Transitioning to adulthood from residential childcare during COVID-19: Experiences of young people with intellectual disabilities and/or autism spectrum disorder in South Africa

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Accessible Summary
• For young people with intellectual disabilities and/or autism, the transition from children's residential care into adulthood during COVID-19 has been difficult.
• Opportunities for greater independence were blocked because of the lockdown.
• Some of these young people experienced an increase in depression or other mental health difficulties.
• But more time at home due to public health restrictions also helped to deepen the relationship with caregivers.
• Service continuity is crucial, both in person and online, to support care leavers with intellectual disability and/or autism, as well as training and support to caregivers to continue with independent and interdependent living programmes at home.

Abstract

Background: This study focuses on young people with intellectual disabilities and/or autism who, due to child welfare concerns, have grown up in children's residential care and are now transitioning out of care at the age of 18 years towards young adulthood. This transition is termed "care leaving" and the young people in transition "care leavers". The care leaving transition can be particularly difficult for young people with intellectual disabilities and/or autism. These challenges can be magnified in a time of a global crisis like COVID-19, which has resulted in countries being on lockdown and care leavers' transitions being curtailed. Many mental health problems have emerged due to the COVID-19 outbreak and resultant lockdown that may negatively impact on the care leaving transition of young people with intellectual disabilities.

Methods: Semi-structured interviews were conducted with six care leavers with intellectual disabilities and their three caregivers in June 2020 in the Cape Peninsula region of South Africa to explore the impact of COVID-19 on their transitional journeys.

Findings: Three core themes emerged from the analysis: young people evidenced regression of independence, rather than the expected growth in young adult independence, due to disruptions to routines and opportunities to move out into the world;
some young people experienced an exacerbation or emergence of mental health problems, which impacted on their transition to young adulthood; and young people and their caregivers experienced a deepening of caregiver relationships, which enhanced the transition of the care leaver.

Conclusions: Services must continue to facilitate progress towards independence and promote personal and caregiver well-being. Support service for care leavers with intellectual disabilities should be essential services, offered in person or online while adhering to COVID-19 regulations. Caregivers should be trained in continuing independent and interdependent living programmes for care leavers in their care, supported through in person or online training, mentoring and supervision. Service continuity is recommended to avoid the contraction of young people's social world at a time when it should be opening up.

**KEYWORDS**
COVID-19, independent living, intellectual disability, leaving care, transition to adulthood

1 | **INTRODUCTION**

The transition from adolescence towards young adulthood, and from living in parental care towards independence, is potentially challenging for all young people (Barry, 2005; Booysen & Crause, 2014; Dhillon et al., 2011; Philippps, 2014; Young et al., 2011). Research around the world has consistently shown that this transition is especially difficult for young people who grew up in residential or foster care (Mann-Feder & Goyette, 2019; Mendes & Snow, 2016; Stein & Munro, 2008; Van Breda, 2018), who are referred to as care leavers. Similarly, research on the transitions of young people with intellectual disabilities and/or autism towards adulthood shows the transition to be more complex than for nondisabled young people (Gauthier-Boudreault et al., 2017; Young-Southward et al., 2017). However, far less research has been done on the transitions of care leavers with disabilities. The small body of available research in this area indicates the transition from care is even more difficult for young people with disabilities, due to both the possible challenges impairment may create for the young person and the lack of support systems for disabled young people in society (Cheatham et al., 2020; Harwick et al., 2017, 2020; Kelly et al., 2016; Mendes & Snow, 2014; Roberts et al., 2018; Snow et al., 2016).

This study focuses on young people with intellectual disabilities and/or autism spectrum disorder (ASD) who grew up in South African Child and Youth Care Centres (CYCCs). CYCCs are residential care homes for children who have been removed from parental or kinship care by the child welfare or child protection system, due to concerns about the adequacy of care and protection of the children. Some CYCCs have onsite schools (Department of Social Development, 2010). However, few CYCCs make provision for children with intellectual disabilities and/or autism, opting rather to make use of special schools in the local community.

