Evidence Brief Two:

The Experiences and Needs of Young Carers in Aotearoa/New Zealand

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Preamble

The current evidence brief serves as a follow-up from *Evidence Brief One: Understanding the Needs of Young Carers* (Donnan, 2014), which provided an overview of the predominantly international body of young caregiving research. The key themes stemming mostly from international literature outlined in the existing evidence brief remain largely unchanged, as the overarching premises regarding the experience of being a young caregiver internationally have remained consistent. As such, the researcher chose to focus on the voices of NZ young caregivers in the current brief – as ascertained in the author's PhD research – in order to provide greater understanding of the experiences and needs of NZ young carers. In doing so, the brief provides some new insights into the experience of being a young carer not discussed in existing research, and which are unique to the NZ young caregiving context. Consequently, additional literature is included only where it provides additional context to the NZ findings from the present research.

Acknowledgements

The researcher would like to acknowledge each of the incredible current and former young carers, and service and agency representatives, who shared their stories for the purpose of bringing about change for children and youth providing care in NZ. Whakawhetai ki a koe. My gratitude to you.

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Key Points

Young carer definition

- For the purposes of this brief, a young carer is a child or youth aged up to 25 years who provides significant, ongoing support for someone with a disability, illness, injury, substance misuse, mental illness, or who is an older person requiring assistance with everyday living.

Research participants

- The research included a total of 39 participants, of whom 28 were NZ young carers, seven international young carers, and four young-carer-related service and agency representatives.
- Young carers in the present research are most commonly females aged 6-12 years old providing domestic, emotional/spiritual, intimate, and nursing support for a time period of at least five years for a family member who has a chronic or mental illness.
- Young carers in this study are most likely delivering care in their familial South Auckland homes, within a family/whānau unit struggling to make ends meet and who are thus in receipt of formal financial benefits.

NZ young carers' experiences and needs

Young carers identified four key areas of impact for their time providing care and their life after caregiving.

1. Education

- Young carers stated that they both enjoyed and wanted to attend school, and highlighted the importance of their time in the classroom as a form of respite, positive affirmation, stability, and normality.
- Caregiving during childhood and adolescence negatively effected children and youth's participation, academic achievement, and enjoyment of school.
- Young carers said that they would benefit from an understanding of young caregiving among teachers, assistance with goal setting and future-planning, and impartial counselling providing them with a safe, non-judgemental space at school to talk through their worries and concerns.

2. Socialisation

- Young carers spoke to feeling isolated and lonely due to a lack of time to socialise and their feelings of being different to their similarly aged peers, which resulted in the participants' inability to form deep friendships.
- Participants said that they would have profited from the chance to identify as a young caregiver, the opportunity to meet and form bonds with other young carers, to have respite opportunities, and a greater awareness of young caring among their peers.

3. Health and wellbeing

- All young carers experienced significant and unaddressed grief throughout their time caregiving that had long-term mental-health and relational impacts.
- Specifically, participants experienced non-finite loss in their loved one's gradually declining abilities, in the absence of a 'normal' childhood experience, and in their deviation from their anticipated educational and vocational pathways.
- Participants said that they would benefit from information regarding the nature of their loved one's disability or illness, and on-going, consistent, and impartial grief counselling.

4. Service provision

- Participants did not utilize formalized services for several key reasons, including maintaining their care recipients' familial roles, the need for care based on love, caregiving being seen as a natural childhood role, the unsuitability of care staff, and previous negative service experiences.
- Young carers spoke to the need for greater awareness of young caregiving among key healthcare and social services stakeholders, and holistic, consistent, individualised service provision aimed at empowering care recipients to maintain their familial and community roles.

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Appendices

Overview of Evidence Brief

The evidence brief is organised into three key components:

1. Young carer profile providing a demographic overview of the 28 NZ young carers involved in the study
2. Young carers' descriptions of their experiences in four key areas:
    - Education
    - Socialisation
    - Mental Health and Wellbeing
    - Service Provision
3. Young carers' expressed needs regarding policy and services, presented at the conclusion of each of the four key areas outlined above.

The brief privileges the voices of the 28 NZ young carers, but also includes insights from the seven international young carers and four service and agency representatives.

Background to the Research

Theory

The research was framed by the ideas of leading child development scholar Uri Bronfenbrenner (1979; 2005), in particular his bioecological systems theory, which focuses on the individual (young carer) within overlapping concentric circles of influence. It includes the context of the young carer's immediate *micro level* of face-to face interactions (e.g., with family and at school), as well as the *meso level* which considers interactions between micro levels, the nearby *exo-systems* that exist beyond the young carer's individual face-to-face experience (such as parent's workplaces or the actions of the local school's board-of-trustees), and the wider *macro level* that includes underlying belief systems and social and institutional environments in which all these interactions take place. It includes a focus on young carers' experiences during caring and in their transition to adulthood.

Method

The methods aimed to capture the experiences of young carers in their own voices. Reflecting the well-documented difficulties of accessing young carers, four initial methods for recruiting young carers were unsuccessful. Only three young carers responded to calls for participants that were included in 1) the researcher's monthly autobiographical column in Family Care magazine, 2) information sent via the Carers New Zealand database, 3) posters displayed at schools, universities, youth organizations and in the community, and 4) the researcher sharing her own experience of young caregiving to groups of young people.

