

Manuscript version: Author's Accepted Manuscript

The version presented in WRAP is the author's accepted manuscript and may differ from the published version or Version of Record.

Persistent WRAP URL:

<http://wrap.warwick.ac.uk/167647>

How to cite:

Please refer to published version for the most recent bibliographic citation information. If a published version is known of, the repository item page linked to above, will contain details on accessing it.

Copyright and reuse:

The Warwick Research Archive Portal (WRAP) makes this work by researchers of the University of Warwick available open access under the following conditions.

Copyright © and all moral rights to the version of the paper presented here belong to the individual author(s) and/or other copyright owners. To the extent reasonable and practicable the material made available in WRAP has been checked for eligibility before being made available.

Copies of full items can be used for personal research or study, educational, or not-for-profit purposes without prior permission or charge. Provided that the authors, title and full bibliographic details are credited, a hyperlink and/or URL is given for the original metadata page and the content is not changed in any way.

Publisher's statement:

Please refer to the repository item page, publisher's statement section, for further information.

For more information, please contact the WRAP Team at: wrap@warwick.ac.uk.

1 **What is known about this topic? What does this paper add?**

- 2 • Care-experienced young people experience greater physical, social, and mental health
3 concerns during and beyond their time in care in comparison to same-aged peers not in
4 care
- 5 • Young people in care experience difficulty accessing healthcare through the system.
6 This has contributed to long-term chronic health conditions that may have been avoided
7 if prevention or early intervention was prioritised.
- 8 • Empowering young people through positive, responsive, and trusting relationships, and
9 listening to their health concerns is necessary to prioritise and improve health service
10 delivery to young people in care.

11
12
13
14
15
16
17
18
19
20
21
22
23
24
25

Under Review - Do Not Distribute

1. Introduction

In Australia, out-of-home care (OOHC; also referred Internationally as ‘looked after children’ or ‘children in care’) is alternative housing for those under 18 years of age (herein referred to as young people) who are removed from their parents, typically due to abuse and/or neglect (Australian Institute of Health and Welfare [AIHW], 2020). Locally and internationally, OOHC encompasses various placement types, including kinship (the carer is a relative or known to the young person), foster (placement with a non-related accredited carer), and residential care, where a group of children are cared for by employed staff (AIHW, 2020). Across Australia (excluding the Australian Capital Territory and Victoria), OOHC formally ceases at 18 years of age, yet some countries (i.e., New Zealand, United Kingdom, America) have extended care and support to 21 years (Home Stretch, 2018).

Young people living in OOHC are exposed to significant adversity, including childhood trauma, and the impact of this is often carried throughout life, culminating into complex behavioural, psychological and social challenges (Leloux-Opmeer et al., 2016). It is well-established that health-related outcomes for this population, both locally and internationally, are significantly poorer than their same aged peers living with their birth family (Maclean et al., 2016; Szilagyi et al., 2015). Young people in care are more likely to experience emotional, behavioural, social, dental, and physical health concerns (Berlin et al., 2018; Conn et al., 2015; Greger et al., 2016; Moeller-Saxone et al., 2016). This includes being four times more likely to experience mental ill health (Baldwin et al., 2019), at greater risk of substance dependence (Pilowsky & Wu, 2006), and high rates of chronic physical health conditions, such as obesity (Cox et al., 2014; Skouteris et al., 2011).

There is increasing evidence that the health needs of young people in care are not adequately met nor supported in the care environment (Commission for Children and Young People [CCYP], 2019; Smales et al., 2020a). Research has identified a number of barriers to

1 addressing and prioritising health in care, including the crisis-driven nature of the OOHC
2 system (Smales et al., 2020a), placement instability (Rock et al., 2015), and lack of support
3 for carers (CCYP, 2019; Monson et al., 2020). Additional barriers include difficulty
4 accessing required health documentation (i.e., disconnection from health history, McLean et
5 al., 2020a), a lack of involvement of the young person in health care planning (Smales et al.,
6 2020a), and haphazard transition from care processes that do not comprehensively support
7 health (Haggman-Laitila, 2019). These barriers inherent within the OOHC system
8 compromise health service delivery to this vulnerable population. Resultantly, health
9 concerns tend to persist beyond care into early adulthood, contributing to significant health
10 inequality and increased health service use among care-experienced young people
11 (Brannstrom et al., 2017; Brown et al., 2015; Smales et al., 2020a).

12 To date, the voice of care-experienced young people has largely been absent in
13 research examining their health and health care needs (Bromley et al., 2020). Typically,
14 participatory research with young people in care is neglected over the views of researchers,
15 professionals, or policy makers, due to challenges gaining consent and difficulties translating
16 young people's recommendations into policy and practice (Mannay et al., 2018). A review of
17 the literature examined young people's involvement in health research, finding only three of
18 39 studies directly interviewed care-experienced young people about their health status
19 and/or needs (Smales et al., 2020b). Encouragingly, emerging research has begun to focus on
20 understanding the factors that contribute to poor health outcomes from the perspective of
21 care-experienced young people (Monson et al., 2020; Smales et al., 2020a). However, there
22 remains limited understanding of how young people view and manage their health while in
23 care, and whether they are given a 'voice' in the management of their health care.