The COVID-19 crisis, which is likely to reverberate through the coming years, has raised additional challenges for all young people transitioning to young adulthood. This is due to the lockdowns and their negative impact on national and global economies and educational institutions, potentially delaying learners’ transition into employment. Many job opportunities such as apprenticeships have evaporated because of workplaces closing or reducing staff. The freedom of movement to explore, socialise and mature that is typical of young adulthood has been substantially curtailed, keeping young people housebound and isolated. Research on the impact of COVID-19 on youth transitions is rapidly emerging, though much of it is conceptual and not based on interviews with young people (Blustein et al., 2020; Jackson, 2020; Settersten et al., 2020).

Research on the impact of COVID-19 on care leaving is beginning to emerge, initially in the form of online pieces (Canning et al., 2020; Coram Voice, 2020; Ward, 2020) and in grey literature reflecting research findings (Baginsky & Manthorpe, 2020). Academic publications on care leaving during COVID-19 (Crawley et al., 2020; Kelly et al., 2020) and on disabled young people during COVID-19 (Ameis et al., 2020) are only beginning to emerge, and attention has not yet been given to the impact of COVID-19 and lockdowns on the care leaving journey of care leavers with intellectual disabilities.

This paper’s authors initiated a longitudinal study in South Africa of the care leaving journey of young people with intellectual disabilities and/or autism in October 2019, with the intention of regular interviews with a group of care leavers and their caregivers over the following 12 months, to narrate their journey towards greater independence. In late March 2020, however, the country was locked down with stringent public health restrictions (Arndt et al., 2020), many of which remain in force at the time of writing. Our study was consequently undermined, not only by the inability to continue face-to-face interviews, but also by the structural limitations on our participants’ move towards independence, which was the focus of our study.

The aim of this paper, therefore, is to explore the implications of COVID-19 and its associated lockdown periods on the experiences of care leavers with intellectual disabilities and/or autism.
of leaving CYCC care among this group of care leavers with intellectual disabilities and/or autism at 18 years of age, drawing on their own and their caregivers’ perspectives. This will shed light on a rare event in global history, where young people’s movement into adulthood is being curtailed due to a public health crisis.

In the following section, we briefly review the literature on the transitional experiences of care leavers with disabilities, located within a critical social model of disability. Following the account of our methodology, we present three themes that emerged through our analysis of the data. We then discuss these findings, outline key limitations and present lessons for improved services to care leavers with intellectual disabilities during a pandemic like COVID-19.

2 | REVIEW OF LITERATURE

There is a wealth of global literature on the challenges facing the general population of young people with intellectual disabilities and/or autism as they transition to adult life (Gauthier-Boudreault et al., 2017; Young-Southward et al., 2017). They can experience paternalistic approaches to transition planning with low expectations for their futures and restricted opportunities for employment and further education (Kelly, 2013; Shogren & Wehmeyer, 2020). There are also reports of inadequate planning and transition supports and a lack of collaborative services as young people exit children’s services and move into adult care programmes (Kelly, 2013). As a result, there are heightened anxieties for these young people and their caregivers during the transition process with a detrimental effect on their overall health and well-being (Gauthier-Boudreault et al., 2017; Young-Southward et al., 2017).

Similarly, research on the transitional experiences of the general population of young people leaving care has shown that they face a range of challenges, including practical difficulties related to finding appropriate housing, securing employment or places in further education and coping financially (Mann-Feder & Goyette, 2019; Stein & Munro, 2008; Van Breda, 2018). In addition, these young people may find it difficult to access informal support post-care as they renegotiate their relationships with caregivers and birth family members and experience stigma or social exclusion (Mann-Feder & Goyette, 2019; Mendes & Snow, 2016; Stein & Munro, 2008; Van Breda, 2018).

These transitional challenges are compounded for young people with the dual experience of disability and leaving care (Kelly, van Breda, et al., 2020; Kelly, Walsh, et al., 2020; Mendes & Snow, 2016). The small body of research on the experiences of care leavers with disabilities has revealed difficulties with access to support, as these young people straddle both disability and care leaving services (Fudge Schormans & Rooke, 2008; Harwick et al., 2020; MacDonald et al., 2016). Young people with severe impairments and complex long-term needs often move from children’s residential care into protective adult residential care settings although these are often age-inappropriate (Kelly et al., 2016). Others with mild-to-moderate levels of impairment or borderline needs find it difficult to access consistent support after leaving care and may move to unstable or inappropriate housing, where they are at risk of poor outcomes with limited access to formal and informal support systems (MacDonald et al., 2016). The move from children’s residential care homes with high levels of support from staff to living independently with minimal support networks can leave some young people isolated in the community, leading to loneliness and potentially a deterioration in mental health (Mann-Feder & Goyette, 2019; Mendes & Snow, 2016; Stein & Munro, 2008; Van Breda, 2018).

