when young people are also transitioning from foster or residential care, known as care-leaving, due to the lack of support from family and limited aftercare services (Bennwik et al., 2023; Kelly et al., 2016, 2022). For care-leavers with disabilities, these challenges can be compounded. In many cases, as in this study, these care-leavers must transition from formal alternative care but still require a range of formal and informal supports for interdependence in adult life (Storø, 2018). However, research suggests that the child welfare system struggles to adequately address the specific needs of care-leavers with disabilities and promote their inclusion in society (Bennwik et al., 2022; Harwick et al., 2020; Kelly et al., 2022).

While international research has recently advanced in explicating the challenges faced by care-leavers with disabilities during the transition to adulthood (Bennwik et al., 2023; Kelly et al., 2016; MacDonald et al., 2016; Wainwright et al., 2025), care-leaver studies in South Africa have entirely overlooked the experiences of care-leavers with disabilities until recently (Mupaku et al., 2021). Furthermore, a substantial knowledge gap exists regarding the perspective of caregivers of youth with disabilities who are leaving care (Dada et al., 2020).

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[1] This study adopts person-first language aligning with policy and practice in South Africa and the preferred language of study participants (Mutanga, 2017).

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This study, therefore, aims to explore the perspectives and experiences of South African informal caregivers living in the Western Cape province regarding the transition of care-leavers with intellectual disabilities and/or autism from residential care to young adulthood. This research captures caregiver perspectives on their experiences of and insights into caring for care-leavers with intellectual disabilities and/or autism, including their own needs as caregivers, at this critical phase of transition.

The paper is structured into several sections, beginning with an exploration of the care-leaving context in South Africa, including policies and service provision, and a review of the literature on caregivers of care-leavers with intellectual disabilities and/or autism. Subsequent sections outline the methodology employed in the study and present the study findings. The discussion and conclusion summarise key points and map implications for future research or practice.

## Disability and Care-leaving Policy and Legislation in South Africa

In South Africa, principles of inclusivity, equality and human rights underpin policies and legislation about people with disabilities. Chapter 2 (Bill of Rights) of the Constitution of the Republic of South Africa recognises the fundamental rights to dignity, equality and access to services for people with disabilities (Republic of South Africa, 1996). The United Nations Convention on the Rights of People with Disabilities (UNCRPD), ratified by South Africa in 2007, also forms the foundation for protecting and promoting the rights of individuals with disabilities (United Nations, 2006). The UNCRPD defines persons with disabilities as those "who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" (p. 4). Various policies and laws have also been formulated at national, district and community levels to address the unique needs of this population. The White Paper on the Rights of Persons with Disabilities (Republic of South Africa, 2016) is a strategic framework aimed at empowering and supporting people with disabilities in a range of areas, including accessibility, education, health, employment and social welfare. The Mental Healthcare Act (Republic of South Africa, 2002) also plays a crucial role in shaping South Africa's mental healthcare system.

There is also a range of policies relating to the welfare and well-being of children and young people in South Africa. The Children's Act (Republic of South Africa, 2005) is the cornerstone of child protection in South Africa, providing a comprehensive framework for safeguarding children's rights and well-being. The White Paper on Special Needs Education (Republic of South Africa, 2001) is a guiding policy that ensures equitable access to education, while the National Strategy for the Integration of Services for Children with Disabilities (Republic of South Africa, 1997) addresses the specific needs of children with disabilities by promoting a coordinated approach across different government departments and organisations. These policies underscore South Africa's commitment to creating an inclusive and supportive environment for children and youth with disabilities.

However, there is little policy and provision for aftercare for all care-leavers in South Africa (Strahl et al., 2021), particularly those with intellectual disabilities and/or autism. Furthermore, there is a void in care-leaver policy regarding care-leavers with disabilities, leaving this vulnerable group transitioning out of care without sufficient support and resources (Mupaku et al., 2021). Youth and adults with disabilities draw on a range of services, including the Department of Social Development, the Department of Health, the South African Social Security Agency (SASSA), and the Department of Education, as they transition into adulthood. However, these services are often poorly coordinated across sectors and not easily accessible (Hussein El Kout et al., 2022; van Biljon et al., 2022). Furthermore, the extent to which these services meet the complex needs of care-leavers with disabilities and their informal caregivers is not known.

## Literature Review

Transitioning to adulthood is complex, particularly for care-leavers, marked by rapid changes in housing, education, employment and family context within a condensed timeframe (Crous et al., 2021). Youth leaving care also often face marginalisation and disadvantage in society and are recognised as a population vulnerable to poor outcomes in adulthood (Soyez et al., 2024). Similarly, it is well documented that youth with disabilities living in the community (not in alternative care) face many transitional challenges as they leave school and move into young adulthood (Pearson et al., 2021). However, the combined experiences of transitioning as a young person with disabilities and as a care-leaver have often been overlooked in studies on both care-leaving and transitions of youth with disabilities (Mupaku et al., 2023).