24 Adopting new research designs is necessary to better incorporate young people's
25 perspectives on health matters. Giving care-experienced young people an opportunity to

1 inform academic health research is particularly important, due to their poor health outcomes
2 across various domains (Moeller-Saxone et al., 2016; Nathanson & Tzioumi, 2007; Ward et
3 al., 2002; Webster, 2016). It also provides opportunities to acknowledge them as experts in
4 their own lives, increase self-efficacy and agency, improve understanding of the unique
5 barriers they face, and inform realistic change (Scherer, 2018; Ward et al., 2002). This paper
6 seeks to enhance our understanding of Australian care-experienced young people's past and
7 present health issues; interactions with health professionals; accessing health services; and
8 health literacy development, to make recommendations to improve the delivery of health
9 services to young people in OOHC. It is driven by two key questions: (1) what are young
10 people's experience of health and health services while living in OOHC; and (2) how can we
11 improve health service delivery to young people in OOHC?

12 **2. Methods**

13 The consolidated criteria for reporting qualitative research (COREQ) checklist was
14 used to improve reporting. The Monash University Human Research Ethics Committee in
15 Victoria, Australia, approved the research. The methods of this study have been described in
16 more detail elsewhere (Smales et al., 2020b).

17 Care-experienced young people – who at some point in their lives, have been placed
18 on child protection orders and subsequently entered kinship, foster or residential care - were
19 engaged to codesign the study. This involved seeking young people's feedback and support in
20 developing participant materials (i.e., recruitment advertisements, consent forms, explanatory
21 statements) and the interview guide. The co-design group comprised of five care-experienced
22 young people. This process ensured that this study explored topics that were important to
23 young people, acknowledged the importance of their involvement in health research,
24 empowered them to share their opinions, and ensure their voices are valued, heard and acted
25 upon.

1 Young Australian adults with a lived experience of OOHC were invited to participate
2 in an interview via social media and community service organisation contacts. Ten care-
3 experienced young adults, ranging from 18 to 27 years of age, agreed to participate (five
4 females, five males). Participants had lived in residential (n=6), kinship (n=5), or foster care
5 (n=4); five participants had experienced more than one placement type. Informed consent
6 was obtained prior to the interviews, which lasted between 30-90 minutes. Interviews were
7 conducted over the phone or face-to-face, depending on the participants' preference, and
8 were audio-recorded. Young people were asked about their health, access to healthcare, and
9 interactions with health professionals. The interview guide is presented in the Supplementary
10 Materials. Participants were provided with a \$50 gift voucher to thank them for their
11 contribution.

12 A phenomenological approach to the data analysis allowed for a descriptive and in-
13 depth approach. All transcripts were double-coded (i.e., independently coded by two
14 researchers, MS and HM) in NVivo (qualitative data analysis software, version 12 (2018),
15 QSR International Pty Ltd). Main themes were developed based on the most repetitive and
16 common ideas while the remaining codes were clustered into sub-themes. The analysed data
17 were cross-checked by a third member of the research team (RG) to improve the rigour,
18 integrity and prevent researcher bias.

19 3. Results

20 Four key themes emerged from the interviews with young people: (1) Young people
21 are not given the tools to be active agents in their own health promotion; (2) Accessing
22 healthcare is challenging; (3) Young people generally have unfavourable views of health
23 professionals; and (4) Relationship building may improve young people's engagement in
24 healthcare. Nine subthemes were identified. Supporting quotes are provided to represent each

1 theme, denoted by YP = young person. Additional quotes are presented in Supplementary
2 Table 1.

3 **1. Young people are not given the tools to be active agents in their own health** 4 **promotion**

5 This theme characterises the health environment that the young people were raised in. They
6 described a care system that did not build capacity to respond to health needs, and that their
7 health needs were not adequately or timely addressed, leaving many interviewees with
8 chronic health conditions that persisted post-care. Three subthemes were identified: (1)
9 Health literacy is not established in care: (2) The care environment did not nurture health to
10 improve outcomes; and (3) **Unaddressed health concerns persist beyond care.**

11 **Health literacy is not established in care**

12 The majority of young people had a holistic view of health, and understood health as
13 encompassing physical, mental, emotional and social wellbeing: “*health means how you are*
14 *as your whole, your body, your mind, basically your entire body*” [YP01] and “*I think that it*
15 *encompasses a lot of stuff. For me now, it is physical, mental, even social health*” [YP02].

16 Other young people focused more on the physical determinants of health, “*I have six chronic*
17 *illnesses, so health to me is living unwell every day*” [YP06].

18 How young people established their views on health was unclear, with many
19 describing a lack of education about health from their carers growing up, “*there wasn’t much*
20 *conversation around health. There wasn’t any talk about physical health, diet or mental*
21 *health*” [YP01], and “*they don’t educate us about physical and mental health well enough*”
22 [YP07]. For one young person, this reinforced their idea that health was not something to
23 worry about until they get older, “*I was a skinny twig and I didn’t really care. I just thought,*
24 *because I was a teenager, you just get health problems when you’re old*” [YP02].

