



creating a better life
for children and young
people in care

Health and Well-being

Perspectives of children and young people with an out-of-home care experience in NSW

“Well-being means the happiness of one's life”. (Male, 15 years)

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Contents

List of Tables..... 3

List of Figures 3

Introduction and Background..... 4

Current Consultation 6

Method..... 6

 Participants 6

 Materials 7

 Procedure..... 8

 Data Analysis..... 9

Findings 9

 Being Healthy..... 9

 Well-being..... 10

 Well-being Ratings 12

 Important Factors for Feeling Healthy and Well 13

 Mental health issues. 16

 Respectful Relationships. 17

 Sexual Health. 17

 Fitness. 18

 Alcohol and/or Substance Use and Abuse..... 18

 Support and Information 19

 Support. 19

 Information..... 20

 Sources of Information. 21

 Involvement in Decision-making 22

Limitations..... 23

Conclusion and Actions..... 24

References..... 26

Appendix A: Survey Questions 30

About CREATE 37



List of Tables

Table 1 *Participant Demographics* 7

Table 2 *What a Person Needs to be Healthy* 9

Table 3 *The Qualities of Well-being* 10

Table 4 *A Good and Happy Life* 11

Table 5 *Important Factors for Being Healthy and Well*..... 14

Table 6 *Biggest Concern or Worry*..... 16

Table 7 *What Carers or Health-Care Workers Can do to Help* 19

Table 8 *What Other Supports Would Increase Feelings of Being Healthy and Well*..... 20

Table 9 *Information That Would Assist Young People* 21

Table 10 *Involvement in Decision-Making* 23

List of Figures

Figure 1 *WHO-5 Ratings* 12

Figure 2 *How Concerned or Worried Young People Are at Present with any Health or Well-being Issue*..... 13

Figure 3 *How Supported Young People Feel in Relation to their Health or Well-being* 13

Figure 4 *Ratings of Importance for Young People in OOHC*..... 15

Figure 5 *Sources of Information* 22

Figure 6 *Involvement in Decision-Making* 22

Figure 7 *Being Healthy and Well*..... 24



Introduction and Background


Improving the health and well-being of Australian children, young people, and families is a policy priority for Australian governments (e.g., COAG Health Council, 2015; Commonwealth of Australia, 2009; NSW Government, 2018). Children and young people with an out-of-home care experience, especially, are presented with a number of challenges in relation to their health and well-being. Children and young people typically enter care due to physical, emotional, and/or sexual abuse, neglect, or domestic violence; therefore, many have experienced high rates of complex relational trauma (Bailey et al., 2019). In addition, the process of being removed from their homes, and experiences of multiple placements, can lead to further experiences of trauma and distress, and contribute to a sense of loss, feelings of not belonging, distrust, and difficulties forming secure relationships (Chesmore et al., 2017; Conradi et al., 2011; Delima & Vimpani, 2011).

Young people with an out-of-home care experience who report more positive well-being are more likely to progress to higher education, maintain independent living with support following transition from care, and be less likely to be involved with the police (Akister et al., 2010). Well-being is considered a multi-dimensional concept (e.g., Hamilton & Redmond, 2010; Huppert, 2009; White, 2008), including both positive factors and absence of negative factors. It is defined as self-rated functioning at the individual and interpersonal level, and includes physical, emotional, social, cultural, and environmental dimensions (Hamilton & Redmond, 2010; Rees et al., 2013). These domains are considered to be interconnected, with one influencing the other. For a young person with an out-of-home care experience, this means that their physical and mental health, their feelings, and their relationships are important to their well-being. As well-being is defined as a subjective experience, it also incorporates self-perceptions and self-evaluations of the young person's individual life circumstances and living situation (i.e., their environment).

Research examining the health and well-being of young people with an out-of-home care experience has focused typically on health outcomes more than on well-being, operationalising health outcomes as addressing physical, behavioural, or mental health care needs. This research demonstrates that children and young people with an out-of-home care experience are more likely to have poorer physical and mental health, and higher rates of developmental difficulties, compared with children and young people in the general population (Arora et al., 2014; Hansen et al., 2004; Hill & Watkins, 2003; Kaltner & Rissel, 2011; Nathanson & Tzioumi, 2007; Raman et al., 2011). For example, Nathanson and Tzioumi (2007) found that children in out-of-home care had poorer health ratings (e.g., more likely to have speech difficulties or delays, behavioural health problems, and/or dental and vision problems) compared to the general population in NSW. Further, when dealing with the Indigenous sub-population, Shmerling et al. (2019) found that, except for immunisation rates, children and young people with an out-of-home care experience accessing the Victorian Aboriginal Health Service had poorer ratings on physical, developmental, and mental health care, even when compared to other samples of children with an out-of-home care experience.

One large-scale Australian study, the *Pathways of Care Longitudinal Study* (Australian Institute of Family Studies, et al., 2015; Paxman et al., 2014) collected data over five waves¹ from a cohort of children and young people who entered care between May 2010 and October 2011 using in-depth interviews with children and young people,


¹ Data from four Waves publically available; Wave Five data currently being collected (from April 2019 and August 2020).



carers, and parents; online surveys with teachers; and standardised measures to assess a range of children development outcomes. Measures of health and socio-emotional well-being included young people's self-reported levels of emotional states (i.e., happiness, worry, sadness, and anger), felt security, and the extent to which they had been in trouble, carer reports of health and well-being, and scores on the Child Behaviour Checklist (CBCL; Achenbach & Edelbrock, 1983). Baseline results indicated that young people's reported experiences of emotional states were consistent with those from a sample of young people from the general population in 2008 (Australian Institute of Family Studies, et al., 2015), and carer reports of health were consistently positive across four waves of data collection (with ratings of "good" to "excellent" health by more than 90% carers; Butler & Department of Communities and Justice NSW, 2019). At wave 4, collected between 2017 and 2018, a quarter of young people were assessed as being in the clinical range for behaviour-based problems as indicated by total scores on the CBCL; and compared to normative data, average CBCL total problems scores were slightly higher than those in the general population. Baseline and longitudinal results have provided invaluable insights into the progression of individuals through the care system; however, because of its size and scope, limited attention could be directed to the views of specific children and young people. It is critical that the voices, views, and experiences of children and young people are heard in all areas that are related to their care and support. In this context, understanding what being healthy and well means to young people with an out-of-home care experience, and hearing what they need to support their health and well-being needs, are essential.

Studies have attempted to characterise well-being experiences for young people in out-of-home care. Children and young people generally, and those with an out-of-home care experience, who participated in the *Australian Child Well-being Project* (Redmond et al., 2016) ranked six domains in terms of importance for a good life. Most frequently, young people from both groups rated family as the most important domain, followed by health, friends, school, community, and money. However, the focus of this project was not solely on children with an out-of-home care experience; thus, questions did not cover issues that might be uniquely important to this group. The *Our Lives, Our Care* project (Selwyn et al., 2018) conducted focus groups with children and young people with an out-of-home care experience in England and Wales (aged 11–18 years) and identified four key domains for "what makes a good life?". These were *Relationships* (e.g., having trusting and positive relationships with those they live with and their social workers, feeling satisfied with the amount of family contact, and having a good friend and/or pet); *Rights* (e.g., participating in decision-making, feeling safe, and having access to their social worker); *Resilience* (e.g., having a trusted adult in their lives, having chances to be trusted and having second chances, and having access to education, internet, hobbies, and nature); and *Recovery* (e.g., feeling settled where they live, having explanations for why they are in care, having adults who notice their feelings and are available to talk about their worries and other things that matter to them).

