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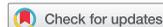
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# ***“Our Unified Voice to Implement Change and Advance the View of Young Carers and Young Adult Carers.” An Appreciative Evaluation of the Impact of a National Young Carer Health Champions Programme***

Nicholas Medforth

Faculty of Education, Health and Community, Liverpool John Moores University, Liverpool, United Kingdom

## **ABSTRACT**

A growing evidence base highlights the challenges and support needs of young carers and young adult carers, however research and policy frequently neglect the voice and experience of young people themselves. A team at NHS England developed the Young Carer Health Champions programme to bring together young carers and young adult carers from across England, establishing a network of peer support, sharing of experiences and improving confidence, health literacy and wellbeing. This commissioned independent evaluation aimed to explore the impact of the programme and inform future delivery. Taking a qualitative case study approach, young participants have a central voice, illuminated through the observations of the researcher during residential activities, and data generated during a focus group and telephone and on-line interviews. Findings demonstrate positive impact on the personal development and lifestyles of the Young Carer Health Champions, and their journey from beneficiary to pro-active shaper of services and policy.

## **KEYWORDS**

Young carer; young adult carer; health champions; case study; transition

## **Introduction**

### ***The emergent interest in young carers and young adult carers as a focus for research and policy development***

Until the 1990s, the roles that children and young people undertake in providing informal family care received virtually no academic or policy recognition. (Leu, A. and Becker, S., 2019). We now have a much clearer picture of the extent of young caring in the U.K. and its consequences for children, young people and families; a research – based critical dialogue on young carers has been advanced for over 25 years in the United Kingdom (Aldridge (2017)). This increased focus has created a number of dilemmas for policy makers, and health and social care service providers. Clay, Connors, Day, Gkiza, and Aldridge (2016), for example, visited 22 families to conduct face-to-face interviews with young carers, finding that whilst caring was seen to be a very rewarding role by the majority it also had adverse effects such as anxiety, stress, tiredness, strain within family relationships, restrictions in social activities and relationships, and under-engagement in education.

Aldridge (2017) reminds us that globally we know much less about children’s experiences of living in families affected by parental illness or disability and about expectations of caring in different cultural contexts, although research by Robson, Ansell, Huber, Gould, and van Blerk (2006) has made important contributions to the emerging international comparative literature in sub-Saharan Africa. In a narrative review Joseph, Sempik, Aeu and Becker (2019) discovered that young carers and

**CONTACT** Nicholas Medforth ✉ [n.medforth@ljmu.ac.uk](mailto:n.medforth@ljmu.ac.uk) 📍 Faculty of Education, Health, and Community, Liverpool John Moores University, 79, Tithebarn Street, Liverpool L2 2ER, United Kingdom

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young adult carers are present in every country but countries have responded differently to support young carers: some have well developed services and recognition in law whilst others are only just beginning to recognize the problem, even though it is likely that 2 to 4% of all children take on caring roles within their families (Leu & Becker, 2019).

### ***Identifying young carers and young adult carers and the extent of their caring roles***

The United Kingdom Children and Families Act 2014 (Section 96) defines a young carer as a person under 18 who provides or intends to provide care for another person (of any age) except where that care is provided for payment, pursuant to a contract or as voluntary work. Caring may involve support for family members who are disabled or chronically ill, or for adults who have alcohol or drugs related problems and involvement in a range of day-to-day tasks; cooking; housework and shopping; physical care, such as helping someone out of bed or to dress; managing the family budget, collecting prescriptions and helping to give medicines. They may also provide emotional support; talking to someone who is distressed; helping someone communicate; interpreting language and looking after brothers and sisters (The Carers Trust, 2019; Wong, =2017).

It is difficult to establish the exact number of young people taking on caring roles in England. Estimates range from 166,000–700,000, with an 80% increase in the number of five to seven-year-old young carers in England over the last decade to almost 10,000. Many may go unrecognized by professionals and support services. Some may not identify themselves as young carers, or be hidden within marginalized groups; they are 1.5 times more likely than their peers to be from black, Asian, or minority ethnic communities and twice as likely not to speak English as their first language (The Children's Society, 2018).

The Children and Families Act 2014 and the Care Act 2014 emphasizes the rights of young carers to an assessment of their needs for support and the right to have their views heard and responded to are highlighted (Children's Society, 2018). A Department for Education qualitative report indicates, however, that young carers' needs assessments and uptake of services may be restricted by parental fears that disclosure to health and social care professionals might lead to repercussions for their family. Another barrier is confusion among both young carers and their parents as to whether children have received their own young carers needs assessment (Clay, Connors, Day, Gkiza and Aldridge, 2016). Those who come from hidden and marginalized groups and young adult carers may be particularly invisible. (The Children's Society, 2018; Chickhardze, Knecht and Metzging, 2017; The Carer's Trust, 2019). The Department of Health and Social Care in England has commissioned a currently unpublished research project to review best practice in the timely identification of young carers (NatCen, 2020).