1 Mental health was identified as an area where education and support were neglected,
2 *“I didn’t know that I was suffering from mental health, just because I’d known trauma my*
3 *entire life”* [YP01], and *“I didn’t really see mental health as health. We weren’t told*
4 *anything about mental health. I didn’t know what depression was, or anxiety, or anything”*
5 [YP07]. Young people also discussed receiving insufficient sexual health education,
6 particularly for young women, *“they don’t provide any support around sexual education or*
7 *what to do if you have an STI [sexually transmitted infection], even general hygiene things*
8 *around being a female, like pap smears”* [YP03].

9 **The care environment did not nurture health to improve outcomes**

10 The nature of residential care (i.e., care provided by staff on rotating shifts), can
11 negatively impact the delivery and promotion of health education. For example, one young
12 person explained:

13 *“You don’t have parents there to support you, you don’t have two persistent people*
14 *there. It’s two or four people every six hours... You get used to people coming into*
15 *your rooms then leaving every six hours.”* [YP08]

16 The constant staff turnover made it difficult for some young people to build trusting
17 relationships. This left some young people feeling alone or isolated when it came to
18 managing their health, so took it upon themselves to organise their health appointments: *“I*
19 *organised Headspace myself because I needed it... I didn’t want to be on drugs, and I didn’t*
20 *understand what was making me go down that path”* [YP04]. Relying on the ‘house’ to
21 organise appropriate care was often characterised by delays:

22 *“It took staff 14 months to get me into a psychologist... for someone who was*
23 *suicidal, self-harming, drug use, speculated sexual abuse... If I’d killed myself and*
24 *there was an inquest, they would’ve been fired.”* [YP09]

1 Health care also appeared to be offered in response to immediate needs that required
2 timely attention. However, prevention or routine check-ups were not prioritised:

3 *“I didn’t go to the dentist...I’d been to the dentist three times in my life up until I was*
4 *18. The last time was when I was 15...no one had told me about the importance of*
5 *seeing a dentist regularly.”* [YP01]

6 **Unaddressed health concerns persist beyond care**

7 Young people spoke about their ongoing experience of long-term physical health
8 problems, which began during their time in care. One young person explained:

9 *“I’m still trying to work out all the physical stuff that may be wrong with me. I have*
10 *got a trigger finger in my right pinkie finger...it’s either from being stabbed in the*
11 *hand in OOHC or having a shard of glass through my hand.”* [YP07]

12 Young people described many preventable health conditions that were not adequately
13 addressed during their time in care. These have now become ongoing chronic health
14 conditions, *“what happened in the past is affecting me now. I’m turning 27 next month and*
15 *I’m dealing with all these health issues that could have been addressed when I was younger”*
16 [YP02]. This was particularly evident for mental health needs, *“when you live in OOHC, it’s*
17 *very common to develop post-traumatic stress, anxiety and depression”* [YP06]. With proper
18 support, young people thought these concerns could have been better managed and
19 maladaptive coping behaviours (that perpetuate harm) might have been avoided, *“I ended up*
20 *on drugs, like not coping right, because of my mental health”* [YP04].

21 **2. Accessing healthcare is challenging**

22 Young people spoke about accessibility issues related to funding, waiting periods and
23 not having the necessary identification to access health care - a Medicare card gives
24 Australians access to free or subsidised healthcare. Various issues created a dependency on
25 others to help manage their health care: *“if you don’t have any income, or you don’t have*

1 *your Medicare number, it makes it impossible to go to a doctor on your own*” [YP01].

2 Further, *“because my foster mum basically did everything for me, I didn’t have access to my*
3 *Medicare or healthcare card. I couldn’t go to the doctors by myself”* [YP02]. Difficulties
4 accessing healthcare because of the system itself were also described:

5 *“Funding, waiting periods, the quality of the service provided, the fact that one of my*
6 *carers had to advocate heavily for 16 months to even get me into a psychiatrist. When*
7 *you're in the 1% from OOHC, you get thrown down the bottom of the barrel.”* [YP09]

8 Other young people spoke about poor knowledge of what services were available and
9 how to access them:

10 *“It felt like everyone was against me being able to seek help...I had no way to access*
11 *any services, and if I did, I wouldn’t know how to begin.”* [YP10]

12 Further, one young person who had experience of residential and foster care
13 suggested there were differences across placement types in health care access:

14 *“If a kid’s in immediate pain or needs to go to the doctor in residential care, you’ll be*
15 *able to go very quickly to a hospital or the doctor...in foster care, our carers were the*
16 *only people that we could go through to see the doctor. My brother broke his toe, but*
17 *they thought it wasn’t severe enough to take him to the doctors.”* [YP04]

18 **3. Young people generally have unfavourable views of health professionals**

19 Young people discussed negative experiences with medical professionals, which
20 compromised their experience of health service delivery. Two subthemes were identified: (1)
21 Doctors only see the presenting issue; and (2) Medical professionals do not always give a
22 voice or listen to young people.

23 **Doctors only see the presenting issue**

24 Young people’s experiences indicated that their doctors often did not notice critical
25 indicators of mental illness or explore alternative reasons for presenting concerns.

1 *“It was annoying when the doctor sent my foster mum out of the room to ask me to do*
 2 *a pregnancy test. I had to inform them that I was a virgin...it was awkward because I*
 3 *was only 12. Doctors jump to that conclusion...but it’s because I had anxiety.”*

4 [YP02]

5 Another young person thought that the doctor’s focus was not in-depth, and that they
 6 were not listened to because of their age.