Although, at the time of writing this article, there is no research available on the impact of the COVID-19 pandemic on care leavers with intellectual disabilities and/or autism, it is anticipated that these existing challenges have been exacerbated. Across the globe, the pandemic has impacted on young people’s social lives, education and employment opportunities, as lockdowns and restrictions have been imposed to reduce the spread of the virus. In South Africa, where the research reported here was undertaken, the Department of Social Development (DSD, 2020) amended the directives relating to the transition of young people out of care. It stipulated that every young person leaving CYCCs needs to be screened for COVID-19 prior to their departure, the household they are going to needs to be free of COVID-19 and the social worker must be satisfied with the place to which the young person will be moving. For young people who had recently left residential care, the expected benefits of living independently and hopes for work or further education were curtailed. The emerging body of research on the impact of COVID-19 on transitions for care leavers highlights the need for: more sustained contact with support workers, improved access to food, appropriate housing and employment opportunities, a focus on the longer term impact on the mental health of care leavers and efforts to address concerns for those who experience digital exclusion due to lack of access to technology or internet (Goyette et al., 2020; Groundswell, 2020; Kelly, Walsh, et al., 2020: Who Cares? Scotland, 2020).

The small number of studies on the impact of the pandemic on young people with intellectual disabilities more generally has highlighted the higher level of risk for those living in residential care, the impact of changes in routine due to lockdown/restrictions on behaviour, health and emotional well-being and the exacerbation of existing inequalities and stigma experiences by people with disabilities (Abrams & Abbott, 2020; Ameis et al., 2020). While there may be benefits to having more time with caregivers at home, there are serious concerns about the impact of the pandemic on the health and development of intellectually disabled young people given restricted access to essential services, education and social opportunities (Neece et al., 2020).

Aside from this emerging evidence based on the impact of COVID-19 on the general population of young people with intellectual disabilities, or young people leaving care more broadly, there has been no research reported yet on the intersecting experience of care leavers with intellectual disabilities and/or autism during the pandemic. In South Africa, there has been no research on this group of care leavers at all. This paper aims to address this gap in literature by exploring the transitional journey of care leavers...
with intellectual disabilities during the COVID-19 pandemic. This research is informed by the principles of the social model of disability, which underline the impact of disabling barriers in society on the lives of people with intellectual disabilities (Oliver, 2013), but is also guided by more recent disability studies, which give further acknowledgement to the experience of impairment and the ways in which disability reinforced by social structures and cultural norms (Goodley, 2017).

3 | METHODS

This study is a component of a larger longitudinal, qualitative study aimed at investigating the transitional processes and outcomes of young people with intellectual disabilities and/or autism transitioning out of CYCCs in South Africa. At eighteen, the young person is considered an adult and must exit the child welfare system to live independently, with adult caregivers or in residential facilities for adults with disabilities (DSD, 2010).

This study adopted a qualitative, social constructionist research approach, being interested in the lived experiences of care leavers with intellectual disabilities, from their own and their caregivers’ perspectives, during the first year of transitioning from care. Participating young people had been diagnosed as having an intellectual disability and/or autism and were due to leave the care of CYCCs in the Cape Peninsula area of South Africa at the end of 2019. The primary caregiver of the young person after leaving the CYCC also participated.

There are no data on the prevalence or location of young people with intellectual disabilities in the children’s residential care system in South Africa. Directors of numerous CYCCs in the Cape Peninsula area of South Africa were, therefore, approached to identify potential study participants. Directors approached young people who met the study criteria to ask whether they would like to participate and contacted the young person's caregiver to ascertain their interest in the study.