In the USA, Kelly et al. (2019), using semi-structured interviews with young people with an out-of-home care experience, identified eight factors important to a sense of well-being, including: cultivating and maintaining relationships; the ability to cope with adversity (which included caregiver support, friend support, and self-care strategies and activities); the ability to manage their own emotions; learning to be happy despite adversity from being in the care system; normalcy (and being like other young people); external perceptions of their well-being (e.g., knowing they are doing well because their caseworker or youth justice worker provides that feedback); their vision of the future (e.g., including projected vision and future goals); and their prioritising of academic



success. While these studies have identified different themes from the comments from their respective group of young people, both this research and the Selwyn et al. (2018) study identified similar issues (e.g., supportive relationships, resiliency skills, placement characteristics, engagement in activities).

Consistent with this, studies have found that having better quality relationships with others, good life and social skills, engagement in appropriate education and/or employment, and placement, school, and caseworker stability have been associated with reports of more positive well-being (Akister et al., 2010; Dixon, 2008; Tomy, 2014; Walsh et al., 2018). Residential care placements, being placed in care at an older age, numerous placement changes, and challenging pre-care experiences have been found to have a negative association with experiences of well-being (Llosada-Gistau et al., 2019; Schütz et al., 2015; Walsh et al.).

The *Our Lives Our Care* project in the UK (Selwyn et al., 2018) found that, in general, young people with an out-of-home care experience had comparable levels of well-being to a sample of young people in the general population. The *Our Lives Our Care* project noted, however, that when well-being scores were separated into low, moderate, high, and very high groupings, young people with an out-of-home care experience more frequently scored in the extreme groups (i.e., low and very high) compared to the sample of young people in the general population. Children who recorded low on well-being ratings also tended to indicate more dissatisfaction or unhappiness with multiple areas in their lives (e.g., that they did not feel safe or settled in their placements, have trusted adults in their lives, have a good friend, and did not feel included in decision-making). A review by Walsh et al. (2018) suggested that it was the interaction between the different risk and protective factors, rather than the individual factors themselves, which had the greatest impact on well-being for young people with an out-of-home care experience.

Current Consultation

Studies in Australia have measured a number of health (e.g., Nathanson & Tzioumi, 2007; Shmerling et al. 2019) and well-being outcomes (e.g., Australian Institute of Family Studies et al., 2015). However, while studies in the UK and the USA (Kelly et al., 2019; Selwyn et al., 2018) have attempted to characterise what well-being means to young people in out-of-home care, no study was identified that sought to understand the well-being experiences for young people in out-of-home care in Australia. The United Nations Convention on the Rights of the Child (UNCRC, 1989) states that children who are “capable of forming [their] own views” have “the right to express those views freely in all matters affecting the child” (p. 5). The current consultation was conducted by the CREATE Foundation in conjunction with the Children in Care Collective as part of a larger project aimed at assisting agencies in their work with young people with an out-of-home care experience. The aims of this report were to listen to young people’s voices, opinions, and experiences regarding what being healthy and well means to them and what will help them meet their health and well-being needs.

Method

Participants

Participants in the consultation were 26 young people (14 females and 12 males; age range 12-17 years) with an out-of-home care experience in NSW. Eleven young people identified as Indigenous (nine Aboriginal and two as both Aboriginal and Torres Strait Islander). Most frequently, young people reported that they were living in a

foster care type placement ($N = 16$), were younger than five years of age when they first entered care ($N = 17$), and had lived in one to two placements during their time in care ($N = 17$). No young person reported living in a residential care arrangement. Twelve young people reported living with one or more disabilities, including attention-deficit/hyperactivity disorder (6), intellectual disability (5), autism (3), foetal alcohol spectrum disorder (3), dyspraxia (1), anxiety (1), oppositional defiant disorder (1), and reactive attachment disorder (1). Those who reported a disability also reported receiving support for their disability (e.g., medication, counselling, educational support). Details of age, placement type, the age the young person first entered care, and number of placements are reported in Table 1.


Table 1
Participant Demographics

Participant demographics	Number of Young People
Age	
12	6
13	6
14	3
15	6
16	2
17	3
Placement Type	
Foster Care	16
Kinship Care	4
Permanent Care	6
Age first entered care	
0-2 years	10
3-5 years	8
6-8 years	5
9-10 years	2
unsure	1
Number of placements	
1-2	17
3-4	4
5-6	3
7-8	1
9-10	1

Materials

This consultation used a mixed-method approach, employing quantitative and qualitative research methodology. This approach allows for young people's voices to be heard directly and is consistent with the view that collaboration with children and young people produce better outcomes and more child-centred focus and practice (Moore et al., 2008). The survey consisted of 36 items, including demographic questions (e.g., age, sex, placement type and number, and cultural group), one check-list question (for young people to tick who they go to for information), 13 rating-scale questions (with 6-point response format), and 10 short-answer open questions.

The rating-scale questions included the 5-item World Health Organisation Well-being Index (WHO-5; WHO, 1998), which consists of positively-framed statements (e.g., "I have felt cheerful and in good spirits") attached to a 6-point response format. Items were examined individually and at the total scale score level. The WHO-5 has



been used with child and adolescent populations and has reported sound to good reliability (.78 and .85 for children [M age = 10.5] and adolescents [M age = 14.3], respectively; Allgaier et al., 2012) and validity (e.g., De Wit et al., 2007; Topp et al., 2015). The Cronbach's alpha reliability coefficient for the current sample was .87.

Three questions asked how concerned or worried, how supported, and how involved in decision-making young people were in relation to their health and well-being (6-point rating scale; higher scores indicated being more worried, less supported, and less involved); and five questions asked how important young people thought several health and well-being issues were for young people in out-of-home care (e.g., mental health issues, finding respectful relationships, fitness; 6-point response with higher scores reflecting less importance). For these last five questions, the young people also were able to indicate, using a free-space for responding, what they considered was the biggest concern or worry for children and young people in out-of-home care.

Finally, ten short-answer questions were asked to determine what health and well-being meant for these young people, what support and information they needed, and in what way would they have liked to be involved in decision-making. The questions (excluding the questions from the WHO-5) were developed and written by the Children in Care Collective and the CREATE Foundation² (see Appendix A for a list of all questions).

Procedure

Young people from the *clubCREATE*³ member database who were placed in an out-of-home placement affiliated with the Children in Care Collective were contacted by telephone and email over a three week period and invited to participate in the consultation. Young people could answer the consultation questions over the telephone with a CREATE staff member ($N = 8$ participants) or answer the questions online ($N = 18$ participants). As most young people opted for completing the survey online, this might have limited the richness of the data, but enabled more young people to respond at a time convenient for them. It also might have meant the responses were less likely to be influenced by socially-desirably responding. Consultations over the telephone with a CREATE staff member were recorded verbatim to retain the authenticity and integrity of their views. A written record was available from the online respondents. Thus, the quotes contained in this report were taken directly from the voices (both oral and written) of the children and young people.

To protect the identities of the young people involved, quotations are attributed to the young person using sex and age. The consultation was conducted in accordance with the *CREATE Consultation with Children and Young People* and *CREATE Disclosure* policies. Information about the consultation, including information about consent, confidentiality, and the right to withdraw at any time without negative consequences, was provided at the beginning of each telephone call and/or in a downloadable information sheet that could be accessed at any time on the CREATE Foundation website. Informed consent was obtained from the young people and their carers (either obtained in written form or recorded by the interviewer). Young people were provided with a \$25 gift voucher in recognition of their time and effort.

² See end-page for details on the CREATE Foundation.

³ All children and young people who participate in CREATE events and programs are invited to join *clubCREATE*, which entitles them to receive additional invitations to special events, regular magazines, birthday cards, and to be consulted on issues relevant to their life in out-of-home care.