7 *“I’m not sure they really paid attention to a 13-year-old kid. They should pay a lot*
 8 *more attention and go a lot more in depth...there wasn’t much of that.”* [YP03]

9 Young people felt that these experiences highlighted a lack of understanding about the
 10 unique issues they face. One young person identified some other common barriers:

11 *“Showing a bit more self-respect towards the individual and understanding that they*
 12 *might have barriers like a disability...who might not be able to understand things as*
 13 *well as someone with a higher IQ.”* [YP10]

14 **Medical professionals do not always give a voice or listen to young people**

15 Young people reflected on when they weren’t given opportunities to share and discuss
 16 their concerns with health professionals:

17 *“Part of it was the anxiety and part of it was just that I thought that was the role. As a*
 18 *young person and/or child, people around me knew better and it’s not my place to be*
 19 *talking about what’s happening to me.”* [YP01]

20 Therefore, many young people felt that, *“in terms of listening to me, a lot of the time it*
 21 *wasn’t me talking, it was the doctor”* [YP07]. Instead, young people identified that their

22 voice should be valued because of the expertise they bring:

23 *“The system thinks that we don’t have a voice and don’t have the right information to*
 24 *share...that’s where they’re wrong, because how would they know, when they’re not the*
 25 *ones that have experienced it.”* [YP10]

1 The young people perceived that health professionals thought they were malingering
2 about their health complaints when attempting to receive necessary health care:

3 *“I once went into hospital because I had appendicitis. I was in there for a week*
4 *because they didn’t believe that I actually had pain...They treated me like crap until*
5 *they actually removed the appendix and discovered it was appendicitis.” [YP09]*

6 **Theme 4: Relationship building may improve young people’s engagement in healthcare**

7 Young people emphasised the importance of consistent relationships, trust, and
8 listening to improve health care delivery to youth in OOHC. Three subthemes were
9 identified: (1) Strong, long-term relationships increase capacity for health promotion; (2)
10 Listening to young people builds trust and enables care; and (3) Dedicated health
11 professionals to respond to kids in care might improve access and treatment.

12 **Strong, long-term relationships increase capacity for health promotion**

13 Young people spoke about how to build a relationship with someone in OOHC. Ways
14 of presenting themselves were identified as important, *“The child would feel more*
15 *comfortable and stabilised around their worker if they take into account their appearance*
16 *and how they dress...If the young person is dressed casual, the worker could also dress*
17 *casual” [YP10]. Young people also identified that learning about them would also facilitate*
18 *relationship building:*

19 *“Finding out about the person before you even sit down with them [so] you know how*
20 *to approach them individually...you want them to feel comfortable, whether they want*
21 *to speak on the phone, face to face, go to the park or McDonalds.” [YP01]*

22 This approach to relationship building was seen as an enabler of receiving appropriate
23 healthcare, *“It’s about individualistic approaches and really getting to know the young*
24 *person. If they’re showing signs of a mental health issue...then [you can] get them the help*
25 *they need sooner” [YP02]. Young people suggested this can only happen if there is*

1 consistency among staff: *“the main thing is having the key worker or case manager that*
2 *properly knows the young person and isn’t going to change in six months”* [YP07]. As the
3 relationship develops and trust is established, carers can move towards using their ‘common
4 sense’ and ‘pick up on signals’:

5 *“Being more observant...if their appearance isn’t looking too great, they could be*
6 *struggling with depression...noticing those things the young person isn’t telling you.”*
7 [YP08]

8 **Listening to young people builds trust and enables care**

9 Without strong relationships, genuine communication with active listening can be
10 challenging. When relationships are established, carers can have discussions about health:

11 *“Talk to them about what they understand about health...give them time to think*
12 *about it...then offer advice or ask questions.”* [YP02]

13 A good relationship supports carers to listen to young people about their health
14 service needs:

15 *“It could be that [the young person] wants to be better supported to go to an*
16 *appointment or learn how to book an appointment...or they want someone to come*
17 *into their home to help them with a health problem.* [YP01]

18 Listening to a young person supports their agency and ability to advocate for their
19 needs using their voice. For example, *“taking them seriously from the get-go...believe them*
20 *when they say, I’m hurting”* [YP06] and *“listen to young people when they say something’s*
21 *wrong, and that they need to see a doctor”* [YP04]. Young people recognised that they need
22 to be invited into conversations to be heard and facilitate their health care:

23 *“Include them in discussions...include them in finding support services or things they*
24 *can link into. Let them speak their mind, don’t tell them what they’re experiencing.”*
25 [YP05]

1 **Dedicated health professionals to respond to kids in care might improve access and**
2 **treatment**

3 Young people with residential care experience suggested that either, *“the services*
4 *need to come to them”* [YP09] or *“a staff member goes around to residential units or foster*
5 *care units...and has a conversation with the kids”* [YP01]. There was a shared idea of
6 dedicated staff coming to the home: *“just having a worker that’s specific for health would be*
7 *really helpful in the child’s life...this is the person I see all the time about my health, and then*
8 *developing that relationship, that trust...if it’s the same person.”* [YP02]. This continuity of
9 care and long-term relationships may facilitate healthcare engagement. Another young person
10 suggested that, *“there should be some sort of check-up for physical and mental health every*
11 *six months, if a young person wants to do that.”* [YP04]