Caregivers play a vital role in providing ongoing support for youth with intellectual disabilities and/or autism transitioning to adulthood. Global research reports that these caregivers encounter emotional, practical and psychological challenges, resulting in increased stress and anxiety

(Cheak-Zamora et al., 2015). In addition, caregivers often grapple with societal stigma and barriers to accessing services for the young person and to meet their own support needs (Gordon & Bila, 2023). Studies in India and Nigeria exploring caregiver perspectives also underscore the insufficiency of social and financial support available for caregivers of youth with intellectual disabilities, exposing them to the risks of burnout (Dada et al., 2020; Ugwuanyi et al., 2023).

Youth leaving care also report transitional challenges as they progress towards independent living and into further education or employment (Henson et al., 2024). Some young people continue living with their former caregivers, who provide practical and emotional support as care-leavers navigate these challenges (Höjer & Oterholm, 2025), while others rely on ongoing state support (Van Breda et al., 2020). The literature also indicates a need for further caregiver training and improved collaboration across services to support their caregiving role (Rice & O'Connor, 2023). A study in Ethiopia (Van Breda et al., 2022), for example, explored the experiences of caregivers of youth transitioning from care. Caregivers were generally passionate about providing care, but were inadequately skilled for their roles and often unable to meet young people's needs due to limited resources. Overall, however, in the broad body of care-leaver research, limited attention has been given to the experiences and needs of caregivers (Höjer & Oterholm, 2025).

In the context of limited research on the experiences of caregivers of youth leaving care, there is even less research on the transition of care-leavers with disabilities from care (Bennwik & Kelly, 2025), and virtually no research on the experiences of caregivers of these youth with disabilities transitioning from care (Kelly et al., 2016). The extant research on care-leavers with disabilities highlights concerns about the lack of involvement of the young person in transition planning, delayed decisions about ongoing support, and gaps in provision as youth move into young adulthood (Bennwik & Oterholm, 2021; Bennwik et al., 2023; Kelly et al., 2022; Pearson et al., 2021; Snow et al., 2016; Wainwright et al., 2025). However, these studies have mostly excluded caregiver perspectives, with the exception of the YOLO (You Only Live Once) study in Northern Ireland (Kelly et al., 2016), which emphasised the need for aftercare support and training for caregivers to effectively support care-leavers with disabilities.

Caregivers of youth with disabilities leaving care may face particular challenges in South Africa's harsh socio-economic contexts (Van Breda & Hlungwani, 2026), where this study was conducted. In these contexts, high poverty and unemployment rates and limited statutory aftercare resources are likely to compound pressures on caregivers (Gordon & Bila, 2023). Yet there are no studies in South Africa that have examined the experiences of caregivers of youth with disabilities leaving care. This knowledge gap necessitates dedicated research capturing the caregiver perspective in South Africa. Prioritising caregiver voices is important for informing the development of more effective support for caregivers who continue to support youth with disabilities leaving care and for improving outcomes for care-leavers.

In summary, existing studies highlight the complex challenges faced by youth leaving care in South Africa (Frimpong-Manso et al., 2026; Kelly et al., 2024; Van Breda, 2024) and the experiences of caregivers of transitioning youth with disabilities more generally (not those leaving alternative care) (Mkabile & Swartz, 2020). However, research has largely ignored the experiences of care-leavers with disabilities, and the voices of their caregivers are notably absent (Scior et al., 2020). This research gap hinders our comprehensive understanding of the nuanced experiences of care-leavers with disabilities (Young-Southward et al., 2017) and their caregivers during this often precarious journey. This study seeks to address this gap in research, to inform the development of more targeted support systems for caregivers of youth with disabilities and/or autism leaving care and to facilitate smoother transitions toward adulthood for this population.

## Methodology

This article draws from a larger study on transitions for care-leavers with intellectual disabilities and/or autism in South Africa. This paper aims to explore the views and experiences of those who care for these young people when they age out of residential care. The study used a qualitative, longitudinal research design in which data were collected in three waves of semi-structured interviews over 18 months.

A positionality statement is appropriate given the research design and topic (Goundar, 2025; The QR Collective et al., 2023). The first author, a doctoral candidate who led this study, is a Black female clinical social worker in South Africa, with experience working with children in residential care and with children with autism, providing a partial insider lens. The second author, co-supervisor of the study, is a White female professor of social work in the UK with extensive experience in research with youth with disabilities and care-leavers. The third author, the study supervisor, is a White male professor of social work in South Africa, with extensive experience of research with young people transitioning out of care, particularly using a social-ecological resilience lens. This team brought a diverse range of demographics, practice and academic expertise to the study.