### ***Young carers and young adult carers slipping through the net despite the impact of caring responsibilities on the development and wellbeing of young people***

Whilst young carers may develop skills and resilience, this may be at their own expense. They face all the challenges other young people usually face but miss many everyday opportunities to participation in education, have time and space to do homework, peruse hobbies or spend time with friends. Whilst prioritizing care for others over looking after themselves young carers may gain fewer qualifications and experience restricted opportunities to progress to further and higher education, employability, sacrificing earning potential and ambitions to look after loved ones (Children's Society, 2013; Chickhardze, Knecht and Metzging, 2019; The Carer's Trust, 2019; Wong, 2017; Robison, 2017).

There is no strong evidence that young carers are more likely than their peers to encounter support agencies, even though they are more likely to have a special educational need or disability themselves, and report "bad" or "very bad" health problems (Wong, 2017).

Thirty nine percent of young carers surveyed indicated that nobody in school was aware of their caring role, whilst 26% experienced bullying because of it. 1 in 20 reported missing school. Juggling education and caring responsibilities often leads to negative health impacts, restricted social life and low self-confidence (The Carer's Trust, 2019) yet evaluation of a school – based programme implemented across England demonstrates that early identification and providing teachers with the tools and guidance to ensure that young carers get the help they need in school can have a positive impact wellbeing, confidence and academic attainment (Coram, 2018).

Chickhardze, Knecht and Metzger (2017) conducted a systematic review of literature published between 2007 and 2017 highlighting the pervasive impact of caring for a family member with a chronic illness on young carers aged 4 to 25 years. They found that young carers spend much of their time at home, concealing the conditions of their relatives. They would like to live “a normal life” and receive professional support that recognizes the real needs of their family members. Many report poor mental health, stress and social isolation, particularly if caring for a lone parent. Hoyt, Mazza, and Ahmad et al. (2020) carried out studies focussing on impaired sleep quality in young adult informal caregivers, concluding that caring extols a physical burden on the caregiver through poor or interrupted sleep and consequent pronounced dysregulation of the Cortisol – the hormone associated with stress responses, and metabolism and the immune system. Around 40% of carers experience high levels of anxiety or depression, with young carers known to have a higher than average prevalence of self-harm (Royal College of General Practitioners, 2014).

Blake-Holmes (2019) summarizes qualitative research that provides a clearer picture of emotional and physical needs when parent-child relationships are influenced by the severity or chronicity of the parent's mental illness. This particular group of young carers, whilst not homogenous, often experience emotional exhaustion and social isolation as they take on instrumental caring duties, attempt to anticipate needs, respond to unpredictable behavior and remain hyper vigilant to keep their family safe. Consequences include stigma, shame, isolation and a sense of betrayal leading to a “*fractured journey of growth*” (McCormack, White and Cuenca, 2017). For some this is counter-balanced by positive developmental characteristics of resilience, increased self-knowledge and maturity. Joseph, Becker, Becker and Regal (2009) developed PANOC which is a 20-item questionnaire developed for use with young carers as a self-report tool to assess both positive and negative outcomes of caring. Joseph (2013) argues that when considered within the context of what we know about post-traumatic growth young carers can find benefits within the caring experience.

### ***Moving forward: integrating research, policy and practice***

Aldridge (2017) and Joseph et al. (2019) propose a new agenda for the development of policy, research rigor, and a greater awareness of the need for interdisciplinary and multiagency working. They advocate participatory and action led research research with children, young people and families themselves including a focus on gender and transitions to adulthood. (Aldridge, 2017). The evaluation of the impact of a national Young Carer Health Champions Programme reported in this article makes such a contribution.

### **The NHS England\* Young Carer Health Champions programme**

The Young Carer Health Champions programme aimed to establish a group of young carers and young adult carers who would together engage in a year-long developmental programme of activities. The aims were complex, multi-dimensional and ambitious, responding to the range of challenges the young participants faced. They included promoting the social connectivity, health, wellbeing and health literacy of Young Carers and Young Adult Carers simultaneously developing their self-confidence, self-advocacy skills and capacity to participate in the planning and development of young carer-friendly services.

The Young Carer Health Champions were recruited through local support organizations across England. 24 young carers participated in the Young Carers Health Champions programme between July 2016 and August 2017. A further cohort was established in July 2017, engaging 17 young participants in a range of activities, including team-building

challenges, workshops and residential weekends and a Young Carer Festival. These provided opportunities to make new friends, share experiences with peers, overcome fears and take on new challenges. Through a collaborative year-long learning process, together they would decide on priorities for action and generate ideas to develop and implement through their local young carer support services. The project, if successful, would enable young participants to both benefit personally from the Young Carer Health Champions programme and then take away and consolidate their learning from the programme to champion the cause of young carers when back in their own communities.