12 As young people in OOHC have significant mental health needs, a dedicated service
13 was suggested, *“there needs to be a specific service that only caters for kids in care, because*
14 *the complexity of mental health issues of kids in care surpasses most things that kids growing*
15 *up with families have”* [YP09]. However, one young person responded ‘no’ when asked if it
16 would be better if health professionals went into the home because, *“then when you grow up*
17 *and become an adult you will only rely on in-home doctors because I’m too lazy to go to an*
18 *actual doctor”* [YP08]. This was important because *“you [go from] the environment where*
19 *everything’s handed to you and all of sudden everything’s not handed to you and you freak*
20 *out and go into a spiral”* [YP07]. Overall, participants concluded that specialised health
21 services could improve the delivery of health care to young people in OOHC.

22 **Discussion**

23 This study aimed to hear the voices of care-experienced young people as they spoke
24 about health, access to healthcare, and interactions with health professionals. The findings
25 revealed that: (1) the OOHC system does not nurture young people’s health; (2) young people

1 in care experience difficulty accessing and navigating a complex health system; and (3)
2 empowering young people through positive, responsive, and trusting relationships is
3 necessary to facilitate engagement in health care. Young people painted a bleak picture about
4 poor access to healthcare through a system which has set them up to experience chronic
5 health conditions, some of which may have been avoided if prevention or early intervention
6 was prioritised.

7 The findings revealed that young people's health needs (i.e., mental and physical
8 health (including dental health) were not prioritised nor sufficiently addressed while they
9 were in OOHC. Resultantly, the majority of young people reported experiencing ongoing
10 chronic physical and mental health problems. This is consistent with the mounting evidence
11 that young people in care experience poorer health outcomes than their peers not in care
12 (Maclean et al., 2016; Smales et al., 2020a; Vinnerljung & Hjern, 2018), and that such
13 outcomes continue to persist into adulthood (Berlin et al., 2018; Brannstrom et al., 2017;
14 Kaariala & Hiilamo, 2017; Smales et al., 2020b). Specifically, young people discussed not
15 receiving appropriate support for mental health concerns, leaving them to manage significant
16 mental health issues as young adults. For young people in care, mental health services are
17 most likely to be needed but not received (McLean et al., 2020b). This emphasises how the
18 current care environment, particularly residential care, does not adequately nurture their
19 health and wellbeing. This has been attributed to carer inconsistency, lack of health care
20 planning, and the crisis-driven nature of the care system responding only to severe health
21 needs (Smales et al., 2020b). System reform is required to shift care from the current crisis-
22 driven and reactive approach towards prioritising a more preventive and early intervention
23 model of wellbeing.

24 Due to minimal health education or promotion during care, young people
25 acknowledged they were often unaware of what health services were available to them and

1 how to access them. This means young people in care are often not provided with the agency
2 or resources to nurture their health (CCYP, 2019). Health education and opportunities to
3 participate in health-related decisions are necessary to improve young people's health
4 literacy, increase agency and self-efficacy to make informed health decisions, and develop
5 skills needed for adulthood (Bessell, 2011; Grace et al., 2018). Further, young people
6 maintained that their carers neglected opportunities to provide preventive care or did not
7 identify early signs of ill health. This suggests that meeting the health needs of young people,
8 beyond ensuring their basic needs are met, should be prioritised in care. Professional
9 development or training for carers may help to build their capacity to prioritise health
10 promotion, education, and identify/manage early signs of ill health among young people in
11 their care (CCYP, 2019; Monson et al., 2020).

12 The findings highlight that young people in OOHC experience significant difficulty
13 accessing appropriate and affordable healthcare services. Systemic barriers compromise their
14 engagement with health services, including entering care without necessary identification or
15 documents (e.g., a Medicare card) or relevant family/personal medical history information.
16 This can significantly prevent or delay their access to appropriate and affordable health care
17 and further compromises young people's capacity for agency and empowerment over their
18 health (Schneiderman et al., 2012). There is no guidance around obtaining this paperwork in
19 the national standards for OOHC (Commonwealth of Australia, 2011). As young people's
20 experiences suggest that such processes are not being consistently implemented in a timely
21 manner, increased clarity of standards and streamlined collection of documentation is
22 necessary to facilitate young people's timely access to healthcare.

23 A compelling finding was that the majority of young people had negative experiences
24 with health professionals, describing encounters where their health concerns were dismissed,
25 ignored, or not heard. Young people are often not provided opportunities to be consulted or

1 listened to when it comes to their health (Finan et al., 2018; Smales et al., 2020a), and the
2 notion of GPs “ticking the box” when examining young people in OOHC has been previously
3 identified (McLean et al., 2020a). Young people recognised the need to be invited into
4 conversations about their health, listened to, and supported to facilitate their health care
5 (Grace et al., 2018). Building meaningful, supportive, and genuine relationships with carers is
6 foundational to providing opportunities for young people’s needs to be heard (CCYP, 2019;
7 Heyman et al., 2020). Relationships that seek to acknowledge and understand the unique
8 experiences and needs of young people in care need to be prioritised to support young
9 people’s health.