Data Analysis

Data analysis involved statistical analysis of the quantitative data and thematic analysis of the qualitative data. Quantitative analysis included calculating frequencies and percentages of numerical responses. Responses to the WHO-5 were transformed and totalled; and an alpha reliability coefficient and summary data (e.g., mean and standard deviation scores) were calculated. Thematic analysis of the qualitative data used an inductive grounded-theory approach, which allows for categories and concepts to emerge from the young people’s responses, rather than being informed by previous research (Breckenridge & Jones, 2009). In some open response questions, young people were able to mention several points in one answer; therefore, the number of comments can exceed the number of respondents. The coding, categorising, and interpretation of themes were assisted by having two researchers examine the data independently.

Findings

Being Healthy

A total of 79 comments were made when young people were asked what they thought a person needed to do to be healthy. Most frequently young people commented about needing to have a healthy diet (23 comments) and engage in physical activity (21 comments, 15 mentioning the need for “exercise”; see Table 2).

Table 2
What a Person Needs to be Healthy

THEMES	TOTAL	Percent
Nutrition	23	29.1
Physical activity	21	26.6
Mental health	18	22.8
Support and connection	8	10.1
Personal hygiene	6	7.6
Sleep requirements	3	3.8
TOTAL	79	100

Exercise, make good choices in what you eat. (Female, 12)

Like eat healthy foods and run around a lot and be active. Have enough sleep and drink lots of water. And be happy is pretty healthy. I think that is pretty much it. (Female, 12)

Comfortable bed, vegetables, toothbrush, exercise, laughter, and also a good family. (Male, 12)

This is consistent with responses made by children and young people in a New Zealand study (Wright & Burrows, 2004), who commonly mentioned nutrition (e.g., “eating fruit”; “healthy food”, “balanced diet”) and exercise (e.g., “do some more running”; “getting more fit”) when asked what was needed to be healthy. Similar responses were given by children and young people in the Australian Child Well-being Project (2016); they described exercise, eating healthy food, and generally looking after oneself as important for having good health.

Thematic analysis identified that mental health was also considered important for being healthy, with more than 20% of the comments ($N = 18$) mentioning mental health or strategies specific for looking after their mental health, such as laughing, limiting screen time, and having a balanced lifestyle.

Taking care of themselves mentally. (Female, 15)

Be mentally happy. (Male, 13)

Other comments related to having positive and supportive relationships, and maintaining personal hygiene and sleep requirements.

It depends what type of healthy is being asked for but in terms of physical health, a balanced diet and regular physical activity. Emotional health can involve having someone to talk to and having someone listen to anything that's on your mind and support you no matter what the circumstance. (Female, 17)

Probably do some sport each day, read books, eat healthy stuff, brush your teeth two times a day, put deodorant on, change regularly, have a shower, change your socks and that. (Male, 15)

Well-being

When asked what “well-being” meant to them, young people made a total of 34 comments, half as many compared to when asked about being healthy. The two most frequently mentioned individual words describing well-being were “happy” and “healthy”. All comments were phrased in a positive (e.g., “being happy and healthy”) or neutral (e.g., “your mind, your body, and yourself”) way. There were no comments describing the absence of something negative.

Well-being means the happiness of one's life. (Male, 15)

Being happy and healthy. (Female, 16)

Thematic analysis identified that the most frequently commented on theme was mental and emotional health (15 comments; see Table 3). This theme included general descriptions about mental health as well as comments about feelings (e.g., “being happy”). These views were similar to those shared by young people in out-of-home care in the USA (Kelly et al., 2019) who reported mental and emotional health as important to their sense of well-being, specifically commenting on emotional regulation and self-care strategies and activities.

Table 3
The Qualities of Well-being

THEMES	TOTAL	Percent
Mental and emotional health	15	39.5
Being physically healthy	9	23.7
Generally having all needs met	8	21.1
Positive placement	3	7.9
Cultural/spiritual needs met	2	5.3
Choices	1	2.6
TOTAL	34	100

Other themes identified included being physically healthy (e.g., “physically well”, “keep fit”), having all their needs met and generally “doing well”, being in a positive placement, having their cultural and spiritual needs met, and having choices.

Like, if you are ok. If you are doing well. What they look like, what they are doing, how they are doing it. (Female, 12)

Being happy, comfortable and healthy in your placement (Female, 14)

It means that all of the factors of your life are met. You are happy, you are healthy, if you have cultural needs or want to go to church and stuff you have all those factors met. And spiritually and stuff. (Female, 17)

When asked the question, “Thinking about the future, what would a good and happy life look like to you?”, more than one third of the comments by young people referred to having positive relationships (30 comments; see Table 4). Positive relationships included having strong connections with their family (as defined by them, including biological and/or foster family members), friends, potential future spouses and children, and pets.

Table 4
A Good and Happy Life

THEMES	TOTAL	Percent
Positive relationships	30	38.5
Security/independence	16	20.5
Rewarding/meaningful work	12	15.4
Healthy and well	12	15.4
Enjoyable activities	7	9.0
Feeling safe	1	1.3
TOTAL	78	100

The life that I am living right now basically, if that continues. I like the family that I'm with, I'd like to stay with them. The people I'm around, the things we do together. (Female, 12)

Living near the beach near my family so I can still like drive down and visit them and have a happy and healthy family. (Female, 15)

Being near friends and family that support you and being near nature - working with it and working with animals. (Male, 13)

Young people also commented on being secure and financially independent. This theme included statements about having a stable job, being financially secure, and having food, a house, a car, and nice clothes.

Having my career sorted with a healthy and stable income, being able to afford any bills present and being happy within myself and my job. (Female, 17)

It would be the same as now but with a bit more independence and more puppies! (Male, 15)

In addition to comments about having a stable and financially secure job, young people made comments about the type of the work in which they wanted to be employed (e.g., “working with animals”, “a nurse”) and how they wanted to feel about their job (e.g., “a good job that I love”), indicating that engaging in meaningful and interesting work contributes to their living a good and happy life.

Other comments by young people identified that being healthy and well, engaging in enjoyable activities, and being safe contributed to a good and happy life.

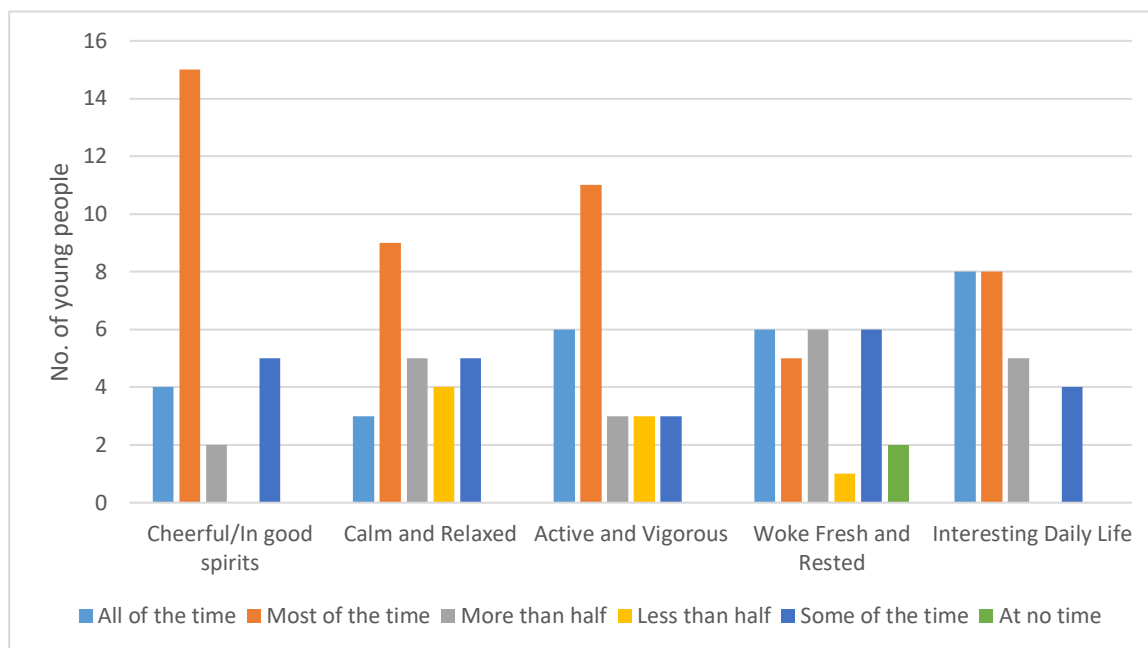
A happy life in the future would look like where I could do activities, when I'm eating healthy and I'm feeling good, and I dress well and my outfits are good, and I'm getting along with everyone. (Female, 12)