We worked closely together to learn from each other and to bring our experience, skills and knowledge to the study. None of us has first-hand experience of caring for young people with intellectual disabilities or autism (we thus have an outsider lens), which may have given us a degree of perspective on the study topic. By working closely with participants, seeing them multiple times, and journeying with them through the challenges of COVID-19, we believe we generated authentic and trustworthy data.

Before selecting caregivers for this study, a sample of six young people with intellectual disabilities and/or autism who were in the care of a residential facility, known in South Africa as a Child and Youth Care Centre (CYCC), was purposively selected for the main study. These four CYCCs were in the Cape Peninsula region of the Western Cape Province. We selected this region because it is the province popularly regarded as offering the most well-developed social services, including care and care-leaving support.

The six young people were supported through the transition out of care by three informal caregivers, who comprise our study sample. Caregivers had to be either birth parents or informal carers of the young person when they left care. To be included in the study, caregivers were required to be actively involved in the young person's life and to have maintained contact for at least one year while the young person was in care.

Before data collection, the Faculty of Humanities Research Ethics Committee at the University of Johannesburg approved the study (REC-01-079-2019, dd. 7 June 2019). The CYCC social workers and the first author met with the caregivers of each young person participating in the main study to explain the study and secure their written informed consent to participate. Before each interview, the researcher reminded caregivers of the confidentiality boundaries and their right to withdraw from the study. Data was securely stored on a laptop and backed up on a password-protected external hard drive. Pseudonyms are used to refer to the study participants to protect their anonymity. Avery was a birth parent, and Ellen and Dorothy were legal guardians while the youth were in care and became informal caregivers when they aged out of care. Each participant is briefly described.

**Avery** is Sue and Gary's biological mother. She was their primary caregiver before they entered care due to difficulties at home. Sue lived in care for four years, and Gary for one. Both youths were reunified with their mother on ageing out of care. Sue resides permanently with Avery, while Gary primarily resides with his father and visits Avery on weekends. Both Sue (female) and Gary (male) have autism, and Gary has limited speech. Avery was interviewed three times for Sue and three times for Gary, for a total of six interviews.

**Dorothy** was Sihle's foster mother for five years after his family abandoned him, before he entered the CYCC. Dorothy considers herself to be his family. Sihle (male) lived in care for eight years and, upon ageing out of the CYCC, returned to Dorothy's care as an informal caregiver. Sihle has an intellectual disability with limited speech. Dorothy participated in three interviews.

**Ellen** is the director of the CYCC where Ann, Clive and Buhle were placed in her formal care as children. Ellen also founded an adult care farm offering informal extended care for youth with intellectual disabilities leaving CYCCs. These three young people transitioned into Ellen's informal care after ageing out of the CYCC. She has known them since they entered care as young children. Ann, Clive and Buhle faced neglect, abandonment and abuse necessitating protection and placement in care. On leaving the CYCC, Ann, who has a mild intellectual disability, initially resided at the farm, but returned to her family due to behavioural challenges, while maintaining contact with Ellen. After a short stay at the farm, Clive, who has mild intellectual disability, moved to private accommodation as he resumed work; he remained in contact with Ellen and other farm residents. Buhle, with severe intellectual disability and limited speech, spent eight years in care and now stays at the farm. Ellen was interviewed three times for each of the three care-leavers she cared for, generating nine interviews.

Caregivers participated in three semi-structured interviews, conducted in English, regarding each care-leaver: in person before the young people's disengagement from care (October 2019); online during the COVID-19 lockdown (June 2020); and in person at 18 months (March 2021). These 18 interviews provided a comprehensive understanding of caregivers' evolving experiences and perspectives during the transition period. We designed interview schedules to align with the broader study objectives focused on caregivers' own needs and their views on leaving and aftercare support for the young person in their care. The second and third waves of interviews were informed by analysis of data from preceding interviews. The supervisors reviewed the interview schedules to ensure clarity and alignment with the research aims. To provide real-world accessibility, we also piloted the interviews with a caregiver; their feedback, specifically regarding the need for simpler language around transition and aftercare, was used to finalise the schedules.