NHS England commissioned the independent evaluation reported in this article to gain insight into the impact of the Young Carer Health Champions programme from the perspectives of the young people who participated, thereby informing future development and delivery of the project and young carer support provided through local organizations. The perspectives of the young people were central, with additional supporting viewpoints offered by parents and key enablers (local support workers) identified by the young participants. The term *young carer* is used hereafter to include both young carers and young adult carers between the ages of 16–24.

## Research questions

The PEO framework provided a means for developing research questions to structure the aims of the evaluation

- (1) What is the demonstrable impact of the programme on the personal development of the Young Carer Health Champions in terms of self- confidence, health literacy and behavior?
- (2) What is the evidence that the Young Carer Health Champions are developing the agency, self-advocacy and networking skills required to champion the collective voice of young carers and young adult carers and implement ideas for service development when back in their local communities?
- (3) How can transferable learning illuminated through the experiences and voices of the Young Carer Health Champions assist in the future development of support programmes and services?

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|            |   |
|------------|---|
| Population | Young Carers and Young Adult Carers aged 16–24 who were nominated as service-user representatives by young carer support services across the regions of England.  |
| Exposure   | Participation in the year-long NHS England Young Carer Health Champions programme, with ongoing support from local services for young carers and young adult carers.  |
| Outcome(s) | <ol style="list-style-type: none"> <li>(1) Evidence of positive impact on the personal development of the Young Carer Health Champion in terms of self-confidence, health literacy and health behaviors and self-advocacy.</li> <li>(2) Young Carer Health Champions are empowered to champion the collective voice of young carers and young adult carers and implement ideas for service development in their local communities.</li> <li>(3) Insights gained through the collective voice of Young Carer Health Champions inform future development of the national programme and local services across the regions of England.</li> </ol> |

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## Methods

### *Approach*

The qualitative case study approach used in this evaluation is broadly consistent with the principles of Realist Evaluation and Appreciative Inquiry research, which provide an alternative to empiricist approaches. Case Study enables systematic production of exemplars that contribute to the understanding of a phenomenon or the developing knowledge of a discipline (Flyvberg, 2006). In Realist Evaluation, the aim is to provide an authentic and locatable voice within a sufficiently small sample of typical cases thus enabling an intensive analysis of each case (Pawson & Tilley, 1997). Stakeholders are engaged in a constructivist approach, which incorporates peoples' stories, aspirations and social bonding. Through collective inquiry, this leads to self-determined change (Cooperinder and Whitney, 2001).

### *Participant sample, inclusion criteria and recruitment*

Population sampling was employed – the whole of the second cohort of Young Carer Health Champions were invited to participate during their third and final residential. They were aged 16–24 and involved in the NHS England Young Carer Health Champions Programme because of their caring responsibilities for family members who have long-term conditions and disabilities. The purpose of the sampling approach was to acknowledge the young participants as experts who, having experienced the programme, were able to collectively engage in a constructivist approach to share their stories and aspirations.

Seventeen Young Carers participated; five were male and twelve were female. They were coming to the end of their 12-month programme as Young Carer Health Champions and were invited to participate prior to attending their third and final residential. Three had experienced the programme as Young Adult Carers in the previous year and were now providing peer mentor support to the current group.

1 parent and 3 support workers were also recruited by young participants themselves for follow-up interviews to provide additional complimentary perspectives.

### *Ethical considerations*

The young participants had an established support network through the Young Carer Health Champions programme should the evaluation process throw up any areas of concern, or referral or follow-up be required. Easily understood participant information was provided in written format two weeks prior to the residential with the opportunity for further explanation as required. Informed consent was established, assuring the right to withdraw at any point without prejudice and safeguarding the anonymity of the participants. The right to decline without compromising full participation in the Young Carer Health Champions Programme was assured. Only one of the young participants declined – materials they produced have been excluded from the evaluation. Sensitive personal information was avoided. Ethical approval to conduct the service evaluation followed submission of a proposal to the Ethics Committee of the researcher's university: Ref: 18/NAH/010.

### *Data collection*

The researcher participated in the third residential weekend alongside the second cohort of Young Carer Health Champions and their local Support Workers in spring 2018. There were three approaches to data collection:

- *What have been the “best bits” of the Young Carer Health Champions programme?*
- *How could the programme be even better?*
- *What have been your biggest achievements whilst on the programme?*
- *What will you take away from the programme and/or do next?*

**Figure 1.** Prompts Used for the Focus Group to elicit individual and collective responses of the Young carer Health Champions.