Ultimately, the most successful recruitment method was a video posted on Facebook and other social media. The release of the five-minute video, which outlined the researchers' own young caring experiences and the aim of the research project and included animation to appeal to a younger audience, attracted the remaining 25 NZ young carers:

https://www.dropbox.com/s/pkxwqm8wk0ihzmr/Young%20Carers%20-%20Inspiring%20Stories%20Film%20Competition%20Entry-HD.m4v?dl=0

Overall, 39 participants took part in the research, including 28 NZ young carers, three representatives of NZ and one of international young carer-related services or agencies, and seven international young carers. The service or agency representatives and international young carers were recruited during the researcher's UK Visiting Researcher Fellowship in 2015, and across several international conferences.

Participants

Of the 28 NZ young carers:

- Four were current young carers, aged under 25 years at the time of interview
- 24 were former young carers, aged 25 years or older at the time of the interview, but who provided care for a loved one when they were aged under 25.

For detailed participant information, please see the Participant Demographic Tables in the appendices (p. 26).

Significance

The present research is significant for several reasons, as it:

- Appears to be the first NZ study to access young carers through assisting them to self-identify, rather than utilising social services agencies as gatekeepers;
- Includes the largest cohort of NZ young carers (n=28);
- Includes the most ethnic diversity of any NZ study, including the greatest number of Māori participants (n=6);
- Appears to be only the second study (c.f., Loose, 2004) to consider NZ young carers' transition to adulthood by including former young carers, and;
- Is the only NZ young caregiving study carried out since 2009 (McDonald, Cumming, & Dew, 2009).

This research provides invaluable up-to-date information on the experiences and needs of NZ young carers and fills in many of the gaps in existing NZ research by:

- Including participants of diverse backgrounds;
- Affording agency to young carers by accessing their own conceptions of their roles and support needs;
- Including young carers' conceptions of their transition to adulthood, and;
- Intends to contribute to relevant public policies and practices.

NZ Young Carer Profile

This page provides an overview of data pertaining to the young caregiving experiences of the 28 NZ young carers interviewed. For each bulleted area of interest, the brief offers further information and a corresponding table providing a statistical overview, located in the appendices.

Snapshot

Overall, NZ young carers in this study are more commonly:

- NZ/European (see p. 35)
- Female (see p. 35)
- Primary carers (see p. 34)
- Aged 6-12 years old (see p. 35)
- Who are the oldest female in their family/whānau unit (see p. 42).

Young carers are most often providing care for:

- One care recipient who is a family member (see p. 38)
- And most commonly the child's mother (see p. 38)
- Who has a Chronic- or Mental Illness (see p. 39)
- And who is struggling to carry out routine daily tasks (see p. 36).

Young carers are most likely delivering care:

- In their familial home (see p. 40)
- In South Auckland (see p. 40)
- In a household with three occupants (see p. 41)
- That is struggling to make ends meet and is thus in receipt of formal financial Benefits (see p. 43).

Young carers are most likely to carry out care:

- For a time period of at least five years, and past their 18th birthday (see p. 37)
- Through performing a range of tasks including domestic, emotional/spiritual, intimate, and nursing support (see p. 44)
- And commonly attend appointments with their care recipients and as such, are most likely to have been observed providing care by professionals (see p. 44).

Please note that the age at which each young carer's role began, the number of care recipients that they supported, and judgements regarding who was the primary carer were not always easy to identify due to the fluctuating nature of caring and care recipients' needs.

NZ Young Carers' Experiences and Needs

For the purpose of the present evidence brief, four key areas of impact have been chosen: (1) Education; (2) Socialisation; (3) Mental health and Wellbeing, and; (4) Service Provision. These areas were chosen as young carers themselves identified that they had the greatest impact on their young caring experience and their life after providing care. Furthermore, these are also the areas in which the greatest impact can likely be made through implementing key young-carer-informed policy and service changes, and can provide opportunities for significant, measurable outcomes.

1. Education

Positive school experiences

Young carers stated that they both enjoyed and wanted to attend school, and highlighted the importance of their time in the classroom as a form of respite, positive affirmation, stability, and normality.

School as respite

Young carers perceived school as their key and often-sole form of respite from their caregiving roles.

> "Learning has always been a bit of a salvation for me, like a comfortable place ... it gave me an outlet" (Lucy).

Young carers' time in the classroom was seen as respite due to the time that it afforded participants away from their home, the focus placed on the children themselves, the chance to experience a 'typical' adolescent experience, and the opportunity to 'escape' via academic, creative, or physical pursuits.

School as positive affirmation

Receiving recognition at school for their academic, artistic, or sporting achievements was positioned as very important to the children.

> "At school I was good at schoolwork and [I] was good at sport ... I guess I shamelessly hid behind that a little bit because I got really positive reinforcement for it ... And I needed positive reinforcement 'cause I had nothing. I had no role model as a father figure except [mum's] alcoholic boyfriend who was violent ... I had to deal with so many things at home" (Dan).

School as stability

School provided consistency and stability that young carers said could in turn mediate the chaos and unpredictability at home.

> “[School] gave me a huge foundation. School gave me my sense of belonging because my home life was way too volatile and too unpredictable and too emotive to give me any sense of security ... so school was my real grounding. [School] gave me everything” (Lisa).

Sense of normality

Young carers said that their time at school was crucial as a means of maintaining their identity as a child or adolescent outside of their caregiving roles.

> “I just wanted to be normal like everybody else [and] at school there was some normality” (Dan).

Negative school experiences

Caregiving during childhood and adolescence negatively effected children and youth’s participation, academic achievement, and enjoyment of school.

Inability to participate in education

Despite their desire to participate fully in school, young carers experienced distraction, absenteeism, and the inability to complete homework or take part in extra-curricular activities.