The first interview gathered information on caregivers' perspectives on how well CYCCs prepared youth and caregivers for the transition from care, and on whether they engaged in effective transition planning. Youth transitioned out of formal care soon after the first interview. The second wave of interviews was conducted in June 2020 during the COVID-19 lockdown and sought to gather data on the post-care experiences of care-leavers in their care, as well as the

**Table 1** Exemplar items from interview schedules

Interview at disengagement from care (wave 1)

1. I am wondering how you see you see your role in preparing the disabled young person to leave care.
2. How do you think ____[2]will cope after leaving care?
3. Who has actively participated in the planning for ____'s transition?
4. Was there someone who sat with you and ____ to discuss long term goals?
5. Did you discuss adult services for ____?
6. What challenges do you think ____ is likely to experience after leaving care?

**Interview at wave 3 (during COVID-19 lockdown)**

1. Looking back, what where your feelings about ____ leaving care and explain?
2. How has the pandemic affected you and your family?
3. Has the pandemic delayed the progress of ____ in any way?
4. How are you coping with the pandemic in terms of your relations, emotions and finances?
5. Have you or ____ experienced periods of isolation and if yes how was it?
6. What challenges did ____ experience after leaving care?
7. Do you think their disability affects ____'s transition to adulthood or care-leaving experience?

**Interview at wave 5**

1. If you were to evaluate ____'s care-leaving journey, what would you describe as successes and failures?
2. What do you think needs to be done for a successful transition of ____ out of care?
3. What has been your role in ____'s care-leaving journey thus far? Were there any opportunities or difficulties with their journey?
4. How has ____'s intellectual disability impacted their transition out of care? And their transition towards independent living or young adulthood?

[2] The ____ was filled with the name of the care-leaver

impact of the pandemic on care-leavers and their caregivers. The final interview further explored the caregivers' roles and experiences of aftercare support for youth in their care and for themselves. These interviews also explored caregivers' views on the future for youth in their care and their perspectives on how best to support youth with intellectual disability and/or autism after leaving care, including support for their caregivers. The multiple interviews enabled a comprehensive in vivo exploration of the caregivers' experiences, perspectives and insights across the first 18 months of the care-leaving journey of young people with intellectual disabilities and/or autism. Table 1 provides a sample of interview questions for each interview.

With prior consent, the researcher recorded and later transcribed the interviews. The research analysed the interviews as stand-alone interviews, with attention to each caregiver's ongoing experiences over time, reflecting the longitudinal approach to data collection. Transcripts were analysed inductively using Braun and Clarke's (2006) reflexive thematic analysis approach. This process began with familiarisation with the data and initial first-level coding of each transcript. Similar initial codes were then grouped together into broader categories (second-level coding). For example, when caregivers mentioned there was "no clear plan after care" or "limited information about next steps" (first-level code), we recognised a pattern of "gaps in planning" and "inadequate preparation" (second-level code) that merged with similar codes to form an overarching theme focused on: "Inadequate Transition Planning and Preparation." By following this approach across the full range of data collected over time, we turned raw stories from caregivers into a clear picture of their perspectives and experiences, and of how the system fails to support their role in caring for youth with disabilities as they age out of care.

The extended engagement with the caregivers over 18 months established a strong rapport and trust between the researcher and caregivers, thereby enhancing the trustworthiness of the data (Braun & Clarke, 2006). A two-stage validation and member-checking approach was employed to support this process (Brantlinger et al., 2005). First, transcripts were sent to caregivers to check for accuracy and verification that the raw data accurately captured their accounts. During the pandemic, this process also helped to support ongoing engagement with caregivers.

Second, to further enhance the study's confirmability, the first author analysed the transcripts of earlier interviews before subsequent interviews with caregivers. This process allowed caregivers to verify that the themes identified in their previous interviews accurately reflected their experiences, rather than being influenced by researcher bias or misinterpretation. This verification practice was carried out at the start of each subsequent set of interviews, thereby enhancing the robustness of the study data. This ongoing dialogue over the 18 months ensured that the analysis remained deeply grounded in the participants' perspectives. Furthermore, the second and third authors checked and verified the alignment of themes and participant quotations, providing credibility of the findings.

## Findings

This section provides insights into the experiences and perspectives of South African informal caregivers regarding the transitions of young people with intellectual disabilities and/or autism as they move from residential care to young adulthood. Five themes emerged through the data analysis: (1) inadequate transitional planning and preparation; (2) limited aftercare opportunities; (3) barriers to accessing formal support; (4) caregiver unmet support needs; and (5) the value of informal relational support.

## Inadequate Transitional Planning and Preparation

Caregivers reported being unclear about the care-leaving process, creating uncertainty and stress for both the young person and their caregiver. Caregivers felt that youth had been ill-prepared for the transition from care, and there was a lack of transition planning to support the transitional process and mobilise necessary support systems. Avery said, “The transitional process made me feel anxious and scared. There was so much that I feel could have been addressed ahead of time, as the young person was in transition. However, not much attention was given to that.”