The first author then met prospective participants at the CYCC to explain the study using an accessible study brochure and seek their agreement to participate. Six care leavers with intellectual disabilities and their three caregivers consented to participate, yielding a combined sample of nine individuals. Table 1 provides the pseudonyms and selected demographic data for the participants to protect the anonymity of study participants. Care leavers left residential care between the ages of 18 and 20 and were aged 19–21 at the time of this interview. Two care leavers were diagnosed as having autism, and four had an intellectual disability. Levels of impairment were reported to range from mild (n = 2) to moderate (n = 2) and severe (n = 2). Prior to the pandemic, one young person was engaged in school, one was in full-time employment and four were attending sheltered workshop programmes. All these educational and work-related programmes ceased with the introduction of COVID-19 lockdown restrictions.

Table 2 provides pseudonyms and further information about the caregivers who were all in their mid-fifties.

All of the young people had left care prior to COVID-19 pandemic. Care leaving occurred at different times; some stayed after

| Pseudonym | Gender | Years in residential care | Type of disability | Years young person has known caregiver |
|-----------|--------|---------------------------|--------------------|---------------------------------------|
| Sue       | Female | 4                         | Autism             | 20 years                              |
| Gary      | Male   | 1                         | Autism (limited speech—caregiver assisted with the interview) | 18 years |
| Ann       | Female | 9                         | Intellectual disability | 18 years |
| Clive     | Male   | 4                         | Intellectual disability | 14 years |
| Buhle     | Male   | 8                         | Intellectual disability (limited speech—caregiver assisted with the interview) | 9 years |
| Sihle     | Male   | 8                         | Intellectual disability (limited speech—caregiver assisted with the interview) | 6 years |

Table 1  Pseudonyms and profile of care leavers with intellectual disabilities
TABLE 2 Caregiver pseudonyms and profile

| Pseudonym | Relationship to young person | The young person being cared for |
|-----------|-----------------------------|---------------------------------|
| Avery     | Biological mother           | Sue Gary                        |
| Ellen     | Adult disability caregiver and founder of the children's home and disability adult facility | Clive Buhle Ann                  |
| Dorothy   | Adult disability caregiver who accommodates care leavers in her home | Sihle                            |

their eighteenth birthday to complete a school or therapeutic programme before leaving. Sue and Gary transitioned into the care of their biological mother due to lack of autism adult facilities (earlier welfare concerns were addressed), while Clive, Buhle and Ann transitioned to the adult care facility that was founded by Ellen and they live on her property. Sihle transitioned to Dorothy’s care due to lack of alternative adult placement options. Dorothy worked at a CYCC where Sihle previously lived.

The first two waves of data collection took place in October/November 2019 (before leaving the CYCC) and February 2020 (at the post-CYCC home) just before the COVID-19 lockdown on 27 March 2020. The data for this paper are drawn from the third wave of interviews in June 2020 conducted via WhatsApp video call, except for Sue who was interviewed in person at her request. Buhle, Gary, Ann and Sihle were interviewed conjointly with their caregiver, because they were anxious about the online format. The caregiver was then interviewed separately.

Since interviews were conducted online, they were kept short and focused on how COVID-19 was impacting their life after leaving care. Questions addressed their daily routine under lockdown, the positives and negatives of life during the pandemic and how they were coping with related challenges. For the care leavers, picture exchange communication (PECS) was used to support the researcher’s communication with participants. In some cases, the caregiver would hold up the PECS to the camera so that the care leaver could point out their response. Interviews were audio recorded and transcribed for analysis.

Data were manually analysed thematically following Braun and Clarke’s (2006) phased approach to thematic qualitative data analysis, beginning with immersion in the data through repeated reading of the transcripts, followed by coding data segments. Emerging themes were reviewed and refined in collaboration with the study supervisors. The rigour or trustworthiness of the study (Lincoln & Guba, 1985) was enhanced through the longitudinal design, which allowed for multiple interviews with each participant, enabling prolonged engagement with participants, contributing to the building of a deep relationship between interviewer and participants. In addition, interviewing both the care leaver and the caregiver allowed for triangulation of findings and clarification of key points.

An ethics of care (Ellis, 2016; Hochfeld & Graham, 2012; Tronto, 2005) was adopted for this study, meaning that we endeavoured not only to avoid doing harm and to tick off the standard ethics requirements for qualitative research, but also to work to make the study as helpful for participants as possible, while retaining our role as researchers. Written informed assent (from care leavers deemed to lack capacity to consent) and consent were negotiated with all participants at the start of the study and at each successive interview.