- (1) **Direct Observation** of residential activities involving the Young Carer Health Champions, including workshops exploring the development of personal impact and communication skills. One activity in particular (“*Elephants Revisited*”) is reported as it provided the Young carer Health Champions with an opportunity to reflect on the achievement of health and wellbeing related goals they had set themselves during a previous residential. A Youth Worker facilitated had encouraged them to draw elephants “*who never forget*” to construct a representation of goals and lifestyle changes which would improve their own health and wellbeing “*one chunk at a time.*” During the session observed by the researcher the Young Carer Health Champions reflected on the goals they had previously set themselves and the progress they had made in achieving them.
- (2) A **Focus Group** conducted during the residential involved all 17 of the Young Carer Health Champions. The researcher facilitated and recorded the focus group without the direct involvement of the NHS England programme team and the young peoples’ support workers. A creative icebreaker activity facilitated initial discussion. The young people were invited to draw their own representation of a Young Carer or Young Adult Health Champion on a sheet of flip chart paper using drawings, words and symbols. This enabled subsequent exploration and discussion about the overall impact of the programme on them as individuals and collectively. The young people then added post-it notes to the flip charts to summarize individual responses to prompts based on the strength-focussed principles of Appreciative Enquiry (Cooperinder and Srivasta (1987); Preskill & Catsambas, 2006) Please see [Figure 1](#).
- (3) **Follow-up telephone and on-line interviews** enabled the development of individual Case Studies. Of the seventeen invited participants three young people offered to share their experiences in greater depth. They also distributed Participant Information and Consent Forms to prospective parent and key enabler interviewees they had selected themselves. This resulted in one parent and one support worker completing on-line interviews and another support worker participating in a telephone interview.

### **Data analysis**

Thematic Analysis (Braun & Clarke, 2006) enabled a process of familiarization with the data; searching for, naming and reviewing themes and a more detailed description of key messages and learning. Findings from the focus group and interviews are summarized and explored in the Results and Discussion section. These are preceded by observations made by the researcher during the “*Elephants Revisited*” activity and included with the consent of the participants. (One young person preferred not to be included – their material was not included in the analysis.)

Case Studies of individual Young Carer Health Champions were developed using data generated through telephone and on-line interviews with the three Young Carer Health Champions who volunteered following the focus group. This data was supplemented with data generated through additional interviews with the parent and support workers nominated by the three young people. The Case Studies illustrated of the journeys of the Young Carer Health Champions, integrating supporting perspectives of parents and support workers. The full Case Studies can be found in the appendices.

Guba and Lincoln (1989) highlight the importance of accuracy, trustworthiness and validity in qualitative research. The Case Studies were returned to the participants involved in the interviews and a summary of the findings of the Focus Group and *Elephants Revisited* activity to all the participants by e-mail to verify the authenticity of the researcher's interpretation. Three of the young people, one parent and one support worker responded with suggested minor amendments which have been incorporated to enhance the authenticity of the Case Studies. No adjustments to the summaries of the findings from the Observation and Focus Group were suggested by the participants.

## Results

The summary which follows explore how the findings of the evaluation research relate to the three research questions established earlier. The perspectives of the Young Carer Health Champions on their own journey, developmental progress and individual and collective achievements remain central.

***What is the demonstrable impact on the personal development of the Young Carer Health Champions in terms of self-confidence, health literacy and behavior?***

### Observations from the elephants revisited activity

One Young Carer Health Champion felt that they had been successful in achieving all the health and well-being focussed goals they set themselves. Others acknowledged that they had made progress in some areas, but still struggle in others. Key emerging themes were:

- (a) ***Healthy eating and drinking.*** Six young people said that they were drinking more water and less caffeine. One young person still felt the need to work on having breakfast. Five of the young people were now planning meals more regularly and making meals from scratch at least once a week (some up to four times a week). One described making smoothies in batches and storing them in freezer bags. Others said they were eating more fruit and vegetables, or at least "*working on*" it, as well as trying to add less salt to their food; eating less cheese and chocolate and fewer sweets, crisps and snacks, or trying unfamiliar fruits such as melon.
- (b) ***Exercise and fitness.*** The majority of the young people indicated that they were trying to build more exercise into their daily lives by consciously walking more. Two have "*lost a bit of weight*" and another noted an improvement in their own body image after joining a gym. For others, worrying less about body image is still hard. Spending less time on-line remained a challenge for some of the young people – for some turning off the phone and social media was a step too far!
- (c) ***Mental health, wellbeing and self-care.*** Three of the young people said they were now getting more sleep, whilst three continue to struggle. One young person said they were now focussing more on themselves, not just other people and another had realized that they are happy to be single. Several of the young people reflected on their improving confidence, communication skills, and expanding social circle. They reported that they are thinking more about developing stronger relationships with other people and balancing that with continuing to care. One young person was "*Still working on knowing myself.*"

- (d) **Aspirations and achievements.** One young person reported trying to become more motivated and another had changed their longer-term goals. Progress ranged from still working on GCSEs; gaining more confidence in job seeking; actually getting a job; progressing at university or starting a “*real life*” business plan. Some of the young people were also focussing on being supportive to others, contributing to the expansion of their local carers’ network or making a film to raise awareness of young carers in schools and colleges.