In the face of such uncertainty, former foster mothers often felt duty-bound to continue caring for the young person. Sihle’s former foster mother, Dorothy, reported that she was unsure of Sihle’s transitional plan:

> I was not sure about what was going to happen to him. The social worker did not explain anything to me. I do not think there was a plan or date of leaving the children’s home. I have cared for him before when he was younger, and I volunteered to take him again. He is ‘my child’, and he has nowhere to go. His family does not care.

Even those with experience of caring for other care-leavers found that the transition process was different for each young person. Youth had varied timeframes for leaving CYCCs and had different post-care placement options. Avery indicated that the transition processes for the two young people in her care (Sue and Gary) varied. On the one hand, she had clarity on aftercare plans for Sue, who had applied to go to college:

> Sue was applying to go to a college. Her plan was a bit clear… I knew she was coming back home… We met several times with the social worker before she [Sue] finally came home and I took over all the support. She stays with me alone and visits the father on some weekends.

By contrast, Avery was very uncertain about Gary’s transitional plan and expressed concern about the lack of follow-up support:

> [Gary’s] preparation was a little different. There was no plan on how he will spend his days. He was also going to come home, but I could not stay with both children with autism. Gary needs a lot of support, and he is physically getting strong. The social worker came to do a home visit and was happy, but there was no clear plan on his medical check-ups. We did not get any assistance to get him into a protective workshop. The process was rushed and not much information was provided to help him… his living arrangements were not clear, due to his high needs.

Ellen oversaw a smoother transition for Clive, Buhle and Ann, who were leaving the CYCC. Due to her concern about the lack of adult placements for care-leavers with intellectual disabilities and/or autism (including those with foetal alcohol syndrome), who could not return to live with their birth family, she had established an adult care farm that all three young people could transition to:

> Often, the society rejects them and there is a lot of stigma around how the disability is acquired. In my experience, most of the families of origin do not want to be involved. This leaves you alone with little or no governmental support. I started an adult care farm. The aim is to provide extended care for young people… [so] they continue being safe, protected and engaged in meaningful activities.

This farm placement was important for Clive and Buhle, who had no contact with their birth families and could not secure appropriate supported housing. Ellen explained:

> Their transition plan was not focused on family reintegration… The transition plan was focused on assisting them to get appropriate adult disability accommodation. However, for Buhle, it was impossible to get appropriate adult disability accommodation, because his condition is severe, and his external social worker could not get him a place.

For these three young people, Ellen managed a gradual transition, beginning with weekend visits to the adult placement and mentorship from a local organisation. The gradual transition is an example of a more person-centred and supported planning process that prepared each young person for their transition from the CYCC to an adult placement. However, this was not due to adequate transition support from the state. Instead, Ellen, as a proactive caregiver, facilitated the establishment of a new service to address the unmet needs she identified among these youths while they were still living in the CYCC, and committed to an ongoing informal caregiver role for each young person.

## Limited Aftercare Opportunities

Caregivers consistently expressed concern about inadequate aftercare services and post-care opportunities for youth with disabilities. The lack of suitable aftercare support was a primary source of concern for caregivers and posed significant challenges. For example, Dorothy said:

> There are not many places to go and ask for help for Sihle. Right now, he has my family. Before I was asked by the social worker if I could take him, they said they had not found place for him. I love him and did not want to see him thrown out and go on the streets. He is now part of my family, and my own children are his brothers now, since there is nothing for children like him.

Ellen shared Dorothy's concerns about insufficient aftercare support for care-leavers. The theme, 'limited aftercare opportunities,' refers to a systemic lack of supported, semi-independent living models. Participants identified a critical need for transitional housing that fosters autonomy while providing on-site assistance. Ellen explained:

> In Europe there are lots of places where young people live, but we don't have anything like that in our country… They have got flats, each one has their flat and do their thing, if they need help or anything staff goes to help, but they do not interfere with their lives or anything … so they know how to navigate life. So that is a programme I am busy with. Now I need government involved to find a building.

Ellen also indicated the need for further investment in longer-term planning and support to enhance the opportunities and quality of life for care-leavers with disabilities:

> It has to be a life plan and not just an individual transitional plan. These kids have to have a life plan… The focus is now up to 21. So what becomes after 21? It's so frustrating. You just want these young people with disabilities to have real chances, but the system keeps letting them down. It's not enough to tick a box and call it support.

Additionally, Ellen highlighted the significant gap in aftercare services for youth with disabilities like Buhle, who have no contact with their birth family, which could provide an adult placement:

> The places in Western Cape for disabled youth are very scarce. Of the few that have space, they are expensive and need family members… to pay a monthly fee towards the care of the youth. Buhle's family's whereabouts are unknown. They neglected and abused him, and he has not received visitation… to them since he was in the Children's Home.