Having fun, playing games, laughing and being happy with the people who love you. (Female, 13)

Well-being Ratings

For the individual WHO-5 scale questions, more than 70% of young people rated that they were cheerful and in good spirits over the past two weeks *most of the time* or *all of the time* (see Figure 1). In addition, more than 60% rated that they had felt active and vigorous and that their daily life was filled with things that interested them *most of the time* or *all of the time*. While there was more spread across the ratings for feeling calm and relaxed and waking fresh and rested, more than 60% rated *more than half the time* or more to these two items.

Figure 1
WHO-5 Ratings



The WHO-5 Well-being index ranges from 0 to 100 (the highest level of well-being possible). Respondents in this consultation scored 67, which can be compared with the Danish population reported by Topp et al. (2015) as having a WHO Well-being index of 70. Christensen et al. (2015) reworked the WHO-5 index in their study of 294 young people (14 – 16 years) in Denmark and Norway, 46 of whom were experiencing depression. After reflecting (reversing) the scale item scores (to allow for comparison with other measures they were using in their study), these authors found that their mean index score for the non-depressed group was 7.3 ($SD = 4.4$); by comparison, their depressed group scored 15.2 ($SD = 4.7$). Using the same measure, respondents in the current consultation scored 8.3 ($SD = 5.7$). This result in the present consultation was not significantly different from the non-depressed groups, but was significantly lower than the score for the depressed group.⁴

In addition to the WHO-5 questions, young people were asked how concerned or worried they were in relation to any health or well-being issues, and how supported they felt in relation to their health and well-being. Most frequently young people reported that they were not at all concerned with any health or well-being issue (57.7%) and that they were very supported (76.9%; see Figures 2 and 3, respectively). Of those young people who reported being worried or concerned about a health or well-being issue, three young people reported that they were worried or concerned about coronavirus. Other concerns identified were allergies, asthma, anxiety,

⁴ $t(69) = 5.48, p < .001$.

depression, family members' health, and completing Grade 12 (one comment each). Another young person commented about being worried or concerned about the needs of children in care being met.

Figure 2

How Concerned or Worried Young People Are at Present with any Health or Well-being Issue

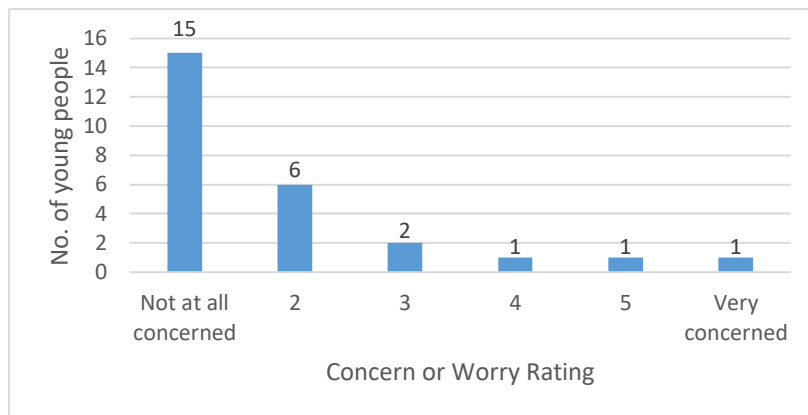
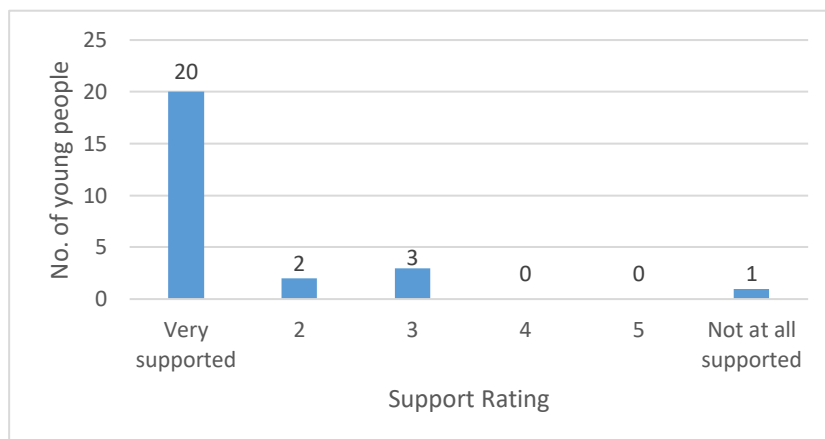


Figure 3

How Supported Young People Feel in Relation to their Health or Well-being



WHO-5 scores were associated negatively with young people's ratings of how concerned or worried they were with any health or well-being issue (greater well-being related to being less concerned or worried; $r = -.68$; $p < .001$) and positively with ratings of support (greater well-being related to more support; $r = .67$; $p < .001$). However, these relationships need to be interpreted with caution, given the small sample size and skewed distributions.

Important Factors for Feeling Healthy and Well

Young people were asked what they thought was the most important factor that could lead to children and young people in out-of-home care feeling healthy and well. More than 40% of the comments indicated that relationships were the most important factor for being healthy and well (see Table 5). This is consistent with their statements about what a good and happy life looked like to them, with young people most frequently mentioning that a good and happy life included having positive relationships. Young people with an out-of-home care experience in the UK and the USA also identified relationships as important to their sense of well-being (Kelly et al., 2019; Selwyn et al., 2018).

Having people who love you and care for you. (Male, 16)

Great support network of friends and family. (Female, 16)

Having a good family that loves them and that they are getting a good amount of visits with their biological family and that if they don't want to see family members they don't have to. I would also recommend if the child has siblings that they stay with at least one of them. (Male 12)

Communication with carers, having good and healthy relationships. (Female, 15)

Table 5
Important Factors for Being Healthy and Well

THEMES	TOTAL	Percent
Positive/support relationships	20	42.6
Being active and healthy	12	25.5
Enjoyable activities	4	8.5
Safety	4	8.5
Placement	3	6.3
Being happy	2	4.3
Other	2	4.3
TOTAL	38	100

A quarter of the comments by young people indicated that lifestyle factors were the most important factors for being healthy and well.

Healthy food and [being] active. (Female, 16)

Having an active lifestyle, not eating too much KFC, being around people that you like. (Male, 15)

Giving fruit, meat, vegetables, and outdoor activities. (Female, 14)

Other comments related to engaging in enjoyable activities, feeling safe, having a stable and happy placement, and being happy.