***What is the evidence that the Young Carer Health Champions were developing the agency, self-advocacy and networking skills required to champion the collective voice of young carers and young adult carers and implement ideas for service development when back in their local communities?***

## Findings from the focus group

### ***The best things about the NHS England Young Carer Health Champions Programme***

**a) *The value of having new experiences.*** The young participants universally valued the new experiences gained through involvement in the Young Carer Health Champions Programme; meeting other people and making friends was perhaps the most empowering aspect highlighted. They universally valued meeting “*fabulous*” young people like themselves from across the country; the chance to socialize, and the new ideas this generated. For some the first residential had been their first time traveling alone to another part of the country, whilst for others overcoming fears and getting on a plane or ferry was a huge achievement. All of the young participants valued “*Trying new things and so many amazing opportunities.*” They recognized the contribution “*building up my courage*” made to their own personal development.

**b) *Networking; opportunities for making friends, social bonding and finding a shared purpose.*** Most of the young people acknowledged that they felt isolated before the Young Carer Health Champion programme, explaining that adventure and team building activities during the first residential “*forced people out of their shells*” with the support of Young Carer Health Champion Mentors from the previous cohort. Having trusted Support Workers from their own local services there also helped.

Involvement in activities led to “*smiling and talking, making new friends and learning about other groups,*” understanding similarities, acknowledging shared experiences and respecting differences. They valued opportunities to meet up with the group at subsequent residentials and talking through social media about how everyone was doing in between. This led to the development of some “*amazing*” and enduring friendships and “*The community around us all coming together helping each other when needed.*”

One of the Young Carer Health Champions said knowing that the NHS wants to improve the lives of carers and having the support to make a difference empowered them to use “*our unified voice to implement change and advance the views of young and young adult carers.*”

**c) *How could the programme be even better?*** The Young Carer Health Champions agreed “*It is really good at the moment*”, but also offered suggestions for improvement. Two of the young people would have liked the programme to last longer than a year so they could continue to be Young Carer Health Champions. Others felt more young people could be involved each year, or recruited more widely. Twelve (the majority) of the young people felt that longer or more frequent residentials could be even more beneficial. Traveling consumed a lot of time for some of the young people but one would have liked at least one of the residentials to be in Spain or France, as they had not traveled overseas before. One Young Carer Health Champion would like more opportunities to be able to meet decision makers, indicating that they had valued the opportunities they had to influence policy development, for example by meeting health ministers at an event and raising concerns about the under-

identification, invisibility of and lack of support for many young carers. They wanted to be clear that despite their suggestions they appreciated the support they had received and qualified their comments by saying that being involved in the programme has been “Awesome.”

**d) Achievements, including developing confidence and self-advocacy skills.** The majority saw their biggest achievement was “Being able to come and do this!” Workshops exploring communication skills and personal impact had particularly contributed to overcoming initial fears. One Young Carer Health Champion said, “(I) would never have believed I was capable or confident enough to do improv(isation) or enjoy it.” Others examples of how “Trying new things; doing stuff I wasn’t comfy with” built confidence included sleeping in the same room as others; going on a ferry; going on a plane; learning a new game. “Coming out of my shell and opening up” in a safe and supportive environment was important to the young people who recognized that this enabled them to have “a better voice” and “talk more and louder to everyone.”

**Table 1.** The personal impact of becoming a Young Carer Health Champion.

|   |   |
|---|---|
| (a) Peer support and developing networks                    | Developing into a peer support network; messaging each other privately or as a group through Instagram; Twitter and WhatsApp.<br>Overcoming fears and anxiety; learning to connect with other young people in a similar situation, becoming more social and making new friends. “I wanted to be here – everyone was friendly approachable.”   |
| (b) Positive new experiences and developing self-confidence | Ability to try new things including “increased confidence in travelling distances on my own.”<br>Having a good experience; not being pressured and having opportunity to be able to explore your own interests, for example using creative and social media to develop an awareness campaign.<br>Consulting, traveling and seeing examples of good practice; “Going to meetings I would never have got to go to.” |

**Table 2.** Take – away learning points and next steps in contributing to the development of services.

|   |   |
|---|---|
| (a) Finding a voice and feeling empowered                   | Feeling empowered; becoming a voice for others nationally and turning ideas into ways of supporting people across England; “Learning you have a voice that is valid (you are screwed without a voice).”   |
| (b) Becoming a change agent – supporting and helping others | Becoming a Mentor and providing advice and guidance for new Young Carer Health Champions.<br>Being part of a process of sustained change; having the will to change things and situations; bringing back learning locally; developing strategies for improvement in local services.<br>Being able to work together to make changes across the country; influencing NHS Leaders and government ministers by championing young carers concerns when introduced to them at an event. |

**e) What it means to me.** “When we came we were a blank canvas – the NHS Young Carer Health Champions Programme gave us a toolkit – now we can help other young people build their toolkit.” During the focus group, the Young Carer Health Champions highlighted how the residential can be an important starting point: “I suffered anxiety before becoming a Young Carer Health Champion – it is almost non-existent now. The bottom line is I wouldn’t know so many people and I wouldn’t be here.”