Ellen calls for more tailored services for individuals like Buhle, emphasising their absence in South Africa. She highlighted the urgent need for specialised services in the transition to adulthood for individuals with intellectual disabilities. Avery echoed similar frustrations regarding the absence of aftercare services for both young people in her care, resulting in a sense of loneliness, exclusion and concern for their well-being:

> I find it frustrating that there is almost nothing out there for our kids. There is no one to turn to. All they have is you when they turn eighteen. It is hard to get a social worker to assist… they have limited resources on what they can cover. For Gary, there was nothing much given or recommendations on how to improve his quality of life. I had to find him a protective workshop.

These caregivers' accounts highlight a scarcity of assistance and limited aftercare options, indicating systemic inadequacies in the post-care support available for care-leavers with intellectual disabilities and/or autism. Challenges in accessing social workers, a lack of adult day opportunities or supported training schemes and the absence of supported housing options were significant concerns for caregivers seeking to promote the well-being and social inclusion of care-leavers with intellectual disabilities and/or autism. These findings expose gaps in comprehensive aftercare for this population and reflect a lack of strategic planning to meet their transitional needs. Moreover, the lack of support significantly impacts their well-being as caregivers, as they feel entirely responsible for providing care without access to specialised aftercare services tailored to their young people's needs.

### Barriers to Accessing Formal Support

The findings highlighted not only the lack of available support but also the barriers to accessing services that did exist. Caregivers reported that accessing existing formal support for both care-leavers and caregivers is difficult, partly due to the lack of targeted resources and poor coordination across formal service systems. A further barrier was the application of high eligibility thresholds for care-leavers to access specialist disability support, often centred on the severity of impairment rather than care-leaving or transitional support needs. For example, caregivers of young people who received the Disability Grant (a monthly financial grant for people with permanent, severe disabilities) found it beneficial for fulfilling their caregiving responsibilities. They appreciated the increase in this grant during COVID-19.

Dorothy explained that the rise in the Disability Grant that Sihle received greatly helped during the pandemic:

> This helped us a lot – we could get more food. It was good to have more money because Sihle was at home all the time, and his eating increased since he was just at home all day and not at the workshops since COVID-19.

However, Clive initially did not have the necessary identification forms to apply for a Disability Grant. When he obtained the documentation, he was still denied the grant because his level of impairment was deemed too mild to qualify. Ellen explained:

> We spent months fighting just to get his ID [identity document], thinking that was the only hurdle. But when we finally got to the South African Social Security Agency (SASSA), they told us he was not 'disabled enough' to qualify for the disability grant.

Furthermore, whilst the increase in this payment was helpful, other pandemic support measures were not as beneficial for youth or caregivers. Participants reported that during the lockdown, all daycare activities, including school and workshops, were closed, and no online options were available. The Department of Education's lack of support meant care-leaver participants had to stop learning for extended periods, negatively impacting their development and well-being. This impacted caregivers who had to provide full-time care to the young people at home. Although there was formal financial support, the caregivers did not report receiving additional practical or emotional support from formal child welfare or adult disability services during the 18 months of data collection.

### Caregiver Unmet Support Needs

The lack of aftercare support for care-leavers negatively affected young people. Moreover, services targeted to the primary caregivers of young adults with intellectual disabilities and/or autism who had transitioned from care were lacking. The absence of formal support systems for caregivers left them feeling abandoned and alone, as Dorothy said:

> I feel like the government forgets that he [Sihle] exists after he leaves the home. No one comes for him or to support me and my family with some of his needs, emotionally, financially and medically … There is nobody to help me.

While caregivers were grateful for the additional financial income from social security during the peak of COVID-19, they expressed a general dissatisfaction with the level of formal support offered by the state to care-leavers with intellectual disabilities and/or autism and to themselves as primary caregivers. They felt 'dumped' with the full responsibility of providing challenging care, without safety nets to protect and support them in their often-challenging caregiver role.

In this context, unsupported caregivers experienced fluctuating emotions about their caregiving role. Caregivers consistently reported feeling inadequately prepared for their caring role, especially with no prospects of additional support. The absence of respite services to provide caregivers with a break was notable. Barriers to accessing support for the young person in their care compounded caregivers' practical and emotional challenges, underscoring the urgent need for sustained aftercare support for caregivers. Caregivers provided consistent support and, in some cases, accommodation for care-leavers with complex and changing needs as they matured into adulthood with limited or no formal support.

With knowledge that they were the sole source of care for these young people, informal caregivers experienced high levels of anxiety about the well-being of youth in their care and concern for the future when their own ageing and mortality may impact their caregiver role. COVID-19 significantly exacerbated this fear. Avery said, "I think, knowing you are the only person for your child is a scary feeling, and I found myself wondering how Gary and Sue would cope if something were to happen to me."