Accessible data collection tools were used to facilitate gathering information from the care leavers with intellectual disabilities. Interview questions with pictorial symbols were sent in advance to the caregivers, and the care leavers were contacted via WhatsApp video call for the interviews. Interviews with care leavers were conducted individually, where possible and preferred, or with the caregiver present where necessary and preferred. Information disclosed individually by the care leaver was not shared with the caregiver, without the care leaver’s consent. Abuse or neglect, or the intent to harm self or others would have been reported had this been revealed in the interviews, but no participants revealed such experiences. The study was reviewed by the Research Ethics Committee of the Faculty of Humanities of the University of Johannesburg and approved on 7 June 2019 (REC-01-079-2019).

4 | FINDINGS

Three themes regarding the care leavers’ transitions during COVID-19 emerged through the analysis of the interview data: regression of independence due to disrupted routines; emergence of mental health problems; and deepening caregiver relationships. While these themes emerged primarily through the care leavers’ words, in some cases the caregiver assisted in interpreting the care leavers’ communication, so their quotes are also included where relevant. Information presented by the caregiver was checked by asking the care leaver if they agreed with the caregiver’s interpretation of their response.

4.1 | Regression of independence due to disrupted routines

The abrupt implementation of a stringent national lockdown caught participants off guard. All caregivers reported having limited time to establish new home routines. While they understood the reasons to curb the spread of the pandemic, they all reported experiencing...
difficulties in implementing a different routine and immediately stepping into full-time care. This abrupt and unprecedented change in routine led to a regression of independent living among the care leavers, as Clive explained:

\[ I \text{ was supposed to move out of the facility before lockdown, but all that had to stop. I stopped working and I wasn't earning money so that meant I could not afford to pay rent. I was ready to start my life independently, cook, wash for myself and pay bills. But because of COVID-19 lockdown, I had to remain at the adult facility where I still got a lot of help with things like cooking, shopping and paying for expenses.} \]

Ellen also described the sudden change in routine and its impact on the three young people in her care:

\[ \text{Hard lockdown was difficult! All the young people had different routines and that suddenly changed. There simply wasn't enough time to prepare. At first all the young people resorted to watching television before I could come up with a routine that allowed them to participate in daily activities. However before coming up with a plan, it was chaotic; I noticed changes in their moods, more tantrums, poor motivation to complete tasks, increased appetite, withdrawn, poor self-care, they all seemed anxious and frustrated by not being able to do everything they could previously do like taking a walk or go shopping. The change was too abrupt and threw everything, programmes and activities out of the window...} \]

Ellen added:

\[ \text{For Clive lockdown completely disrupted his transition. He was supposed to move out to a shared apartment, but since he had to abruptly stop working, he was not earning any money, so he had to put a hold on the plans of living independently. He was sad, but he bounced back after a couple of weeks of being at home. He began to engage with the others at home, he used the free time to pack some of his belongings to prepare for the move in the future.} \]

Ann and Buhle validated what their caregiver said. Buhle said, "No shop now", and Ann explained:

\[ \text{I cannot go shopping anymore. Aunt Ellen has to go and shop for all of us. Before lockdown I could also shop, but now I have to stay at home.} \]

Shopping independently was one of the skills Ann was being taught as she transitions to adulthood, but that stopped due to the risks of infection in public places. Regardless of the disruption in the transitional journey, Ellen improvised to assist some of the care leavers to retain some of the skills:

\[ \text{Although Ann cannot go shopping, she still does budgeting and gives me a list of everything she needs. It is Buhle I am worried about, who gets upset when he cannot go with me to the shops, he doesn't understand what's happening and thinks I am rejecting him.} \]

Ellen highlighted that this frustrates Buhle, as he is not able to participate in the shopping. She emphasised that he must stay at home because he has a weak immune system and does not understand mask wearing, social distancing and sanitising. Additionally, Ellen reported that Clive was loafering around on most days. However, his routine partially came back when lockdown restrictions were relaxed and he was able to return to work as a plumber.