> “There was all sorts of things that just made it really difficult to think, to concentrate, to be present [at school], because in the background you’ve got this pressure and worry: Is today the day that I’m going to be called ‘cause she’s been successful [in suicide]?” (Sally).

Feeling unsupported by teachers

Participants did not disclose the reason behind their struggles at school – being their significant caregiving roles – as they perceived that their teachers would not understand. As a consequence, participants understood that their teachers viewed them as ‘disinterested’ in their education, or as the ‘naughty kid’.

> I found school hard ‘cause of ... that [teacher] expectation, ‘cause most kids would just go home and all they have to do is school work. [School work] wasn’t really a priority for me, but [my teachers] wouldn’t get that” (Louise).

Being classed as the ‘naughty kid’ meant that young carers often felt unsupported by their teachers.

> “Teachers just saw me with shitty grades, where I would just wag classes, forge notes, you know? They just saw me as a badass, but really I was just wanting help. As much as it didn’t look like it, I just wanted *help*” (Grace).

Life after school

Early school exit

Several young carers left school aged 14 and 15.

I was 15 years old when I didn't go to school [anymore] ... I sort of like regretted it at the time because I love my study. [But] I basically just have to stay home with grandma and auntie" (Amelia).

Young carers stated that rather than having any actual desire to leave the education system, their early exit from school was due to the reality of having a family member with a significant illness or disability, the demands of their caregiving roles, and a lack of teacher support to maintain both school and caregiving.

No future planning

Uncertainty regarding the length and intensity of their continuing young caregiving roles resulted in the participant's inability to plan for their future.

"My future is a really scary thought. It scares me man ... I know mum's getting older ... so I think I'll end up looking after [my sister] long-term" (Grace).

Feeling trapped

Particpants spoke to feeling 'trapped' or 'stuck' as a result of being unable to plan for their future, and/or where their plans had been interrupted by young caregiving.

"It sucks because you kind of feel *stuck* and there's not a lot what I can do right now. I didn't get to finish my degree because I had to drop out of uni because ... there was no one else willing to give up their time for my mum" (Terrence).

Different life trajectories

Young carers spoke to their anticipated life trajectories being significantly altered due to their young caregiving roles.

"My trajectory I suppose has just been different to my friends. Like I kind of finished school, looked after mum, mum died, [I] ran away ... now finally [I] have kind of settled into a course but it's seven years later" (Lucy).

Educational needs

Young carers said that they would benefit from an understanding of young caregiving among teachers, assistance with future-planning, and impartial counselling providing them with a safe, non-judgemental space at school to talk through their worries and concerns.

An understanding of young caregiving among teachers

Participants spoke to the positive impact that their teachers being able to identify them as young carers and thus offer support would have had.

> "I was just wanting help ... [but] it's easier if someone approaches you with help than to go and ask" (Grace).

Participants identified multiple opportunities when their teachers could have picked up on their caregiving role, but did not due to their lack of understanding of young caring. Participants believed that if teachers were made aware of young caring, then they would be able to offer students greater flexibility with their school work, which would assist the child to be successful in both the classroom, and in their caregiving role.

> "Schools need to know about [young caring] so that it doesn't interrupt [children's] education 'cause that's major man ... if schools are aware, there's exemptions, *flexibility* – that's the key word" (Peter).

Assistance with future planning

Young carers wanted assistance with goal setting and future planning, and highlighted the need for clear and flexible pathways in order to avoid being left without direction when their care role ended.

> "I was 19 [and] had just started university when I began caring, [and] I pulled out of my papers ... [then] when [caring] was all over it took a lot of recovery time because ... I wasn't actually a student anymore and I wasn't a carer and my life was on its head really" (Melanie).

Qualifications attached to caregiving

Participants suggested attaching qualifications to their caregiving roles, so that their time providing care could contribute towards their Curriculum Vitae and enrich their future job prospects.

> "To actually have another way of being validated for the things I was doing would have been fantastic ... [then] at the same time as caring I could have been getting a Red Cross certificate in first aid. That would have made me more confident as a carer as well. And who knows, I might have wanted to have turned it into a career!" (Fleur).

Counselling at school

Young carers asked for counselling at school to provide them with a safe, non-judgemental space to escape to when things got 'too much'.

> "I had one really great teacher who was incredibly supportive. A couple of times I had like complete breakdowns at school and I had a key to her office and could just go there ... But there wasn't a huge amount of support; I could have used more support at school" (Lucy).

2. Socialisation

Isolation and loneliness

Young carers spoke to feeling isolated and lonely due to a lack of time to socialise, and their feelings of being different to their similarly aged peers, which resulted in the participants' inability to form deep friendships.

Limited opportunities to socialise

Participants said that due to their caregiving commitments, they had limited chances to join their peers in social activities, and little energy to enjoy the few socialising opportunities that they had.

> "Having that constant commitment and knowledge that really my brother was completely dependent on me for all sorts of things [meant that] I just didn't have the spontaneity you might expect as an 18-year-old" (Rachel).

Restrictions on social opportunities could be self-imposed by young carers who were hesitant to leave their care recipient and thus resistant to spend time outside of the home.

Feeling different to their peers

Young carers said that the greater level of commitment and maturity required of them due to their caregiving roles made it hard to "bond" (Grace) or "connect" (Greg) to their peers, whose priorities were very different to their own.

> "You just felt a complete disconnect to people your own age" (Anna).

Young carers felt that their peers were unaware of the reality of their home lives, and would not understand even if they were told.