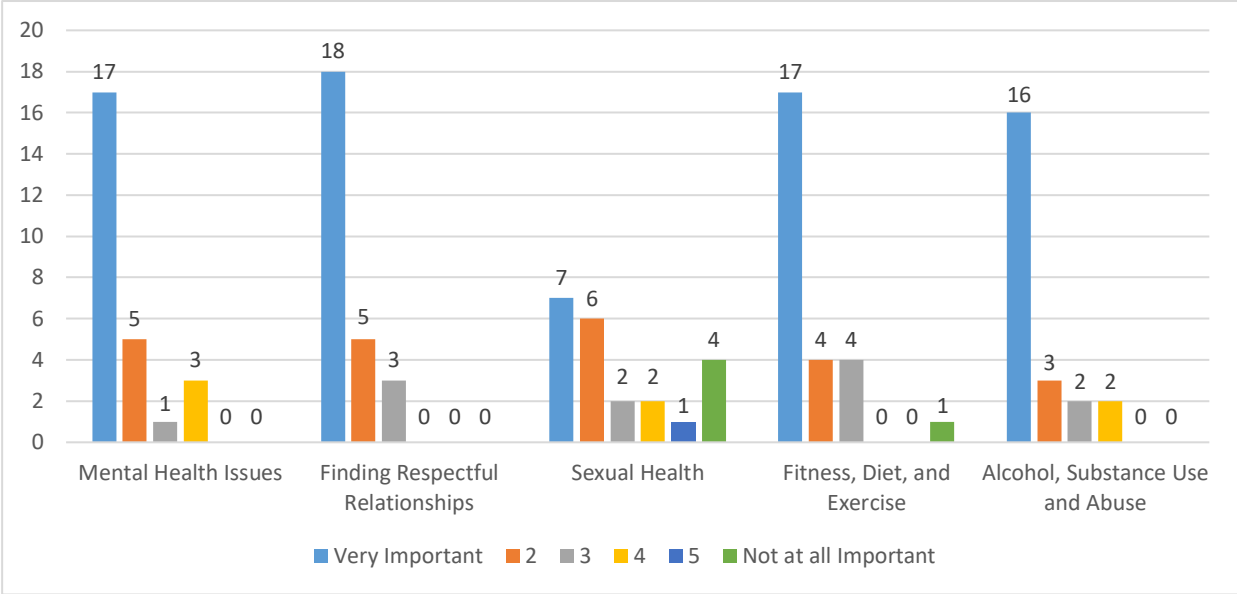
[Being in] a home that is well looked after and a home where you can have enough sleep and where you can enjoy yourself and do activities, like play board games and stuff like that. A home that keeps you safe. (Female, 12)

One young person commented that she thought “knowing your story” (Female, 13) was important for the health and well-being of children and young people in out-of-home care. In the qualitative component of the *Our Lives Our Care* study (Selwyn et al., 2018), young people also raised the importance of having the reason for care explained fully. Finally, one young person commented that he thought “never giving up” (Male, 12) was the most important factor for the health and well-being of young people in out-of-home care. Statements about self-agency and persistence have been made by other young people with whom CREATE have consulted when asked what they would like to tell other young people in out-of-home care (e.g., “Never give up on your dreams. You can do it. You can’t have a rainbow without a little rain”; CREATE, 2018, p. 11).

Young people were also asked to rate several topics associated with being healthy and well in terms of how important they thought each issue was for young people in out-of-home care. The issues that they rated were mental health issues, finding respectful relationships, sexual health, fitness, and alcohol and/or substance use and abuse. Most frequently, young people rated the importance of all health and well-being topics as *very*

important for young people in out-of-home care (see Figure 4). While this was true for the topic of sexual health, fewer young people chose to rate this topic ($N = 22$); there was more spread across the ratings, and more young people rated this topic as *not at all important* compared to other topics.

Figure 4
Ratings of Importance for Young People in OOHC



Young people also were asked a follow-up question for each topic, seeking their thoughts as to what were the biggest concerns or worries for young people in out-of-home care generally. The main themes and issues for each topic identified are presented in Table 6.

Table 6
Biggest Concern or Worry

THEMES	TOTAL	Percent
Mental Health Issues	30	29.1
Specific mental health issue or concern	10	33.3
Emotional health	9	30.0
Access to help and support	8	26.7
Relationships	3	10.0
TOTAL	30	100.0
Respectful Relationships	23	22.3
Quality	13	56.6
Attainment	9	39.1
Bullying	1	4.3
TOTAL	23	100.0
Sexual Health	8	7.8
Readiness	4	50.0
Being educated	2	25.0
Access to support	1	12.5
Abuse	1	12.5
TOTAL	8	100.0
Fitness	29	28.2
Maintaining a healthy lifestyle	8	27.6
Barriers to being healthy	8	27.6
Weight	8	27.6
Psychological aspects	5	17.2
TOTAL	29	100.0
Alcohol/Substance Use and Abuse	13	12.6
Consequences of use and abuse	6	37.5
Precipitating factors	4	25.0
Abstinence	2	12.5
Access to support and help	1	6.3
TOTAL	13	100.0
TOTAL of COMMENTS	103	100.

Mental health issues. For mental health issues, most frequently young people commented on a specific mental health or emotional health concern (see Table 6). The most common mental health concern mentioned was depression (four comments). Others included being bullied, self-harm, and suicidal thoughts. The most common emotional health concern was in relation to young people in care feeling different (three comments). Other comments included feeling alone, sad, worried about the unknown, and not knowing their life story.

It's extremely important! You know... if someone has suicidal thoughts and are not feeling good about themselves. (Male 14)

Them not feeling like they know their life story, them being sad and feeling alone in the world. (Male, 13)

Access to help and support was mentioned in eight comments. These comments highlighted how vital young people thought it was for children and young people in out-of-home care to be able to access the help and support they need.

That every child gets the help that they need (Female, 13)



Making sure we get the help needed (Male, 13).

Several young people commented on previously needing help or support and not being able to find it.

In the past I experienced depression and felt like I did not belong as my caseworker was not supportive (Female, 16)

Nobody would listen to me before I found my forever home (Male, 12)

Access to help and support was mentioned as an important issue for several health and well-being topics, with young people making comments about being able to access support in relation to sexual health and alcohol/substance use and abuse issues as well.

Some comments indicated that the biggest concern for young people in relation to mental health issues was the relationships in their lives. These comments were particularly focused on family contact (e.g., “not seeing their real parents”).

Respectful Relationships. Comments about respectful relationships were predominantly about friends and romantic relationships. Most frequently, comments were in relation to the quality of their relationships, such as being able to build respectful and trusting relationships with friends and potential partners, and being able to feel comfortable, understood, loved, and supported within these relationships.

Very important because you don't want to be in a one-sided relationship. (Male, 15)

Maybe the other person won't respect you. (Male, 13)

Probably first meeting them - you don't know what they are like and you have to build trust and get to know them. (Female, 12)

Other comments identified that young people were concerned about attaining and/or cultivating respectful relationships.

To choose friends wisely. (Male, 12)

Maybe that they won't have [a respectful relationship]. (Female, 17)

One young person also mentioned bullying as the biggest concern for young people in relation to respectful relationships.

Kids and teenagers get bullied every day and having some friends and classmates to help them and protect them is something very important. (Male, 12)


Sexual Health. Sexual health had the smallest number of comments out of all the health and well-being topics, with a total of eight comments. Half of these were in relation to readiness.

Both people need to be ready. (Female 14)

Making sure it's the right decision (Male, 13)

Other comments were in relation to young people in out-of-home care being informed and receiving adequate sexual health education, having access to support, and “sexual abuse.”