Avery reported major difficulties in providing care for Sue and Gary who both had autism and were confused by changes to their routine. Avery shares custody of the children with her ex-husband; however, in the early stages of the unanticipated lockdown, it was difficult to get relevant permission for parents sharing custody to move between houses:

\[ \text{For Gary the change in daily routine was difficult. He had to stop going to the [work programme for disabled adults] and there was little stimulation for him. Tantrums became frequent, poor concentration and patience and he was irritable. He became unhappy because he could not go out or visit his father. I had to run around to find out where I could get permission for them to move between parents.} \]

Gary said:

\[ I \text{ am in the house every day, it is boring. My mum says I cannot go out, I do nothing here. I can't go to my programme.} \]

Avery reported that the closure of Gary’s work programme led not only to his frustration, but also to a regression in his independence:

\[ \text{This left him with no stimulation. I noticed that he became withdrawn and anxious especially when the initially hard restrictions were in effect. He started becoming dependent again, needed me to prompt him for self-care. He would not clean after himself and his eating has increased and he walks around the house aimlessly.} \]

Sihle’s adult disability recycling programme also ceased, and his caregiver was reluctant to allow him to attend again for the rest of the year due to concerns that he would become infected with COVID-19. As a result, Sihle said he spent all day at home engaged in limited activities:
4.2Emergence of mental health problems

In addition to regression of independence, some of the care leavers experienced early stages of mental health challenges during the COVID-19 lockdown, including anxiety and depression. In Sue’s case, these pre-dated COVID-19, but for Ann and Buhle, the psychological distress seemed to be a response to the lockdown.

Sue was previously diagnosed with depression and was on medication. Sue did not talk about her depression, but allowed her mother Avery to explain:

As for Sue, she began to read horror novels and spend more time on social media. She became withdrawn, moody, and selfish. And her posts were negative – she is preoccupied with the worst outcome... We were always able to manage her emotions, but depression intensified because of lack of socialization... A week ago, it became too much I think. She took an overdose of pain tablets... She doesn’t want to speak about it with me, but I am glad a psychologist is seeing her again. She is always thinking of the worst possible outcome on everything these days and I am not sure how to help her. I also noticed she was not taking her antidepressant tablets, so now she has to drink them in front of me. She is not happy about that, but I am worried about the suicide attempt.

Avery thinks the lockdown triggered some painful experiences of isolation that Sue had growing up as an autistic child with few friends. Additionally, Avery reported that Sue had informed her about 6 months previously that she was undergoing some sexuality changes and identified as a lesbian; however, her father was reported to be ignoring this disclosure and not engaging with Sue.

Ellen also reported that Ann was becoming depressed due to ongoing isolation at home and they had to arrange for her to go to the charity shop and resume her work when lockdown restrictions were adjusted. However, she has minimal contact with customers due to her limited understanding of COVID-19. Ann said:

I now go to the charity shop, it is better there. In the house I am too worried and sad. No one is making me feel sad. I just feel like that when I cannot go out.

Avery pointed out that Gary was also becoming anxious and depressed as his routine was modified:

His behaviour was a bit difficult to manage when he had to stop going to the [adult work programme] where he would cut materials, do gardening and washing cars to suddenly being at home and indoors always. He just grabs you and he can even bruise you because he wants to go for a walk or to the programme. He does not understand why we cannot do the old things now... He is sadder and feels rejected when I cannot take him out or he cannot drive with me.

Caregivers had to be vigilant to the emotional state of the young people in their care during this disruption to their established routines due to COVID-19 restrictions, especially for care leavers who were not aware that their mental health was deteriorating.

4.3Deepening caregiver relationships

Despite many challenges during lockdown, all young people also reported that it also created unique opportunities to deepen meaningful relationships with their caregivers. Having left care 6 to 7 months previously, the care leavers appreciated the time to bond with their caregivers. The forced house-stay pushed them to identify new interests and skills. Ann said:

I enjoy having fun now, we play Monopoly, PlayStation and watch TV. Sometimes I help Aunt Ellen to cook and write a list of groceries needed for the house. We all sit and eat together. Sometimes I am lazy and I do not want to do anything, but Aunt Ellen calls me to come and learn.