> "I really struggled to identify with other people at school because there was no way that they could have understood what I was doing ... I was in an adult world when I was essentially still a child" (Lucy).

Bullying

As a result of being different to their peers, some young carers described being bullied or harassed.

> "I got a lot of bullying at school, a hell of a lot of it ... emotional and physical bullying: I was beaten up a couple of times and hassled ... [I] just must come across as being different ... more grown up" (Dan).

A lack of deep friendships

Due to their limited opportunities to socialise, and their fear of 'opening up' to their peers about their caregiving roles, young carers found it difficult to both establish and maintain deep and meaningful friendships.

“I just struggled to actually have really honest relationships, because I didn’t want to talk about the truth” (Lucy).

“I didn’t have deep friendships because I had to protect mum [by] not telling people what was going on ... I was very good at covering up at school: I just told little lies about whether everything was normal. [I was] a bit of an actor ... so I never had close friends” (Dan).

However, where young carers and their peers shared similar life experiences, strong bonds could be formed.

Socialisation needs

Participants said that they would have benefitted from the chance to identify as a young caregiver, the opportunity to meet and form bonds with other young carers, to have respite opportunities, and a greater awareness of young caring among their peers.

Identifying as a young carer

For over 90% of participants, the term ‘young carer’ – and their identity as such – was only realised after watching the participant recruitment video outlining the researcher’s own young caregiving experience.

“For the first time I had a way to articulate that experience ... that was quite a revelation to me: ‘I had a young carer experience’” (Melanie).

Young carers said that having their newfound shared identity as a ‘young carer’ lessened some of their feelings of loneliness and gave meaning to their caregiving roles.

Opportunities to meet other young carers

Participants wanted the chance to meet other young carers in order to alleviate their feelings of isolation, to be truly understood, and as a means of ‘normalising’ their caregiving experiences.

I felt so alone. I felt like no one had been through what I’d been through ... I would have like *died* to just have someone in my situation to be able to say, ‘oh my God, it’s so lame that I have to like give my mum this injection’. But I had no one” (Lucy).

None of the partcipants had met another young carer during their time caregiving, nor knew of any services specifically for young carers in NZ. Young carers asked for multiple platforms to help them to self-identify and connect with other young carers, including physical meetings and social media groups.

Respite opportunities to connect with peers

Participants wanted to have respite from their caregiving roles – "where you don't feel guilty for having fun with your friends" (Mary) – in order to build or maintain the friendships that they had formed at school and university.

Greater awareness of young caring

Young carers understood that by generating a greater understanding of young carers' roles among children and youth, and of disability and illness in general, young caregiving could be something that was celebrated among peers.

> "We need to change people's views [of young caring] first so they're accepting of us ... eventually young carers will be cool kids ... and they'll be respected for doing that" (Dan).

3. Health and Wellbeing

Grief

All young carers experienced a significant sense of grief throughout their time caregiving.

Non-finite loss

Young carers grieved the loss of their care recipient even where their loved one had not passed away. This was because their loved one's physical presence endured, but their appearance, abilities, personality, and behavior gradually degenerated, a grief phenomenon known as non-finite loss (Bruce & Schultz, 2001).

"[Mum] was there but she wasn't anything like how I remembered ... it was really hard to have a mum but yet not have a mum" (Louise).

Participants also faced non-finite loss in the absence of a 'normal' childhood experience, and in their deviation from their anticipated educational and vocational pathways.

"I've missed out on my childhood" (Dan)

The present study appears to be the first study – both nationally and internationally – to identify the non-finite loss experienced by children in caregiving roles.

Inescapable grief

The continual and repetitive nature of caregiving meant that young carers were constantly confronted by the gradual loss of their loved one.

"Caring for mum was a constant reminder that things were different now and not how you wanted them" (Louise).

Young carers also spoke to the intensity of their roles that in turn meant they could not "take time out" (Terrence) to get perspective of or address their real feelings of loss and grief.

"You get in that cycle [of caring] ... [and] weeks and weeks just went past with me not having my time as well ... to process it all" (Lola).

Unaddressed grief

The intensity of children's caregiving roles, coupled with a widespread absence of counseling or any other consistent support to address their many losses, resulted in participants experiencing unaddressed grief throughout their time caregiving.

"[My caregiving role] ended when mum was picked up by the police and committed into a mental institution [and] I was put into a social welfare home ... I was in trauma for a long period of time [but] I was given no counseling [and] not a single sentence was uttered to me about it" (Dan).

Unhealthy coping mechanisms

Young carers described 'coping' with their unaddressed grief throughout and following the culmination of their caregiving roles using drugs and alcohol, self-harm, and violence.

"As a teenager I did self-harm ... I was cutting myself [and] I'd hit myself really hard ... I think it just assisted me in like externalizing that feeling of hurting" (Lucy).

Long-term impact

Children's unaddressed grief had a significant mental-health and relational impact both during their time providing care, and on their life after caregiving.

"I watched my mum slowly dying [and] it was fairly graphic ... and then when I was out in public I used to get flashes of it and I would just freak out, even like just in a café ... [caregiving] affects every other part of your life" (Mary).

Health and Well-being needs

Speaking to their heath and well-being needs, participants said that they would benefit from information regarding the nature of their loved one's disability or illness, and on-going, consistent, and impartial grief counselling.

Information provided to young carers

Young carers wanted information regarding their care recipient's illness or disability to give them both context to understand the changes that were occuring for their loved one, and a 'heads up' on what to expect as the disability or illness progressed.