Some valued “*Everything and more!*” whilst others mentioned specific gains such as friendships, social knowledge; being able to make and maintain eye contact; feeling more confident talking to people in a group; awareness of self and body language. Tables 1 and 2 below summarize emerging themes evidencing the impact of the programme from the perspective of the Young Carer Health Champions:

*“I will take away that I am capable of more than I imagined.”* One of the young people said they would take away a better understanding of the type of sector they want to work in and use the skills gained to enhance their employability. Two of the participants had been motivated to gain more experience of public speaking in the future, whilst others appreciated the option to carry on and help the new group as a Mentor the following year. Several of the young people highlighted that they were considering how they could continue to make a difference. Concrete examples offered included making a film to raise awareness for use in schools and colleges and a comic-book to help young carers new to services. They were aware that they were experiencing ongoing transitions: *“It is like a ‘set of wheels’ – not only travel; moving on upwards. This is not the end – the wheels keep in motion. Hopefully we can get the journey for other young carers to carry on.”*

## Case studies

The three Case Studies tell the stories of individual Young Carer Health Champions. Pseudonyms chosen by the young people are used. It is beyond the scope of this article to provide more than a brief summary, however the full Case Studies are available in the appendices. Discussion Conclusions and Recommendations draw on the full case studies in combination with the findings from the Observation and Focus Group reported above.

**Sam’s Story** is one of developing confidence in her ability to communicate through identifying with other young people from around the country. She recognized they shared her experiences. Sam was concerned about variations in the support offered to young carers

and young adult carers across the country and this led to involvement in a national event where she was able to contribute to making a difference, in particular valuing the opportunity to raise concerns and priorities for change with policy-makers. Sam shared her ideas about improving services by making them more consistent and accessible to young people wherever they may live.

**Cindy’s Story** is one of overcoming personal challenges when reading people and situations. She started to develop better relationships with her family and recognize her personal impact through writing a report on the services available to young carers near her home. She has considered issues such as public information; accessibility of services; how visible young carers are in publicity materials; policies, charters and pledges to young service users. She has highlighted the need to improve local services, ensuring that young carers do not get lost in the system; identifying key areas for system change including a focus on identification and referral pathways.

**Hope’s Story** is one of a journey from being initially unaware that she was a young adult carer to leading strategic changes and policy developments at her university, ensuring that young adult carers in higher education received enhanced and comprehensive support.

During the residential, the other Young Carer Health Champions also revisited the numerous ways in which they had a positive impact on local services, for example by developing local and social media campaigns which highlighted the need to improve recognition, identification and support for young carers and young adult carers.

## Discussion

The qualitative case study approach to the evaluation provides an authentic and locatable voice which represents the views and experiences of the participants in the Young carer Health Champions. According to (Cooperinder and Whitney, 2001) collective inquiry leads to self-determined change. In this evaluation, the NHS England Young Carer Health Champions Programme itself becomes a case study, as do exemplars of the experiences of individual Young Carer Health Champions. The approach

has been useful in helping to illuminate both the individual and shared experiences and reflections of Young Carer Health Champions. These align with several themes from the developing body of literature reviewed earlier.

Numerous authors highlighted how the development of young people may be compromised or fragmented because of their caring responsibilities (The Children's Society, 2018; Clay et al., 2016; Chickhardze, Knecht and Metzing, 2017; McCormack, White and Cuenca 2017; Robison, 2017; Wong, 2017). The findings of the evaluation reported in the results section highlight that Young Carer Health Champions acknowledged how caring had impacted on their own personal development, health and wellbeing. Whilst some may not have initially recognized themselves as young carers or young adult carers, and none voiced resentment of their caring responsibilities many were aware of struggling to maintain healthy lifestyles, overcome isolation, limited opportunities and experiences and difficulty or lack of confidence in communication and making new friends. They reported limited experience of travel – some flying, taking long train journeys or catching a boat for the first time so that attending the residential and “*coming out of their shells*” had involved overcoming significant initial

fears. Continuing to worry about families left at home was a concern during the residential, as was restricted phone signals.

### **How well did the Young Carer Health Champions Programme achieve its aims?**

Realist evaluation aims to illuminate “What works, for whom, in what respects, to what extent, in what contexts, and how?” (Better Evaluation, 2021). The reflections of the Young Carer Health Champions demonstrate that the programme was ambitious, yet successful in achieving its aims. Outcomes are difficult to quantify because of their complexity and the evolutionary nature of the changes generated; it is clear from the voices of the young participants they are on a developmental journey rather than reaching a clearly mapped destination. Numerous positive outcomes are, however, illuminated in the insights generated through the qualitative data, illustrating how involvement in the programme enabled young participants to both benefit personally from the national Young Carer Health Champions programme and then take home their learning from the programme to champion the cause of young carers through their local support organizations.