Buhle also said, “I watch TV and charge phone”. Buhle particularly enjoys charging everyone’s phone. Dorothy also echoed the same sentiments of having more sleep-ins and better-quality relationships because of the bonding time:

We are at home always and the children watch TV, it is nice. I just don’t like that I cannot go to Eastern Cape now to visit other family members [due to the provincial borders closure]. We are not as busy now, so we relax
and have fun in the house. And since we cannot go out, we have to cook all our meals. And no one is running to school or other activities. Everyone wakes up at home and we do most of the things together. Sihle is always playing with his brothers and sometimes he likes to take naps in the afternoon in my room and play with my teddy bears.

Sihle echoed Buhle and Ann's views, saying:

I like watching TV and playing games at home with my mother and brothers.

Sue reported quality caregiver time as one of the benefits of the pandemic:

I sometimes do chores in the house, cook with mum, and see my horse every second day, and I watch TV and study.

Avery also indicated that the lockdown has allowed her some time to teach Sue how to cook and spend some quality time together. Clive echoed the same:

We watched TV and cooked together when we could not go anywhere. It is good, but sometime my brothers annoy me because they want to play with me when I do not feel like it.

All participants were locked down at home with their caregivers and the time away from the routine schedule assisted in establishing strong relationships due to increased interaction and availability especially after leaving care.

5 | DISCUSSION

A key positive of the lockdown restrictions in response to COVID-19 was the opportunity to have valuable time for care leavers with intellectual disabilities and/or autism to bond with caregivers and other family members and to learn new skills at home. Caregivers also reported a slower pace of life with more time to rest and have fun together.

However, it is clear from the findings that the sudden end to educational, supported employment and social care programmes and the shift to staying home full-time was a challenge for care leavers. In addition to the cessation of daily activities, there were breaks in parental contact arrangements. Care leavers found it difficult to understand the reasons for this disruption to their daily lives and struggled to cope with ongoing restrictions. Those who did understand why these restrictions were underway still experienced a complete withdrawal of support and activities outside their home, which impacted on them negatively. This radical change is particularly challenging for some young people with intellectual disabilities and/or autism who depend on a predictable routine to their daily lives (Neece et al., 2020). It is not surprising then that young people exhibited changes in mood, self-care and behaviour and found it difficult to find meaningful and stimulating daily activities at home (Courtenay, 2020). Young people also experienced low mood or symptoms of depression, anxiety and frustration, with one young person attempting suicide. Young people were also facing other challenges typical for their stage of transition from adolescence to young adult life, including one young person who was experiencing sexual identity issues.

Addressing these sensitive issues may be more difficult for young people in the context of limited contact with peers and professionals and constant contact or surveillance of caregivers. With the cessation of all programmes, nonessential work and recreational/sporting activities, young people were spending most of their time watching television, sleeping or eating, indicating a possible negative effect on their overall health and development. Caregivers reported struggling to help young people to continue with learning in relation to daily living tasks, such as shopping and independent travel while living in lockdown. Caregivers also had to be more attentive to the emotional well-being of young people in their care, as they tried to adapt to changes in established routines and understand the restrictions imposed by COVID-19.

These findings indicate that impairment impacted on young people’s understanding of restrictions in response to the pandemic but, in alignment with the social model of disability, also emphasise how structural barriers to accessing essential services had a significant negative impact on their opportunities for social relational experiences and developing independence (Goodley, 2017; Oliver, 2013). The findings reinforce the critical impact that the social environment has on the well-being and functioning not only of individuals but also of families, captured in the ecological concept of person-in-environment (Weiss-Gal, 2008). Contemporary research on resilience is increasingly showing the central importance of the social ecology, rather than personal attributes, for the resilience of vulnerable individuals (Ungar & Theron, 2020; Van Breda, 2016). It is through the interaction of individuals with a range of social factors in their environment that psychosocial health and well-being are enabled. The COVID-19 lockdown has cut participants off from family, friends, work and education, restricting their social-relational support systems. With this social atrophy came a reduction of resilience and, thus, deteriorations in behaviour and mental health, with one suicide attempt.