"[Caring for mum] was the most terrible time of my life really 'cause I just didn't understand what was happening to her ... No one ever told me [about bipolar], like what to expect or anything like that ... I wish I was *told*." (Kelly).

Participants said that in an attempt to protect the child, adults often overlooked or dismissed young carers' roles and thus their need for information regarding the nature of their loved one's disability or illness.

"It's scarier *not* knowing what's going on" (Atalanta).

Young carers said that receiving information regarding the nature and reality of their care recipient's ill health would also assist them to form realistic and achievable caregiving goals.

“I always thought, ‘she was in my care, solely, and she died. I could have done more to save her’” (Mary).

Grief counselling

Young carers asked for on-going, consistent, and impartial counselling where they could open up about the intensive and emotionally-challenging aspects of caring, and share their worries and concerns.

“I felt at that time like I didn’t really have anybody to turn to, and there was nobody that can really give me that support ... I felt like, ‘what about me? I’m hurting too, this has been hard for me’ ... So I really needed to see somebody externally” (Chun).

Young carers also emphasised the importance of consistent counselling for their care recipient and their entire family/whānau unit.

“The topic of suicide was discussed amongst myself, my sister and my mum ... everybody had a time where they contemplated it or thought about it ... we all needed an outlet” (Chun).

Young carers stressed the importance of counselling being long-term as grief could transpire years after the culmination of their caregiving roles. Participants noted that counsellors could be key in identifying children and youth as young carers, and offering support.

4. Services

Participants outlined a number of key reasons that their families did not utilize formalized services, including maintaining the care recipient's familial role, the need for care based on love, caregiving being seen as a natural childhood responsibility, the unsuitability of care staff, and previous negative service experiences.

Acknowledging the reciprocity of relationships

Young carers said that service providers viewed their unwell family member as a 'patient' and thus did not acknowledge nor nurture the interdependence inherent in their key familial relationships. Participants particularly emphasised service providers' oversight of the reciprocity of care between parent and child where the child was the young caregiver for their mother or father.

"[Caregiving is] absolutely a reciprocal relationship. [Dad] is caring for me too" (Kahurangi).

Maintaining familial roles

Participants highlighted the importance of their care recipients maintaining their previously-held or traditional familial roles – for instance as a parent or grandparent – despite their ill health. However, young carers believed that formal care staff could not support their care recipients to maintain such roles, because they did not attempt to learn who the unwell individual was antecedent to or outside of their disability or illness, nor familiarize themselves with the person's wider family/whānau unit.

"You don't really want these strangers coming into your home every day ... you want someone that really knows your family ... and gets that's he's still a dad" (Ben).

This was particularly worrisome for Maori and Pacific young carers who said that upholding their care recipient's traditional familial role was key for maintaining their loved one's respect in their family/whānau/aiga and community.

Care based on love

Young carers understood that a caregiver should be someone who knew and loved their unwell family member, and was thus dedicated to their overall wellbeing.

"Mum found it nice [having me as her carer] 'cause she had someone that actually cared about her, as opposed to services that didn't really ... I think she liked to know that someone was helping her get better" (Mary).

Young caregiving as a natural childhood role

Participants spoke to young caring being a natural extension of their family/whānau/aiga role, for instance as a son, daughter, sibling, or grandchild.

"[Young caring] was just something that I naturally fell into, and not [something] that was expected of me, or that my parents said [that] I should do. Having such a good relationship with my brother ... it just feels natural" (Alice).

Maori, Pacific and Asian young carers in particular emphasised the importance of children providing care in their communities, especially as a means of showing respect to their elders.

"When we go to our marae, if we've got any of our kuia or kaumatua – our elderly – [then] the young ones just automatically come in [and] help feed them ... or they will do the hair and put the blanket on ... it's just a natural part of being for Maori" (Kahurangi).

In our [Tongan] culture we believe in taking care of [and] giving back to our elderlies. As a granddaughter [caregiving] is what I can give grandma for the sacrifices that she made in the past" (Mele).

Unsuitable care staff

Young carers said that their family/whānau/aiga was commonly matched with care staff from the same cultural group. However, participants often emphasised that care staff who aligned culturally with their family/whānau/aiga were deemed inappropriate providers of care because they could expose a 'taboo' or 'stigmatized' illness or disability to their community.

"We wouldn't want Tongans [as carers] because grandma had Dementia which is quite a stigmatized disease ... We're a small community in New Zealand and [Tongan care staff] would expose our family" (Mele).

Negative service experiences

Participants commonly cited negative service experiences that resulted in their family's lack of trust in formalized services, and the child's subsequent ongoing role as caregiver.

"[Mum] put my sister in a facility and she escaped out the window ... and she was found in her sleep suit, in the rain, her nappy full, only half a meter from the road ... Man mum was fuming, and now her trust is just gone completely" (Grace).

Service-related needs

Young carers spoke to the need for greater awareness of young caregiving among key healthcare and social services stakeholders, and holistic, consistent, individualised service provision aimed at empowering care recipients to maintain their familial and community roles.

Greater key stakeholder awareness

Young carers identified healthcare- and social-service-professionals as key individuals who, with greater awareness and understanding of young caring, could help to identify and then offer support to both themselves and their wider family/whānau unit.

"When I was 12 [years old] mum's ACC case manager came in and I remember saying to him, 'we are having to catheterise our mum and bath her [and] we're putting her on the skateboard to cart her around' ... And he just looked straight through me and turned his back and walked out the front door ... He just had no idea what to do!" (Miharo).