I worry that a lot of teenagers in care are oblivious to sexual health and any aspects of sexual life in terms of how it can affect us. (Female, 14)



Maybe if they are sexual, that they don't trust their carer to talk to them about it.
(Female, 17)

Fitness. Four themes were identified from the comments in relation to the biggest concern or worry for young people in out-of-home care regarding fitness: Maintaining a healthy lifestyle, barriers to being healthy, weight, and psychological aspects. Four comments under the theme maintaining a healthy lifestyle were in relation to exercising. Nutrition and being healthy or unhealthy were also mentioned:

It is important for everyone to be healthy regarding fitness and food. (Female, 14)

You might not eat what you need or go out enough. (Male, 13)

Barriers to being healthy included comments about sedentary lifestyles, medication, lack of enjoyment, and a limited education in relation to how to have a healthy lifestyle.

Well kids just sitting down and hardly doing any sport or not doing any sport at all.
(Male, 15)

Feeling tired. (Male, 16)

I don't like running and walking and lifting. (Male, 12)

Medication which makes me hungry, but I try my best to contain it. (Male, 12)

Children in care are being allowed to do whatever they want, which is therefore not teaching them the correct ways to go about having a healthy lifestyle if that is what is wanted in the child. (Female, 17)

Weight was mentioned predominantly by girls, although raised by both genders. Being overweight and being underweight were both possibilities for concern (e.g., “being too big or being very skinny”). Five comments mentioned psychological aspects, such as body image, body ideals, fitting in, and bullying.

People can die and be bullied because they are overweight. (Male, 12)

Not acting very differently [to how] other people act and not looking [differently to how] other people look. (Female, 12)

Alcohol and/or Substance Use and Abuse. As with comments about sexual health, fewer comments were made in relation to alcohol and/or substance use and abuse (13 comments). Young people's general perception of alcohol and/or substance use and abuse appeared to be that it was negative and should be avoided. Most frequently, comments were in relation to worries about the consequences of using and abusing alcohol and/or other substances (e.g., getting into trouble for under-age drinking, getting drunk and getting hurt, and addiction). Other concerns or worries identified by young people included: precipitating factors to alcohol or substance use or abuse (such as a lack of information, underlying life difficulties, genetic components to addiction, or access), child safety issues, abstinence, and support.

Kids can be hit and abused and that is a major reason kids get put into car. (Male, 12)

Making sure to stay away from it all. (Male, 13)

People with problems need help as they can get aggressive or breakdown. (Female, 14)

Obviously, that means they are not living a good life, they might not be fitting in with the crowd at school, they might not get treated like other kids do. (Female, 12)

A lot of cases of children in foster care stem from substance or alcohol abuse and can impact the child in multiple ways. (Female, 17)

Support and Information

Support. When asked what carers and health care workers can do to help young people with their concerns or problems in relation to the topics discussed above, most frequently young people made comments about carers and health care workers communicating with young people and providing support and information (22 and 20 comments, respectively; see Table 7).

Table 7
What Carers or Health-Care Workers Can do to Help

THEMES	TOTAL	Percent
Communicate with young people	22	39.3
Provide support and information	20	37.5
Quality of communication	6	10.7
Link with counselling/specialist services	5	8.9
Other	3	5.4
TOTAL	56	100

The theme communicating with young people included comments about talking to young people, asking them what they want or need, listening to them, trying to understand them, and ensuring that young people know they can talk with them.

To stay connected and listen to your children. (Male, 12)

Sit down and talk to them. Just talk with them. (Female, 15)

They could listen to child and asked what child wants and need. (Female, 15)

Listening and talking. Offer help and advice. And like someone going with me to the doctors. (Female, 12)

The theme provide support and information predominantly included general comments about providing support and information. Some young people made suggestions regarding who might need support, and the type of support and information that might be helpful.

Listen to us, support us and give us information. (Male, 12)

Talk to them, provide help and resources. (Female, 14)

Help support kids who are a part of the LGBTQI+ community. (Male, 12)

Like someone going with me to the doctors. (Female, 12)

Suggest places for them to go and get some help with their problems. (Male, 12)

Just be there to listen to them at all times and support and assist the children as much as they possibly can. (Female, 17)

Young people also commented on the quality of the communication and the importance of building a relationship with young people (six comments); as well as potential specialists from whom young people could seek help if needed, such as psychologists or therapists.

I think they would have to make sure they are not being judged and they try their hardest to make them feel comfortable when talking with them. They could say that they won't tell anyone unless for their safety, and building up some sort of relationship first, talking about other things first sort of thing. (Female, 17)

Not get angry, but understand, speak calmly to them. Communicate and relate to them, as to not upset them and lead to trust issues. (Female, 15)

Three comments suggested that carers and health care workers could help young people with their concerns or problems by encouraging participation in after-school activities or hobbies, and supporting them in their placement (e.g., by arranging respite if needed).

When asked more generally what other supports would increase feelings of being healthy and well, young people commented on supportive relationships, with several comments reiterating the importance of good communication within these relationships (see Table 8).

Table 8
What Other Supports Would Increase Feelings of Being Healthy and Well

THEMES	TOTAL	Percent
Supportive relationships	7	41.2
Access to services	5	29.4
Healthy activities	4	23.5
Financial independence	1	5.9
TOTAL	17	100

They need people who understand them and who listen to them. (Female, 15)

Good communication. (Male, 13)

People around you, people at school, people that you know. (Female, 12)

Five comments were made about needing to have ample access to support services if needed.

More service[s] for young people in care. (Female, 16)

Children and young people in care need to be able to access additional health and educational supports as they often have some special needs. They need to have a supportive caseworker and family and friend network as well. (Female, 16)

Other comments indicated that being able to access sporting and other recreational activities would help increase their feelings of being healthy and well. One young person raised the financial costs in relation to sporting activities, indicating that how these activities were funded could play a role in how they feel about the activity, and themselves.

That [sporting activities] be paid for by the agency - we hate asking carers for stuff. (Male, 12)

Information. When young people were asked what information they thought would assist them to know their options for increasing their well-being, 21 comments were made suggesting topics they were

interested in or that they thought other young people with an out-of-home care experience might be interested in (see Table 9).

Table 9
Information That Would Assist Young People (N = 21 comments)

Specific Topics
Service type information <ul style="list-style-type: none"> - What all the doctors do - Where to go if I feel unwell - Who young people can talk to (x3 comments) - About services
General health and well-being information <ul style="list-style-type: none"> - Physical health education - Sexual education - Health and well-being strategies - Knowing all the options
Psychological strategies <ul style="list-style-type: none"> - Managing your workload - Bullying – how to deal with it; more support about it - Stress management strategies - Help them to feel like they belong - Identity
About Nutrition <ul style="list-style-type: none"> - To know about the right foods - Eating styles
How to keep myself safe
Information about biological family
Reasons for being in care