Care leavers in this study may have been experiencing a convergence of too many transitional life tasks, which overwhelmed their adaptation capacity. Coleman’s focal model (Coleman & Hendry, 1999; Hollingworth & Jackson, 2016; Stein, 2006) argues that during the transition through adolescence towards young adulthood, young people must navigate various developmental tasks. When these tasks are distributed relatively evenly over time, the transition process can unfold relatively easily. However, when multiple tasks converge at the same time, as is typical of the transition out of care, deteriorations in psychosocial functioning are to be expected. The participants in our study have had to face these cumulative
challenges that all care leavers face as they become young adults but also had to deal with the impact of changes to routine and barriers to support for young adults with disabilities during a COVID-19 lockdown.

6 | LIMITATIONS

Some limitations of the study should be noted. First, the study captures the views of only a small sample of young people which may not reflect the experiences of other care leavers with intellectual disabilities and/or autism. However, the aim of the study is not to gather generalisable data from a representative sample, but rather to collect in-depth data on participant experiences. Second, some of the participants had limited speech and language which impacted on the interview approach and resulted in the findings comprising both caregiver and care leaver quotes. However, caregivers’ verbal representation of the care leavers’ responses was closely checked with the young people and PECS was an effective communication tool to facilitate young people’s engagement in the online interview. Third, all findings relied on participant self-report, which raises the potential for bias. This concern was addressed by triangulation with the caregiver on the care leavers’ routine and well-being. Fourth, in hindsight, active exploration of participants’ access to and use of social media and online platforms would have been helpful and would be an important focus of future research.

7 | RECOMMENDATIONS AND CONCLUSION

Young people with intellectual disabilities and/or autism, transitioning out of residential care towards young adulthood, reported negative impacts from COVID-19 restrictions as independent living skills programmes aimed at preparing young people for the transition from care ceased, plans to move to new living arrangements stalled and employment opportunities ended. It is inevitable, in such contexts, to consider the use of accessible, online service provision to mitigate the challenges found through this study and to strengthen and mobilise the positive opportunities participants report COVID-19 to have created. Access to inclusive digital support during the pandemic has been reported to have positive benefits on the mental health, well-being and connectedness of people with intellectual disabilities (Seale, 2020).

As pandemic-related restrictions are likely to be a prolonged feature of our lives, alternative ways are needed to engage with young people with intellectual disabilities and/or autism as they prepare for life after care. Such approaches should be person-centred, promoting the self-determination of the young people and supporting their interdependence, while adhering to public health restrictions and social distancing rules. The need for robust, detailed, context-specific and participative transitional plans is thus heightened during COVID-19.

The findings highlight a regression in previously acquired independent living skills, as well as mental health. Psychosocial support services after leaving care should, thus, be considered an essential service for care leavers with intellectual disabilities. It is important these support services continue during lockdown, while adhering to COVID-19 regulations, to facilitate resilience and well-being among care leavers, caregivers and other members of the household. This could entail a combination of essential support programmes for people with disabilities delivered in person instead of a complete stop to services during the pandemic, alongside online educational and psychosocial support to care leavers and their caregivers when physical visits are prohibited.

One of the findings was the deepening of caregiver and young person relationships due to the closer living arrangements in the home. When in person formal services are not permitted, caregivers could be trained to use these closer relations to provide independent and interdependent living programmes to the care leavers at home. Thus, strengthening the supportive capacity of the social ecology and reducing the number of transitional tasks young people have to deal with at any point in time. Caregivers could be supported to deliver these programmes via online individualised support from professionals and virtual tutorials or potentially with other caregivers. Caregivers could then engage the young people in a range of creative and structured activities that build the capacities that will later be required for life as a young adult. In line with focal theory, this might assist in spreading the load of transitional demands over a longer time. To avoid over-burdening caregivers, this focus on caregivers helping care leavers to continue to develop their learning and skills during lockdown should be closely supported by professionals and efforts to open usual service programmes as soon as possible should be ongoing.

Despite the negative impact of COVID-19, the lockdown could be used as an opportunity to carefully prepare for future moves in education, living arrangements, relationships, education and so on. The interventions we propose above might have assisted in reducing the transitional difficulties care leavers with intellectual disabilities and/or autism confronted, enabling better mental health and progression towards independence.

CONFLICT OF INTEREST

No conflict of interest.

DATA AVAILABILITY STATEMENT

Research data are not shared.

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