Holistic services

Participants identified the prevailing narrow focus of healthcare professionals only on the unwell individual, at the expense of seeing the child providing care.

"There's so much focus in the system about the person that is living with the disease that no one ever saw us" (Chloe).

Young carers said that the focus of specialists solely on the unwell individual was so great that even where the child was carrying out caregiving tasks during appointments – such as translating information for their care recipients – professionals still did not acknowledge the child as a carer.

"I translate with the social worker, translate Work and Income, translate doctors, the physiotherapy ... All of them I'm sitting there and translating everything and they don't even think [that I might be caregiving]!" (Amelia).

Young carers advocated for the adoption of a holistic approach to service provision, so that the unwell individual's wider familial context could be identified and taken into consideration during the planning of care provision.

Services aimed at empowering the care recipient

Young carers said that services should also adopt a holistic understanding of the care recipient themselves, taking into account and supporting them to continue their life outside of their illness or disability.

"[Mum] needed support to be able to ... be a mum" (Lucy).

Consistency in care staff

Participants highlighted the frustration of having a high turnover of carers in their home, and spoke to the need for consistency in formal care staff.

"Somebody comes once a week [but] they keep on changing ... [so] they don't know aunty or grandma, and I have to tell them everything" (Amelia).

In the several instances where the family had a consistent service provider, young carers spoke to the bond that they forged and the consequent trust that they had in the formal carer who they believed deeply cared for their loved one.

"We've had the same home help lady since I was probably in nappies ... so [she] became a member of the family ... She *knows* us" (Grace).

Individualised services

Young carers highlighted the need for services to individually assess each family, and take into account their unique culture, familial makeup, and caregiving context.

"Pacific [people] tend to be all lumped in one, but all of those different Pacific ethnic groups are different: we have different languages, we have different customs. So services are not tailored to meet the needs of those certain groups, so then we won't [use the services]" (Mele).

Researcher's Concluding Statement

Young carer roles exist in New Zealand due to shortcomings in societal, institutional, and political supports for people with disabilities and illnesses, their informal carers, and their wider family networks. Whilst some young carers may enjoy their roles, children should have choice and flexibility in their care capacities, and the opportunity to socialise, have positive mental health and wellbeing, be educated, and become gainfully employed at their own discretion. Young carers first and foremost require recognition and assistance, so they can become aware of, and be supported in, their crucial care roles.

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APPENDICES TWO: Young Carer Profile (statistical overview)

Caregiving Status

Primary or Secondary Caregiving Status

Roughly two thirds of young carers were primary caregivers. Of those in primary caregiving roles, 14 were providing care with no other support, four with sibling support, and one with the support of their partner. All 11 secondary carers were supporting their parent(s) who was in the primary caregiving role, including three of the four current young carers. All three of the three male participants were primary young carers.

Primary or Secondary Caregiving Status	Percentage (%):	Number of young carers: (total n=31*)
Primary Carer	64.5	20
Secondary Carer	35.5	11

*Please note in circumstances where the young carer had more than one care recipient in the same setting, their caregiving status was counted only once. However, in instances where the child was caring for more than one care recipient across separate environments, their caregiving status in each environment was counted, for the reason that their status could be divergent between settings. As such, the total number reflects this at 31 caregiving status's despite there being 28 participants.

Key demographics

Key demographics cover the gender, ethnicity, and age of participants.

Gender

Gender:	Percentage (%):	Number of young carers: (total n=28)
Female	89	25
Male	11	3

Ethnicity

Roughly one in five young carers identified as Māori, and one in ten as Pacifica.

Ethnicity:	Percentage (%):	Number of young carers: (total n=28*)
NZ/European	64	18
Māori	21	6
Pacific	11	3
Asian	4	1

*Please note that several young carers identified with two or more ethnicities. These statistics represent the primary ethnicity chosen by the young carer.

Age

Age information covers the age that children identified that they began their caregiving role (onset of care), the reason for the onset of care, the age at which their carer role ended, and the number of years the child or youth spent caregiving.

Age at onset of care:

Young carers began their roles as young as three years old, and as old as 22 years old. Young carers most commonly began their caregiving roles aged 6 and 19 years (bimodal), with the average (mean) age that young carers began their roles being 12.6 years.

Age at onset of care (years):	Percentage (%):	Number of young carers: (total n=28)
0-5	11	3
6-12	39	11
13-18	29	8
19-25	21	6

Reason for onset of caregiving role

Almost 60% of participants believed that they became a young carer due to their close relationship with the care recipient, and/or because they were the only person available or willing to care, and over 50% of participants described their young caring as a natural familial role.

Reason for onset of care:	Specifics of onset	Percentage (%):	Number of young carers: (total n=28*)
Primary or co-carer burnout	Caring to support a primary- or co-caregiver (often a parent) who the young carer perceived was experiencing carer burn-out	32	9
Natural familial role	Young carers considered the onset of their caregiving as a natural familial role for them	54	15
Care recipient struggling	The young carer saw their unwell loved one struggling with daily tasks, and stepped in to support them	68	19
Closest to care recipient	The young carer identified their close relationship with the unwell individual as the reason that they provided the care	57	16
Only person available or willing to care	The young carer understood that they were the only person available or willing to care for their unwell family member	57	16
Aversion to services	The care recipient themself, the primary carer, family members, or the young carer expressed their aversion to, dislike for, or fear of services	36	10
Negative experience with services/Services unavailable or too hard to access	The young carer identified one or more negative experiences with services that resulted in the child taking over on the care role. Or the young carer perceived services were unavailable, or too hard to access	32	9

*Please note that these statistics include all the reasons that young carers gave throughout their interviews for taking on their caregiving roles. As such, an individual young carer could give several reasons for the uptake of their role, and consequently there are a total of 94 responses despite just 28 participants. Figures are thus worked out as percentages of the number of participants (28), rather than as a percentage of the number of responses (94).