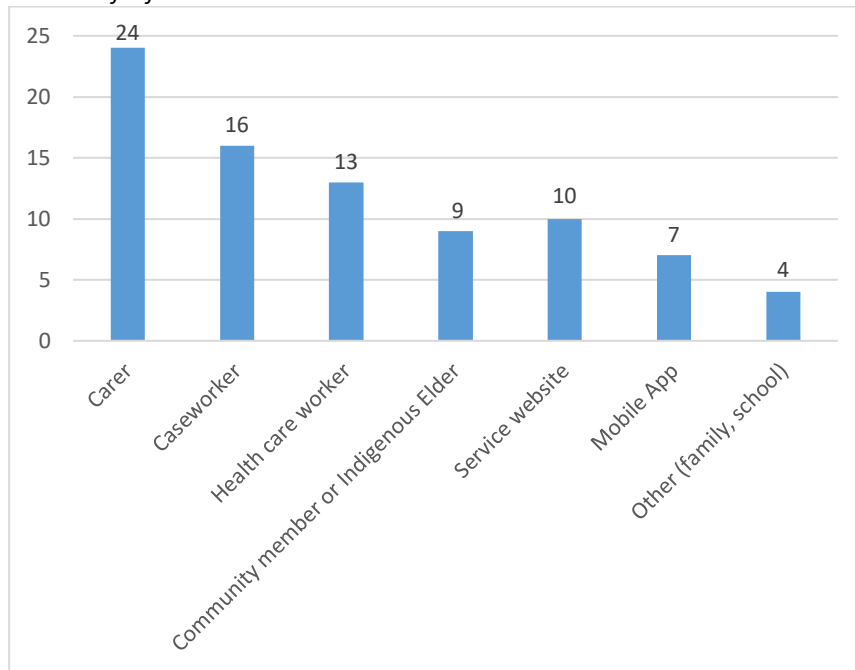
Three young people suggested possible formats for providing information. These were educational classes run by schools, agencies, or the department, online webinars or online communication with health professionals and other support services, and a mobile application.

An app I can use and log things for myself that I can share with my carers so we can do it together.
(Male 12)

Young people also commented about the people who typically provide them with information and those that they thought could provide information to other young people with an out-of-home care experience. These included carer/mum; caseworker; counsellor; and health worker or other community member.

Sources of Information. Young people were asked a specific question about who they would go to or where they would go to access information about their health and well-being. Most frequently, young people indicated that they talked to their carer (see Figure 5). About 50% also indicated that they sought information in relation to their health and well-being from their caseworker or a health care worker.

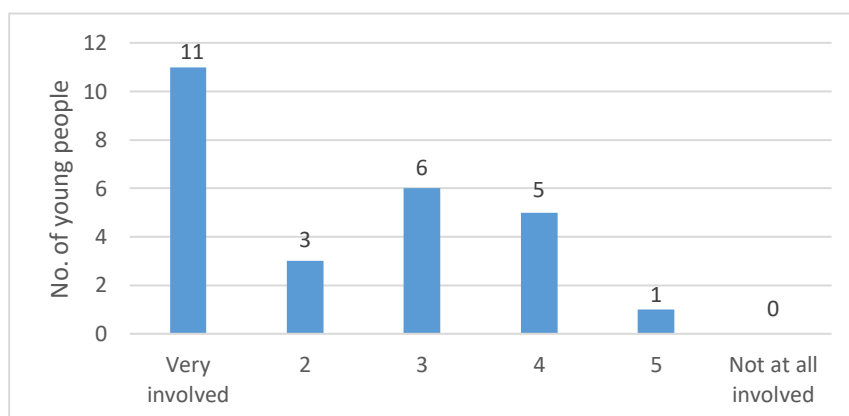
Figure 5
Sources of Information



Involvement in Decision-making

Numerous studies have indicated that participation in decision-making is important for the dignity and self-worth of young people, as it helps create better outcomes and aids in the promotion of respect for children (Bessell, 2011; Cashmore, 2002). However, Bessell (2011) noted that there have been difficulties translating policies into practice in this area. In the current consultation, more than 50% of young people indicated that they felt involved or very involved in the decisions being made about their health care. However, 23% of young people indicated a low level of involvement, indicating that improvements are needed in this area (see Figure 6).

Figure 6
Involvement in Decision-Making



Thirty-nine percent of young people wanted to be more involved in decision-making about their health and well-being. When asked how they would like to be involved, seven comments were made in relation to young people wanting to make their own decisions about their health, two comments were in relation to having improved communication (e.g., being informed about their choices and being “listened to”), and one comment

was in relation to wanting to move towards independence by starting to organise their own appointments (see Table 10).

Table 10
Involvement in Decision-Making

THEMES	TOTAL	Percent
Ideas for how they would like to be involved:	10	38.5
- Make own decisions	7	
- Effective Communication	2	
- Other	1	
Involved as much they would like to be	6	19.2
Other	1	7.7
Don't Know	9	34.6
TOTAL	26	100

Let me make decisions about what I want to do. (Male, 12)

Let me know what the decisions are so I can decide. (Male, 15)

Making my own decisions. (Female, 15)

Six young people commented that they were happy with their current level of involvement; however, nine young people indicated that they did not know how they would like to be involved in decision-making about their health care. This high number of “I don’t know” responses could be due to the fact that the sample of young people in this consultation reported high involvement in relation to decisions being made about their health and well-being already (see Figure 6); however, it could indicate a potential area for providing support and information in relation to options for involvement. One young person commented:

Oh, I haven't been very involved. Not much I can do. I don't think it could be improved. (Male, 15)

Limitations

This consultation reported results from a small number of young people with an out-of-home care experience in NSW ($N = 26$). This is a small proportion of young people with an out-of-home care experience in NSW (as at 30 June 2019, there were 19,342 children and young people in out-of-home care in that State; AIHW, 2020). While the aims of qualitative research are to understand the experiences and perceptions of participants, and not to generalise to all young people, the diversity of the sample was limited in terms of placement type (no young people reported living in a residential care placement). Previous studies have shown that young people with a residential care experience are more likely to have lower ratings of well-being, poorer health, less support accessing health care services, and less opportunity to participate in decisions being made about their lives (Llosada-Gistau et al., 2019; McDowall, 2013; 2018; Schütz et al., 2015).

This consultation was conducted during the early stages of the COVID-19 global pandemic. During that time, there was considerable media coverage in relation to Covid-19 and its impacts worldwide; and the Australian Government was in the process of enacting social distancing requirements for the Australian population. While only three young people specifically mentioned Covid-19 in the consultation, this might have affected how young people reported on issues about their health and well-being. Finally, while the consultation was designed to be an interview-style consultation, a large number of young people opted for completing the survey online (69%),

which limited the richness of data. Further research is needed to determine the prevalence of the views expressed and to explore these issues in more depth, particularly for young people in residential care placements.

Conclusion and Actions


It is critical that the voices, views, and experiences of children and young people are heard in all areas that are related to their care and support. The aim of the current consultation was to hear young people’s voices, opinions, and experiences in relation to health and well-being. In particular, young people described what health and well-being meant to them and what they thought was important in relation to health and well-being for young people with an out-of-home care experience. They also answered questions about the support, information, and involvement they would like in relation to their health and well-being needs.

Young people identified numerous factors important to being healthy and well, including being happy and having their needs met across multiple life domains. This is consistent with the definition of well-being as being multi-dimensional, and consistent with qualitative studies with children and young people with an out-of-home care experience in other countries, which also highlight multiple factors important for being healthy and well (e.g., Kelly et al., 2019; Selwyn et al., 2018). Positive relationships, in particular, were highlighted in these studies, and by young people in this consultation, as crucial to being healthy and well.

A compilation of the different aspects of well-being raised by the young people in the present consultation is presented in Figure 7.

Figure 7
Being Healthy and Well






The comments made by the young people in this consultation reflect the multiple dimensions typically regarded as aspects of well-being. Thus, when considering how to improve well-being of children in this population, narrowly focused interventions are unlikely to meet the needs of all children. Creating respectful relationships, dealing with mental health issues, developing and maintaining fitness, concerns about alcohol/substance use and abuse were all rated as very important by most young people; and other topics were raised including engaging in enjoyable activities, feeling safe, feelings of belonging, and enjoying stability in their placement.