Understanding the experience of the young participants during the Young Carer Health Champions programme and how it was influenced both by their individual circumstances and their experience of support in their own localities was key. Participating in the Young Carer Health Champions Programme brought numerous personal and shared benefits, the most notable impacts being the enduring friendships that had developed as well as the growing confidence they had in themselves, their communication skills and abilities to voice their concerns and ideas. This is consistent with the findings of Phelps (2019) who reports the value young carers placed on support services providing opportunities for them to make many new friends, have fun and talk with others. Their aspirations and achievements varied according to individual circumstances and motivations (an important consideration in Realist Evaluation) but all of the participants recognized personal development and progression in their own health literacy and self-care, social connectivity, self-confidence and capacity to participate in the planning and development of young carer-friendly services. Examples of individual priorities relating to carer role within the family and local context were Cindy's focus on writing a report on how her local support service could improve identification processes, referral pathways and charters and Hope driving the development of university services to support students who are young carers.

The data gathered during the evaluation illustrates an awareness amongst the Young Carer Health Champions that support services are inconsistent across the country. A shared work priority collectively identified by the young participants during the residential was identification and signposting for young carers or young adult carers who may need additional support from their local services but who are not currently aware of what is available to them; a notable concern previously raised by researchers Clay, Connors, Day and Gkiza (2016). Examples of how the Young Carer Health

Champions responded were cited through the focus groups and interviews and included using film and a printed comic to raise awareness of young carers and social media to develop and consolidate peer support networks. Sam attended national events and conferences which presented opportunities to discuss shared concerns and priorities for service development with a Health Minister and NHS leaders. The young carers described developing policies to ensure that tailored support for other young carers was developed in the local agencies who had supported their involvement in the national programme. One

young carer highlighted the particular needs of young carers with a hearing disability requiring peer mentorship.

The reflections of the Young Carer Health Champions evidence a significant social value and return on investment (Social Value U.K., 2019). Reducing the negative health impacts of caring responsibilities and improving the wellbeing and health literacy of young carers and young adult carers will have lasting effects on this group of young people, potentially to be built upon over a lifetime as they work toward self-determined health and wellbeing goals. They recognized successes and some continuing struggles; healthy eating, building more exercise into daily lifestyles and focussing on mental health, well-being, and self-care were some of the themes identified. Sleep was a particular issue raised by Hoyt et al. (2020) and was identified by some of the young carers as an area of their lives they were working on.

Joseph (2013) highlights that positive elements of growth as well as compromises may be associated with the caring experience and the Young Carer Health Champions reported a growing awareness of their own strengths and resilience, and ability to overcome fears to take on new experiences. This culminated in a recognition that they were stronger together, empowered through their collective voice, and developing their individual and shared aspirations. Their growing recognition of their personal impact contributed to a developing sense of agency which Blake-Holmes (2019) recognizes as something young carers sometimes struggle to exercise. The stories summarized in the Case Studies illustrate how they overcame personal barriers and seized opportunities to become pro-active shapers of services. This challenges some elements of the dominant discourse which surrounds young carers and young adult carers that often characterizes them as passive or overlooked “victims” of their circumstances. Instead the Young Carer Health Champions programme has demonstrated that even if they are initially unaware of it, young carers and young adult carers will have resilience and imagination, which with appropriate support will enable them to become change agents and achieve what was previously unimaginable to them.

The term “*Champion*” is often overused but seems ideally suited in this case. The Young Carer Health Champions were experiencing all of the challenges that might be expected on the journey toward young adulthood, yet the researcher observed throughout the residential that none complained about or resented additional hurdles and barriers. They demonstrated kindness and empathy, expressing passion about helping other young carers despite the numerous demands on their time as they balance family lives and friendships with education or jobs.

Perhaps the outcome that best illustrates how the aims of the programme had been achieved was that the young beneficiaries said they had “*found their voice*,” recognizing that individually and collectively they can achieve more than they imagined as they transitioned from beneficiary to proactive shaper of services and policy. They did this in numerous ways and as one of them pointed out – they now recognize that they have a future. This was recognized as the “*domino effect*” by one of the Support Workers – having benefitted personally from the programme in numerous ways the Young Carer Health Champions extended its reach to other young carers and young adult carers.

## **Conclusions and recommendations: How can transferable learning illuminated through the experiences and voices of the Young Carer Health Champions assist in the future development of support services?**

Several key messages from the Young carer Health Champions, a parent and support workers emerged through the evaluation of the programme:

- (1) Most importantly listen to the voice of young service users; enable them to shape activities and support groups, ensuring that the service provides a platform for young people to be heard and influence.
- (2) Keep services young- person focused, embedding peer support and tailoring activity to the needs and aspirations of individual young people as they transition to young adulthood. Include employability and careers guidance, job searching, CV writing and using LinkedIn.
- (3) Recognize that you have a role and responsibility in identifying young carers and young adult carers. Break down the stigma that disengages unidentified individuals by asking the simple question. Whenever a diagnosis of long term condition is made in a family member the question of young carer or young adult carer should be raised.
- (4) Implement processes in health, education and social care services that ensure that the carer's integral contribution to the life of the person cared for is recognized. Provide appropriate and responsive support. Awareness Campaigns, Charters, Identification and Referral Pathways need to be developed.
- (5) There should be an easier open-door approach to engaging young carers and young adult carers through social opportunities, peer support and social media. (An interview and assessment process can be off-putting.)
- (6) Understand that young carers and young adult carers have busy lives, but are passionate about the contribution they can make to improving services – their ideas and concerns should come first in shaping services that affect their lives.