Age at completion of care:

Participants most commonly ended their young caregiving roles aged 25 years, with almost one third of young carers transitioning to adult carers as their roles continued past the age limit of young carers (25 years). Over half (54%) of the participants' caregiving roles ended due to the death of their care recipient [this statistic does include the eight young carers who continued providing care for the same care recipient into the child's adult lives (aged over 25 years), of which four remained adult carers at the time of the interviews, and four had finished care (three due to the death of their care recipient).

Age at completion of young caregiving (years):	Percentage (%):	Number of young carers: (total n=24*)
14-18	25	6
19-24	37.5	9
25	37.5	9

*Please note that these statistics do not include the four current young carers (aged 25 years or under at the time of the interview) who were still carrying out their young caregiving roles at the time of the interview.

Years spent caregiving:

The average (mean) number of years that young carers' spent caregiving was 7.6. Over 30% of young carers provided care for 10 years or more, with the greatest number of years spent caregiving being 19 (n=2). Both participants who spent 19 years young caregiving continued on to be adult caregivers for their same care recipient(s).

Time spent young caregiving (years):	Percentage (%):	Number of young carers: (total n=24*)
0-4	37.5	9
5-9	33.5	8
10+	29	7

*Please note that these statistics do not include the four current young carers' (aged 25 years or under at the time of the interview) whose young caregiving roles continued.

Care Recipient

Care recipient information covers the number of care recipients looked after by each young carer, the relationship of the young carer to their care recipient, and the care recipient's health condition including their number of diagnoses, and their specific health needs.

Number of care recipients

39% of young carers had two or three care recipients.

Number of care recipients	Percentage (%):	Number of young carers: (total n=28)
One	61	17
Two	29	8
Three	10	3

Relationship of young carer to care recipient

Over 45% of young carers were caring for a parent (n=19), and almost 60% of young carers were caring for a female (n=24).

Care recipient relationship:	Percentage (%):	Number of care recipients: (total n=42)
Mother	36	15
Father	9.5	4
Sister	12	5
Brother	21.5	9
Grandmother	7	3
Grandfather	2	1
Aunty	2	1
Non-family/Friend	5	2
Partner	5	2

Care recipient health condition

Number of diagnoses

Half of the care recipients had more than one diagnosis requiring the young carers' attention.

Number of diagnoses being addressed by young carer:	Percentage (%):	Number of young carers: (total n=28*)
1	50	14
2	35.5	10
3	11	3
4	3.5	1

*Please note that this table shows the total number of 'official' diagnoses being addressed by each young carer. Over 30% of young carers reported that their care recipients had an undiagnosed mental illness or significant side-effect of their illness or disability. As such, while their care recipient may have had one, two, or three diagnosed disabilities or illnesses, young carers highlighted that the actual number of health issues that they were addressing was greater.

Health need

Including undiagnosed cases of mental illness, mental illness was the leading health condition requiring care at 40% (n=19).

Care Recipient's Health Conditions:	Percentage (%):	Number of care recipients: (total n=47*)
Chronic Illness	28	13
Mental Illness	21	10
Physical Disability	19	9
Intellectual Disability	13	6
Elderly	10.5	5
Substance Abuse	8.5	4

*Please note that some care recipients had more than one diagnosis.

Location of Care

Geographical location of care

Geographical Location of Care:	Percentage (%):	Number of young carers: (total n=32*)
Auckland Central	16	5
Auckland North	6	2
Auckland South	25	8
Auckland West	3.2	1
Huntly	3.2	1
Ngaruawahia	3.2	1
Hamilton	6	2
Rotorua	3.2	1
New Plymouth	6	2
Wellington	3.2	1
Christchurch	9.5	3
Dunedin	9.5	3
Invercargill	6	2

Physical location of care

Physical Location of Care:	Percentage (%):	Number of young carers: (total n=32*)
Caring within familial home	78	25
Caring outside of familial home	22	7

*Please note that four young carers cared across two settings during their time caregiving (i.e. either they were caring for two people in two separate locations, or they provided care for one person in one location, and then at a later date provided care for another person in another location), and as such the location of care statistics reflect this at 32.

Household makeup

Household makeup information covers the number of people in the household, the young carers' place in family, and the financial status of young caregiving households as perceived by participants themselves.

Number of people in the household:

31% of young carers were providing care for their loved one with no other support in the home (n=10). 35% of young carers were caring in a household with 4 or more people, with the greatest number of inhabitants in one household being 11. The five households with the greatest number of participants (5+ members) were lived in by Māori or Pacific young carers. As such, Māori and Pacific young carers in particular could be hidden within large households where the care may be assumed to be done solely by the adult members of the household.

Number of people in the household:	Percentage (%):	Number of young carers: (total n=32*)
2	31	10
3	34	11
4	20	6
5	6	2
6+	9	3

*Please note that four young carers cared across two settings during their time caregiving (i.e. either they were caring for two people in two separate locations, or they provided care for one person in one location, and then at a later date provided care for another person in another location), and as such the location of care statistics reflect this at 32.