Dorothy shared similar anxieties and highlighted the lack of additional relationships in Sihle's life:

> I do worry about his [Sihle's] future if I am not here anymore… Thinking about that stresses me a lot… It seems nobody thinks about the worst situation where, as a caregiver, I might pass [die] or be ill, that I can no longer continue supporting Sihle with his medical appointments, finding him a protective workshop, and ensuring that he continues to be safe and feels loved. Thinking about this makes me emotional. The Value of Informal Relational Support

Given the lack of formal support, caregivers relied on their informal relationships and viewed them as a resilience enabler. Dorothy said:

> I am thankful to have my friends from church and from this community. They check up on me and the boys regularly. Also, they offer donations especially food. We all need relationships that we can trust that

> can uplift us and share the burden when it becomes too heavy. Some days I am exhausted from all my responsibilities as a single mother with an adult who will need lifelong support.

Avery further highlighted the importance of practical support from friends and family members. Such informal relationships provided a crucial network of interdependent support. Caregivers' informal support networks contributed to their own well-being and strengthened their resilience to overcome adversities, as Ellen explained:

> I have many friends nationally and internationally and they are our champions. I am able to care for three children, not independently, but firstly through my husband's support who shares the same views. I noticed that during COVID-19 lockdown a lot of these champions continued to support us by sending groceries and basic needs. This significantly reduced stress on my part.

Supportive informal relationships, therefore, were a protective factor for caregivers facing significant challenges when caring for care-leavers with intellectual disabilities and/or autism in a context with socio-economic inequalities and limited aftercare support.

## Discussion

This study focused on the experiences of caregivers supporting young people with intellectual disabilities and/or autism transitioning from care towards adulthood in South Africa. Our findings align with existing research on the challenges faced by caregivers of youth with disabilities transitioning from care (Dada et al., 2020; Gordon & Bila, 2023; Mkabile & Swartz, 2020; Park et al., 2018) and caregivers of youth who have left care (Höjer & Oterholm, 2025; Oterholm & Höjer, 2024). Moreover, our focus on caregiver perspectives of care-leavers with intellectual disabilities and/or autism delves deeper into the experiences of this significantly under-researched population with a dual experience of caring for a young person with disability who is also care-leaving (Bennwik & Oterholm, 2021; Harwick et al., 2020).

The five core themes identified in our study – inadequate transitional planning and preparation, limited aftercare options, barriers to accessing formal support, caregiver unmet support needs and the value of informal support networks – paint a complex picture. Caregivers reported feeling excluded from transition planning, mirroring concerns raised in broader care-leaving research (Henson et al., 2024; Kelly et al., 2023). They also reported concern about the inadequacy of efforts to prepare care-leavers with disability and their caregivers for the transition from care. The findings show that social services undertook little preparatory work with youth or caregivers to support a planned and supported transition. This lack of planning and preparation is particularly concerning for caregivers of youth with intellectual disabilities and/or autism, as it does not offer the gradual transitions from care they often need and fails to identify and mobilise the range of post-care support they may require from CYCCs and specialist adult services (Bennwik et al., 2023; Cheng et al., 2023; Mupaku et al., 2021). The absence of coordinated person-centred transition planning results in unplanned and unsupported moves from care (Kelly et al., 2016). Inadequate planning risks the exploitation of the goodwill and genuine commitment of caregivers to continue to care for youth with intellectual disability and/or autism on a long-term basis, with limited recognition or support for the crucial role they fulfil for these young adults.

The absence of aftercare policies and programmes in South Africa creates a significant gap for all care-leavers and their caregivers. Indeed, it places a particularly heavy burden on caregivers of youth with disabilities and more complex needs who are ill-equipped to meet the ongoing needs of these young people as they move into young adulthood (Gordon & Bila, 2023). Furthermore, minimal access to formal support services, such as adult disability services and mental health programmes, places further pressure on caregivers to undertake the additional role of advocating for the youth in their care and negotiating with a range of statutory and community-based services in an effort to have their needs met and to alleviate the sole reliance on the caregiver. This situation exacerbates caregivers' anxieties about the future, compounding their emotional impact (Ezeonu et al., 2021; Kanthasamy et al., 2024; Mkabile & Swartz, 2020). These findings highlight the need for a comprehensive support system tailored to the specific needs of caregivers to bolster their essential role for care-leavers with disabilities.