Young people identified that high quality communication, the provision of information and support, and access to (and support to access) appropriate services were important in helping to meet their health and well-being needs; and that involvement in decision-making allowed young people to make their own decisions. This is consistent with other reports (e.g., CREATE, 2019a; 2019b) where young people with an out-of-home care experience in NSW (aged between 14 to 25 years) emphasised the importance of effective communication. In these consultations, young people highlighted the need for providing (a) opportunities for young people to talk about their health preferences and support needs, (b) age-appropriate information that is suitable for young people from diverse back-grounds, (c) opportunities for young people to consider their options, and (d) the chance for young people to make informed choices wherever possible. Further, open conversations, transparency, and allowing conversations to occur at the young person's pace were identified as important in the communication process.


Well-being ratings for young people in the current consultation compared favourably to a group of young people of similar age from Denmark and Norway (Christensen et al., 2015) and to average ratings for the Danish population (Topp et al., 2015). While the average ratings for well-being, support, and involvement for young people with an out-of-home experience in this consultation were generally positive, it is evident that there were some young people who gave low ratings for subjective well-being, support, and involvement in decisions. Many school and community resources exist to assist young people, including those in out-of-home care, to lead more fulfilling lives. Young people who are struggling would benefit if there were more effective ways of identifying them, of linking them to existing services, or of devising specific interventions to suit their specific needs.

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Appendix A: Survey Questions

Children in Care Collective

WHAT IS THIS SURVEY ABOUT?

This consultation is designed to give children and young people in out-of-home care in NSW and ACT an opportunity to have a say about how they perceive health and well-being, particularly regarding what concerns they may have and how they could be more supported to be healthy and well.

INSTRUCTIONS ON HOW TO COMPLETE THIS SURVEY

Please answer all questions and leave comments where applicable. You can click through the sections by clicking "Next" at the bottom of the screen. At the end of the survey click the "Done" button.

OTHER IMPORTANT INFORMATION

Before you begin, we would like to remind you of a few things:

- Doing this survey is completely voluntarily. You can stop doing this survey at any time and this will not affect you joining in with any other CREATE events and activities.
- You can skip questions if there is a reason you would rather not answer them; however, we at CREATE hope that you will want to share as many of your views as possible.
- Everything you tell us in this survey will be kept confidential (this means private) unless you tell us something that makes us concerned for your safety or for the safety of another young person in care, then we may have to tell someone.
- You can have a support person help you with the survey if you would like.
- We may use the information gained from the survey for reports and presentations but we will NEVER use your name. You will be anonymous in these reports.

Having understood the above information, by continuing with this survey you are giving your consent to participate.

For more information on consultation participation, you can refer to [CREATE's website](#), or ask your local CREATE Office (1800 655 105) for a Consultation Participation Information Sheet.

* 1. What method are you using to complete this survey?

- Online Independent Face-to-face interview
- Online as a group (with a staff member) Other (e.g., hard copy)
- Telephone interview

* 2. In what state or territory do you live?

3. What is your post code?

* 4. How old are you?

5. I identify as:

- Female
- Male
- I identify with another gender

Please specify:

* 6. Culturally, I identify as:

- Aboriginal Other Cultural Group (non-English speaking background)
- Torres Strait Islander No specific group
- Both Aboriginal and Torres Strait Islander

If "Other Cultural Group", please specify:

7. How old were you when you came into care?

* 8. What type of placement do you live in?

Please select only one.

- Foster care Permanent care
- Kinship care Semi-independent supported accommodation
- Residential care Independent living
- Other (please specify):

9. About how many placements have you had while in care?

- 1-2 7-8
- 3-4 9-10
- 5-6 More than 10

10. Do you have a disability?

- Yes
- No
- Prefer not to say

If you answered yes, what type of disability or impairment do you have? Please describe in your own words.



11. If you answered yes to the above question, are you receiving special support for your disability? This could include medication, special education, counseling, etc.

Yes

No

Any comments?



12. What do you think a person needs to do to be healthy?

13. What does "well-being" mean to you?

14. Please indicate for each of these statements which is closest to how you have been feeling over the past two weeks

	All of the time	Most of the time	More than half the time	less than half the time	Some of the time	At no time
I have felt cheerful and in good spirits	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have felt calm and relaxed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I have felt active and vigorous	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I woke up feeling fresh and rested	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
My daily life has been filled with things that interest me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

15. What do you think is the most important factor that could lead to children and young people in out-of-home care feeling healthy and well?

16. How concerned or worried are you at present with any health or well-being issues?

Not at all concerned Very concerned

17. To follow on from the question above, if you have concerns or worries, can you briefly explain?



18. How supported do you feel regarding your health and well-being?

Not at all supported Very supported

19. Thinking about the future, what would a good and happy life look like to you?

Children and young people can have difficulties in a variety of areas. Using the 6-point scale, show how important you think the following issues might be for young people in out-of-home care.

For each, please also tell us what you think is the biggest concern or worry for children and young people?

20. Mental health issues

Not at all important Very important

21. Biggest concern or worry regarding mental health issues -

22. Finding respectful relationships

Not at all important Very important

23. Biggest concern or worry regarding finding respectful relationships -

24. Sexual health

Not at all important Very important

25. Biggest concern or worry regarding sexual health -

26. Fitness (diet/ exercise)

Not at all important Very important

27. Biggest concern or worry regarding fitness (diet/ exercise) -

28. Alcohol/ substance use and abuse

Not at all important Very important

29. Biggest concern or worry regarding alcohol/ substance use and abuse -

30. What could carers and/ or health-care workers do to help children and young people when dealing with these issues?

31. What other supports would help increase your feelings of being healthy and well?

32. We know that giving children and young people choices and involving them in decisions about their health care is important.

How involved do you feel you have been in decision-making about your health care?

Not at all involved Very involved

33. How would you like to be involved in decision-making about your health care?

34. We are interested in what information children and young people need so that they can understand who to speak to or where to get more information about the supports or services they feel they need.

What information would assist you to know about options for increasing your health and well-being?

35. Which of these sources would you go to find this information (select as many as relevant)?

- Carer
- Caseworker
- Health-care worker
- Community member, including Indigenous Elder
- Service web site
- Mobile App
- Other, please give details -

36. Is there something else you would like to share about the health and well-being of children and young people in out-of-home care?

Thank you for completing this survey. To allow CREATE to use your responses in our final report you will need to provide us with your consent. To do this, please copy and paste the link below into your web browser and fill in the details.

https://www.surveymonkey.com/r/Consent_and_Voucher_Health_and_Well_Being

To say thank you for the time and effort you have taken in answering these questions, we would like to give you a \$25 gift card. If you would like to receive a gift card, the link above will ask you to provide your postal address and contact details. If you do not want a gift card, you can simply select no.

Please be sure to submit your responses before you leave this page by clicking the "DONE" below.

If you have any questions about the survey, or if you would like to know more about what CREATE does for children and young people in out-of-home care, contact your local CREATE Office on 1800 655 105



About CREATE

CREATE Foundation is the national peak consumer body for children and young people with an out-of-home care experience. We represent the voices of over 45,800 children and young people currently in care, and those who have transitioned from care up to the age of 25.

Our vision is that all children and young people with a care experience reach their full potential.

Our mission is to create a better life for children and young people in care.

To do this we:

- **CONNECT** children and young people to each other, CREATE, and their community, to
- **EMPOWER** children and young people to build self-confidence, self-esteem, and skills that enable them to have a voice and be heard, to
- **CHANGE** the care system, in consultation with children and young people, through advocacy to improve policies, practices, and services, and increase community awareness.

CREATE achieves its mission by facilitating a variety of programs and services for children and young people in care and developing policy and research to advocate for a better care system.

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