*There are several points to note for this table: (1) This data considers young carers' home makeups in their setting of care and as such, it may not be the child's familial home; (2) The number of people in the home includes the care recipient; (3) Young carers reported a great deal of transience in their households, with people coming and going, therefore only the stable members of the household who were there for a significant period of the child's young caregiving role were counted, and; (4) The number of siblings is irrelevant here as many young carers whose siblings were older than themselves reported that their brother or sister lived outside the familial home for much of their time caregiving.

Young carers' place in family

All 'oldest children' providing care were female, and 6 of the 10 young carers who were not the oldest overall in their family ('other' category) were in fact the eldest female in their family. As such, 39% of participants were the eldest females in their family (n=11) (this statistic does not include young carers who were an only-child).

Young carers' place in family:	Percentage (%):	Number of young carers: (total n=28)
Only child	36	10
Oldest child	18	5
Other (i.e., middle or youngest)	36	10
Not relevant as not caring in familial home	11	3

Participants' place in the family does not take into account the place held by sibling with an illness or disability where that sibling is the receiver of the child's caregiving. As such, categories can be read as "only child *other than sibling with disability or* illness", "oldest child *other than sibling with disability or illness*", and so on. Furthermore, please note that because not all young carers provided care in the familial home, their place in the family may not be relevant. For instance, Lola provided sole primary care to her fiancé with a Brain Tumour and as such, her place in the family is not relevant to her caregiving role. In such instances, their place in the family status was marked as "not relevant".

Household financial circumstances

Despite the researcher not asking for information regarding their families' financial situation, household finance was spoken to by 3/4 of the young carers. This signals that a key concern for many of the young carers was their family's financial situation. 56% of young carers spoke to themselves and their household struggling financially to make ends meet (n=18), and two young carers identified that they were living in poverty.

Household financial circumstances:	Specifics	Percentage (%):	Number of young carers: (total n=32*)
Family struggling to make ends meet	Participants describing their family as being financially 'hard-up', 'tough', 'stretched', or 'tight'	56	18
Family in dire financial circumstances	Participants describing their family as being 'poor', 'in poverty', or 'having no money'	6	2
Comfortable	Participants describing their family as being financially 'comfortable', 'middle of the road', 'okay to get by'	13	4
No mention of financial situation		25	8

Benefit received	Participants speaking to their family receiving official financial support (WINZ, Benefit, Disability Support)	50	16

*Please note that four young carers cared across two settings during their time caregiving (i.e. either they were caring for two people in two separate locations, or they provided care for one person in one location, and then at a later date provided care for another person in another location), and as such the location of care statistics reflect this at 32.

Please note that no formal data was taken regarding the socio-economic status of the young carers' households. As such, this table simply provides a brief overview of young carers' conceptions of their households' financial wellbeing, and is intended only as a reference and not as an official statement about the families' finances.

Caregiving tasks/activities

All young carers provided both domestic and emotional/spiritual support for their care recipient(s). Over 80% of young carers provided intimate care, with 86% dressing their loved one, and 79% assisting them with bathing and toileting.

Caregiving Task	Examples of caregiving task specifics	Percentage (%):	Number of young carers (of a total possible 28):
Appointments	Doctor, hospital, specialist	75	21
Babysitting and childcare	For a child as a result of their care recipient's or parent's illness or disability.	32	9
Domestic	Cooking, cleaning, food shopping	100	28
Emotional/spiritual support	Managing episodes, providing counsel at times of need, supervising where at high risk of self-harm	100	28
Intimate care	Bathing, dressing, toileting	86	24
Intimate care bathing	Bathing, showering	79	22
Intimate care dressing	Dressing, hair, makeup	86	24
Intimate care toileting	Wiping/cleaning, nappies, catheters, soiled sheets	79	22
Nursing	Tube feeding, administering medication, bandage changes	71	20
Paying bills	Pay mortgage, collect Benefit, make online payments on behalf of care recipient	57	16
Physical lifting and turning	Turning in bed, assisting to get up or down, moving between locations (i.e. bedroom to bathroom)	68	19
Translating	Where English is not the primary language. During appointments, translating doctor notes and medication details	14	4
Transporting	Driving, accompanying on public transport, pushing wheelchair	64	18
Working to support their family/care recipient	Paid employment outside of their caregiving role	36	10

Please note that despite many young carers having multiple care recipients, each care task was counted only once per young carer. For instance, while one young carer may provide intimate care for two care recipients, the child's involvement in intimate care tasks was only counted once. This is because the child's involvement in intimate care is being counted here, rather than any attempt being made to quantify the amount of that specific care task done by each child. Additionally, please note that these statistics do not include the care that young carers also provided to other family members, for instance emotional support provided to their parents where they were in a secondary caregiving role.

Prevalence

The present study did not aim to understand the prevalence of young carers, as without a shared understanding and general awareness of young caregiving in Aotearoa/NZ, gathering any 'true' or accurate idea of numbers would be difficult. However, many young carers did speak to their understanding of the prevalence of young carers in NZ. Specifically, Māori, Pacific, and Asian young carers highlighted their understanding of the high instance of young carers in NZ due to the "expected" (Chun), "natural" (Kahurangi), or "normal" (Miharo) nature of young caring in their communities.

"[Young caring] is normal, we just have our natural roles" (Kahurangi).

In particular the data suggests that the strong emphasis on respect of elders in Māori, Pacific, and Asian cultures – and perhaps of other ethnicities not represented in the present study but who also place emphasis on the respect of elders – resulted in young carers' sentiments that their caregiving role was 'common' practice for children in their community.

"[Because of] my ethnic culture, my sort of Chinese model, the importance of respecting the elderly ... was very embedded in my thinking from a young age" (Chun).