In South Africa, the harsh economic climate disproportionately impacts female caregivers, many of whom face unemployment and personal struggles (Dada et al., 2020). However, the South African collectivist culture (Ebersöhn, 2019) might offer some advantages. Our study suggests that informal community-based support networks can play a valuable role, potentially mitigating some of the isolation caregivers experience in individualistic societies (Gordon & Bila, 2023). Further research is needed to explore how to strengthen these networks and ensure equitable access for all caregivers.

Despite strides in disability rights and inclusion through its policies and legislation, South Africa lacks the underpinning support for caregivers of youth with disabilities leaving care required to enable the realisation of these rights

(Mupaku et al., 2021). This gap undermines the significant role of caregivers for youth with disabilities who are leaving care. The social-ecological perspective on resilience emphasises social systems, such as family networks. However, it also emphasises the importance of support from professionals, services and policy, as central to the resilience of caregivers and families (Pinkerton & Van Breda, 2019). Caregiver relationships act as a relational enabler, fostering resilience through emotional and practical support. But these forms of relational support must be accompanied by statutory leaving care and specialist disability services for the youth in their care and targeted caregiver support and training to bolster their role and avoid caregiver burnout (Riches et al., 2023).

## Limitations

This study has several limitations that should be considered when interpreting the findings. First, the study population was small, with only three caregivers. As a result, the transferability of the findings to a broader population of caregivers supporting youth with intellectual disabilities and/or autism during their transition to young adulthood is limited. We also acknowledge that caregivers' experiences and perspectives may vary significantly across individuals and settings.

Second, the study was conducted exclusively in the Western Cape Province of South Africa. The findings may not fully represent caregivers' experiences in other contexts. The availability of support systems and the challenges faced by caregivers of care-leavers with intellectual disabilities and/or autism may differ across regions, influencing their transition process. However, given the paucity of research on this population, the study provides valuable insights into caregivers' experiences and serves as a point of departure for understanding their needs.

Finally, it is worth noting that two of the caregivers in this study were caring for more than one care-leaver. This aspect of the study may have influenced the care context and dynamics within the caregiving relationship, as the care-leavers were receiving support from the same caregivers. The caregivers' experiences and challenges may differ from those caring for a single care-leaver, potentially affecting the study's overall findings.

## Implications and Conclusion

This study sheds light on the perspectives and roles of caregivers supporting youth with intellectual disabilities and/or autism during the transition from residential care to young adulthood. Despite the study's limitations, the findings offer valuable insights into the challenges caregivers face during this critical period and, given the lack of attention to these caregiver perspectives in existing research, make a vital contribution to the field of leaving care research.

Our findings underscore the urgency of a rights-based approach that upholds the UNCRPD and ensures access to appropriate education, employment and interdependent living for care-leavers with disabilities (Kelly et al., 2016). To achieve this, we propose a multi-pronged approach.

First, we recommend developing comprehensive care-leaver policies that consider the specific needs of both care-leavers with disabilities and their caregivers.

Second, we recommend involving care-leavers with disabilities and their caregivers in transition planning and preparation for leaving care and ensuring these processes mobilise and coordinate interdependent support systems for care-leavers and caregivers. Caregivers should be more proactively involved in the transitioning planning and preparation processes to enable a coordinated and supported transition from care into adult life.

Third, we recommend establishing statutory aftercare services for care-leavers with targeted support for those with disabilities and better access to formal specialist support (e.g., adult disability services and mental health programmes). For care-leavers with disabilities, this may require expanding the very limited availability of post-care supported living, training or employment options. The expertise and resourcefulness of care-leavers with disabilities and of caregivers like Ellen can be a helpful resource in the creative design and development of such services within available resources.

Fourth, we recommend establishing statutory aftercare services for caregivers of youth with disabilities leaving care. The study emphasises the need for comprehensive state-mandated, state-funded support for caregivers to facilitate successful transitions and long-term support for this population. Improving access to practical and emotional support for caregivers is crucial to enhancing their well-being and enabling them to continue their critical caregiving roles for youth with disabilities in transition from care.

And fifth, investing in programmes that identify and support existing community-based peer support networks for caregivers, thereby strengthening informal support systems and promoting resilience and social inclusion in local communities.

Our final recommendation is for further care-leaving research that addresses the needs and experiences of caregivers, with particular attention to those caring for youth with disabilities. Future research on this topic should include a larger, more diverse sample encompassing multiple regions and settings to gain a more comprehensive understanding of the experiences and perspectives of caregivers supporting care-leavers with diverse experiences of disability. In addition, we recommend further research with young people with disabilities themselves, as are conjoint interviews with both the young person and their carer. Such research will help inform the development of effective support systems and policies that address the unique needs and challenges faced by caregivers and care-leavers with disabilities, ultimately enhancing their overall quality of life.

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## Declarations

**Competing interests** The authors declare no competing interests.

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