10 Finally, participants called for improvements to the delivery of health services to
11 young people in OOHC. Previous research has identified long waiting times for allied health
12 services, with particular difficulty accessing appropriate mental health services (McLean et
13 al., 2020a; Fergus et al., 2019). Young people in care wait longer for psychological support
14 and have lower mental health utilisation than young people not in care (Swanke et al., 2016).
15 Young people suggested that specialised services may be warranted. There are a few health
16 services in Australia that are specifically designed for and targeted towards young people in
17 OOHC, such as Berry Street’s Take Two service, which provides systemic trauma-informed
18 therapeutic support to young people involved with child protection with significant trauma
19 (Berry Street, 2020). Young people from care may require specialised services or priority
20 access to health services so they can “catch-up” to their peers and reduce health-related
21 inequalities (McLean et al., 2020a). Integrated outreach health services (i.e., health
22 professionals visiting young people in their home) was also suggested, which may address
23 current barriers to accessing health care (McLean et al., 2020b). Ultimately, greater
24 coordination and collaboration between the OOHC and health service systems is needed to
25 provide trauma-informed health care.

1 **Strengths and Limitations**

2 This research was conceived, co-designed and analysed by care-experienced young
3 people, which makes a significant contribution to the literature, demonstrating that research
4 can be successfully conducted with this vulnerable cohort. This empowered young people to
5 share what was important to them and provided an opportunity to promote their voice in
6 health research. Data were also analysed by more than one researcher for improved rigour.
7 However, there are some limitations of the study that bare consideration. Firstly, the data
8 from this paper were sourced from the transcripts of another study (Smales et al., 2020).
9 There was little to no overlap in the data being reported here and in the previous study; it
10 simply was not possible to report on all findings within the one paper. This could be viewed
11 as data mining (Rasid et al., 2017) and should be considered. The sample did not include
12 young people who were currently in care, due to significant constraints gaining consent from
13 guardians. Relying on care-experienced young people may have increased the likelihood of
14 retrospective recall bias, as the accuracy of their recall may have reduced when reflecting on
15 experiences that occurred years ago (Blome & Augustin, 2015). There is some missing
16 context about the participants, including length of time spent in care, and the contributing
17 experiences leading to health concerns prior to entering care – this knowledge could shape
18 our understanding of the findings. Whilst data saturation was met, the small study sample
19 (n=10) also needs to be acknowledged as a limitation. Exploration of the experiences of
20 young people across different contexts is needed to confirm if these findings remain true in
21 other areas where child protection and health care delivery likely differ.

22 **Conclusion**

23 The health of care-experienced youth is often not prioritised by their carers or medical
24 professionals, leading to significant impairment in their quality of life after care. The
25 recommendations offered by young people speak to basic human needs of belonging,

1 relationships and trust, as precursors to health promotion, which can often be lacking due to
2 the circumstantial and situational realities of OOHC. As such, a call to action must be made
3 where the health and safety of young people is always at the centre of practice.

4

5

6

7

8

9

10

11

12

13

14

15

16

17

18

19

20

21

22

23

24

25

Under Review - Do Not Distribute

References

- 1
2 Australian Institute of Health and Welfare [AIHW]. (2020). *Child protection Australia 2018-*
3 *2019*. Child welfare series no. 72. Canberra: AIHW.
- 4 Baldwin, H., Biehal, N., Cusworth, L., Wade, J., Allgar, V., & Vostanis, P. (2019).
5 Disentangling the effect of out-of-home care on child mental health. *Child Abuse and*
6 *Neglect*, 88, 189-200.
- 7 Berlin, M., Mensah, T., Lundgren, F., Klingberg, G., Hjern, A., Vinnerljung, B., &
8 Cederlund, A. (2018). Dental healthcare utilisation among young adults who were in
9 societal out-of-home care as children: A Swedish national cohort study. *International*
10 *Journal of Social Welfare*, 27(4), 325-336.
- 11 Berry Street. (2020). Take Two. Retrieved from [https://www.berrystreet.org.au/our-](https://www.berrystreet.org.au/our-work/healing-childhood-trauma/take-two)
12 [work/healing-childhood-trauma/take-two](https://www.berrystreet.org.au/our-work/healing-childhood-trauma/take-two)
- 13 Bessell, S. (2011). Participation in decision-making in out-of-home care in Australia: What
14 do young people say? *Children and Youth Services Review*, 33(4), 496–501.
15 <https://doi.org/10.1016/j.childyouth.2010.05.006>
- 16 Blome, C., & Augustin, M. (2015). Measuring change in quality of life: Bias in prospective
17 and retrospective evaluation. *Value in Health*, 18(1), 110–115.
18 <https://doi.org/10.1016/j.jval.2014.10.007>
- 19 Brannstrom, L., Vinnerljung, B., Forsman, H., & Almquist, Y. (2017). Children placed in
20 out-of-home care as midlife adults: are they still disadvantaged or have they caught up
21 with their peers? *Child Maltreatment*, 22(3), 205-214.
- 22 Bromley, D., Sampson, L., Brettle-West, J., & Reilly, M. (2020). Hearing the voices of
23 looked-after children: Considering the challenges obtaining feedback on healthcare
24 services. *Journal of Child Health care*, 24(4), 502-514.

- 1 Brown, A., Courtney, M., & McMillen, J. (2015). Behavioural health needs and service use
2 among those who've aged out of foster care. *Children and Youth Services Review*, 58,
3 163-169.
- 4 Commission for Children and Young People [CCYP]. (2019). *Systemic inquiry into the lived*
5 *experience of children and young people in the Victorian out-of-home care system.*
6 Melbourne, Victoria: CCYP.
- 7 Commonwealth of Australia. (2011). *An outline of national standards for out-of-home care.*
8 *A priority project under the National Framework for Protecting Australia's Children*
9 *2009-2020.* Canberra: Commonwealth of Australia.
- 10 Conn, A., Szilaygi, M., Jee, S., Blumkin, A., & Szilaygi, P. (2015). Mental health outcomes
11 among child welfare investigated children: in-home versus out-of-home care. *Children*
12 *and Youth Services Review*, 57, 106-111.
- 13 Cox, R., Skouteris, H., McCabe, M., & Fuller-Tyszkiewicz, M. (2014). Rates of overweight
14 and obesity in a sample of Australian young people and their carers in out-of-home
15 residential care. *Australian and New Zealand Journal of Public Health*, 38(6), 591-592.
- 16 Department for Education and Department for Health. (2015). *Promoting the health and*
17 *wellbeing needs of looked-after children. Statutory guidance for local authorities,*
18 *clinical commissioning groups and NHS England.* England: Department for Education
19 and Department for Health.
- 20 Deutsch, S., & Fortin, K. (2015). Physical health problems and barriers to optimal health care
21 among children in foster care. *Current Problems in Pediatric and Adolescent Health*
22 *Care*, 45(10), 286-291.
- 23 Fergeus, J., Humphreys, C., Harvey, C., & Herrman, H. (2019). Supporting foster and kinship
24 carers to promote the mental health of children', *Child and Family Social Work*, 24, 77-
25 83.

- 1 Finan, S., Bromfield, L., Arney, F., & Moore, T. (2018). *Assessing the quality and*
2 *comprehensiveness of child protection practice frameworks: A report to the*
3 *Australian children's commissioners and guardians*. Australian Centre for Child
4 Protection: University of South Australia.
- 5 Fugard, A., & Potts, H. (2015). Supporting thinking on sample sizes for thematic analyses: a
6 quantitative tool. *International Journal of Social Research Methodology*, 18(6), 669-
7 684.
- 8 Gerard, A., McGrath, A., Colvin, E., & McFarlane, K. (2018). 'I'm not getting out of bed!'
9 The criminalisation of young people in residential care. *Australian and New Zealand*
10 *Journal of Criminology*, 52(1), 76-93.
- 11 Grace, R., Miller, K., Blacklock, S., Bonser, G., & Hayden, P. (2018). The kids say project:
12 Supporting children to talk about their experiences and to engage in decision-making.
13 *Australian Social Work*, 71(3), 292–305.
- 14 Greger, H., Myhre, A., Lydersen, S., & Jozefiak, T. (2016). Child maltreatment and quality of
15 life: a study of adolescents in residential care. *Health and Quality of Life Outcomes*,
16 74(14), doi: 10.1186/s12955-016-0479-6
- 17 Haggman-Laitila, A., Salohekkila, P., & Karki, S. (2019). Young people's preparedness for
18 adult life and coping after foster care: A systematic review of perceptions and
19 experiences in the transition period. *Child and Youth Care Forum*, 48, 633-661.
- 20 Heyman, J., White-Ryan, L., Kelly, P., Farmer, G., Leaman, T., & Davis, H. (2020). Voices
21 about foster care: The value of trust. *Children and Youth Services Review*, 113,
22 <https://doi.org/10.1016/j.chilyouth.2020.104991>
- 23 Deloitte. (2018). *Extending care to 21 years*. New South Wales: Anglicare, Home Stretch
24 Campaign. Available at <https://www.anglicare.com.au/wp->

- 1 <content/uploads/2018/10/Home-stretch-campaign-NSW-Oct-2018-v3-1.pdf>. Accessed
2 on 6/5/21.
- 3 Jones, V. F., & Schulte, E. E. (2019). Comprehensive health evaluation of the newly adopted
4 child. *Pediatrics*, *143*(5), e20190657.
- 5 Kaariala, A., & Hiilamo, H. (2017). Children in out-of-home care as young adults: A
6 systematic review of outcomes in the Nordic countries. *Children and Youth Services
7 Review*, *79*, 107-114.
- 8 Leloux-Opmeer, H., Kuiper, C., Swaab, H., & Scholte, E. (2016). Characteristics of children
9 in foster care, family-style group care, and residential care: A scoping review. *Journal
10 of Child and Family Studies*, *25*, 2357-2371.
- 11 Maclean, M., Sims, S., O'Donnell, M., & Gilbert, R. (2016). Out-of-home care versus in-
12 home care for children who have been maltreated: A systematic review of health and
13 wellbeing outcomes. *Child Abuse Review*, *25*(4), 251-272.
- 14 Mannay, D., Staples, E., Hallett, S., Roberts, L., Rees, A., Evans, R., & Andrews, D. (2018).
15 Enabling talk and reframing messages: working creatively with care experienced
16 children and young people to recount and re-represent their everyday experiences.
17 *Child Care in Practice*, *25*(1), 51-63.
- 18 McLean, K., Clarke, J., Scott, D., Hiscock, H., & Goldfield, S. (2020a). Foster and kinship
19 carer experiences of accessing healthcare: A qualitative study of barriers, enalbers and
20 potential solutions. *Children and Youth Services Review*, *113* doi:
21 <https://doi.org/10.1016/j.chilyouth.2020.104976>
- 22 McLean, K., Hiscock, H., Scott, D., & Goldfield, S. (2020b). Foster and kinship carer survey:
23 Accessing health services for children in out-of-home care. *Journal of Paediatrics
24 and Child Health*, doi: <https://doi.org/10.1111/jpc.15157>

- 1 Moeller-Saxone, K., McCutcheon, L., Halperin, S., Herrman, H., & Chanen, A. (2016).
2 Meeting the primary care needs of young people in residential care. *Australian Family*
3 *Physician*, 45(10), 706–711.
- 4 Monson, K., Moeller-Saxone, K., Humphreys, C., Harvey, C., & Herrman, H. (2020).
5 Promoting mental health in out of home care in Australia. *Health Promotion*
6 *International*, 35(5), 1026-1036.
- 7 Nathanson, D., & Tzioumi, D. (2007). Health needs of Australian children living in out-of-
8 home care. *Journal of Paediatrics and Child Health*, 43(10), 695–699.
- 9 Pilowsky, D., & Wu, L. (2006). Pschiatric symptoms and substance use disorders in a
10 nationally representative sample of American adolescents involved with foster care.
11 *The Journal of Adolescent Health*, 38, 352-358.
- 12 Pizzirani, B., O'Donnell, R., Bruce, L., Breman, R., Smales, M., Xie,, . . . Green, R. (2019).
13 The large-scale implementation and evaluation of a healthy lifestyle program in
14 residential out-of-home care: Study protocol. *International Journal of Adolescence*
15 *and Youth*, 14(2), 1–11.
- 16 Rasid, N., Nohuddin, P., Alias, H., Hamzah, I., & Nordin, A. (2017). Using data mining
17 strategy in qualitative research. *International Visual Informatic Conference*, doi:
18 10.1007/978-3-319-70010-6_10
- 19 Rock, S., Michelson, D., Thompson, S., & Day, C. (2015). Undersatnding foster placement
20 instability for looked after children: A systematic review and narrative synthesis of
21 quantitative and qualitative evidence. *The British Journal of Social Work*, 45(1), 177-
22 203.
- 23 Scherer, D. G. (2018). Paediatric participation in medical decision making: The devil is in the
24 details. *The American Journal of Bioethics*, 18(3), 16–18.

- 1 Schneiderman, J., Smith, C., & Palinkas, L. (2012). The caregiver as gatekeeper for accessing
2 health care for children in foster care: A qualitative study of kinship and unrelated
3 caregivers. *Children and Youth Services*, 34(10), 2123-2130.
- 4 Skouteris, H., McCabe, M., Fuller-Tyszkiewicz, M., Henwood, A., Limbrick, S., & Miller, R.
5 (2011). Obesity in Children in Out-of-home Care: A Review of the Literature.
6 *Australian Social Work*, 64(4), 475-486.
- 7 Smales, M., Savaglio, M., Morris, H., Bruce, L., Skouteris, H., & Green, R. (2020a).
8 “Surviving not thriving”: Experiences of health among young people with a lived
9 experience in out-of-home care. *International Journal of Adolescence and Youth*,
10 25(1), 809-823.
- 11 Smales, M., Savaglio, M., Webster, S., Skouteris, H., Pizzirani, B., O’Donnell, R., & Green,
12 R. (2020b). Are the voices of young people living in out of home care represented in
13 research examining their health? A systematic review of the literature. *Children and*
14 *Youth Services Review*, 113, 1-15.
- 15 Swanke, J., Yampolskaya, S., Strozier, A., Armstrong, M. (2016). Mental health service
16 utilization and time to care: A comparison of children in traditional foster care and
17 children in kinship care. *Children and Youth Services Review*, 68, 154-158.
- 18 Szilagyi, M., Rosen, D., Rubin, D., & Zlotnik, S. (2015). Health care issues for children and
19 adolescents in foster care and kinship care. *Pediatrics*, 136(4), e1142-e1166.
- 20 Vinnerljung, B., & Hjern, A. *Health care in Europe for children in societal out-of-home care*.
21 Stockholm, Sweden; 2018. Available at: [https://www.childhealthservicemodels.eu/wp-](https://www.childhealthservicemodels.eu/wp-content/uploads/Mocha-report-Children-in-OHC-May-2018.pdf)
22 [content/uploads/Mocha-report-Children-in-OHC-May-2018.pdf](https://www.childhealthservicemodels.eu/wp-content/uploads/Mocha-report-Children-in-OHC-May-2018.pdf). Accessed on 6/5/21.
- 23 Ward, H., Jones, H., Lynch, M., & Skuse, T. (2002). Issues concerning the health of looked
24 after children. *Adoption and Fostering*, 26(4), 8–18.

- 1 Webster, S. (2016). *Children and young people in statutory out-of-home care: Health needs*
- 2 *and health care in the 21st century*. Melbourne AUS: Parliamentary Library and
- 3 Information Service, Parliament of Victoria.

Under Review - Do Not Distribute