## **Strengths and limitations**

The complex, multi-faced nature of the aims of the Young Carer Health Champions Case Study and the developmental journeys and experiences of individual young participants meant that quantifiable outcomes were difficult to measure. This may be a consideration for future evaluations where hard metrics are required to demonstrate value for money to commissioners. The Case Study approach was, however useful in enabling the researcher to evaluate the Young Carer Health Champions programme as a case study within which the young service users, their parents, carers and support workers were the knowledgeable experts. They were able to recognize and identify important outcomes. Population sampling conveniently allowed the researcher to select participants who are in the right place at the right time. As with any Case Study the qualitative insights gained are specific to the programme evaluated, but the inherent bias of the method contributes to its efficiency (Bernard, 2002). The aims were idiographic; seeking a small sample of typical cases to enable individuals to have a locatable voice within the evaluation, thus enabling an intensive analysis of each case (Acharya et al 2013; Robinson, 2014). The iterative process led to the production of exemplars that contribute to the understanding of the Young Carer Health Champions Programme and its impact on its beneficiaries as well as social returns on investment highlighted through the authentic voices and experiences of the participants. Aldridge (2017) suggests this is a gap in the current evidence base. The key messages of the participants may be useful for the ongoing development of the Young Carer Health Champions programme, but also be of interest to a wider readership by offering guiding principles for future policy, practice or research.

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## Appendices: Full Case Study Exemplars

### Sam's Story

Sam got a call from her support worker asking if she would be interested in being a part of the NHS England Young Carer Health Champions project. When she was happy, she had enough information she accepted, realizing it was something she would find interesting. Since being involved Sam has found that she is more confident and discovered that she is not alone. She made friends, and believes this is because young people on the programme can relate to each other because they are in similar circumstances.

*"I think one of my challenges was meeting new people because I was quite nervous but now that I think back I'm glad I did because it has made me grow into a better person."*

Whilst on the programme Sam has been involved in three residential weekends, which have involved a lot of activities; some physical; some focussed on learning more about a healthy lifestyle and self-care; and some on developing and improving communication skills. Sam recognizes the positive impact being on the programme has had on her personally. She feels she now speaks a lot more clearly and with confidence. She has learned the importance of posture and body language in presenting her ideas and engaging an audience. Sam says that she learned that *"to be interesting you must first be interested."*

Sam has also been to an event in London with some of the other Young Carer Health Champions. At the event, many people from all over the country came to talk about the NHS and improving support for people in caring roles. This gave Sam an insight into how her ideas would be valued and how she could contribute to making a difference. Sam found the event to be very informative. She has recognized the variation in support offered to young people across the country and that services should be improved by making them more consistent and accessible to young people wherever they may live.

*“Well, it’s different from across the nation I have found out there are a lot of different ways to support young carers. For example, those who live in the north do things that are different from those who live in the south. So I think it starts with learning from each other to make it a better system.”*

For Sam, the starting point is recognizing that many children, young people and young adults are contributing to the care of parents and siblings.

*“I also think it starts with recognition, because we feel that we don’t get the recognition. We all know about adult carers but people forget that everyone can be a carer even if you are a child or young adult.”*

From Sam’s perspective the two best thing about the NHS England Young Carer Health Champion programme are

- (1) That you get to make a change for the better for yourself and for others, by contributing to the improvement of help available young carers.
- (2) You can learn from each other by meeting new people and seeing what it is like for them.

She concludes there is nothing she has disliked about being a Young Carer Health Champion and that *“It has been a great experience.”*

#### **Cindy’s Story**

Cindy’s support worker explained that Cindy had been using her local young carer support service for quite a while. Cindy is very mature; however, sometimes she faces challenges reading people and situations. Cindy welcomed the opportunity to go on the Young Carer Health Champions as the team in her local organization felt that she would be a brilliant advocate for the service and provide innovative ideas to NHS England.

Cindy’s support worker witnessed Cindy and the other Young Carer Health Champions really come out of her their shells throughout their time on the programme. Cindy seized the opportunity to express herself and meet other young carers, making some good friends. She has had an opportunity to give her opinions and learn to listen to and respect other people’s views. Cindy has taken the chance to push herself to do things that frighten her or that she is not sure about, like flying, and this has been very good to promote her independence. During one of the residential weekends, Cindy shocked herself at how easily she got up and preformed improvisation in front of the full group during a *“Personal Impact”* workshop. Her support worker says,

*“It was lovely to see the smiles on everyone faces during this session. I believe it has helped her to build her confidence, make new friends and helped her to become more mature and open . . . I was very proud to see Cindy get up and perform . . . for some, this may seem small but when you know a young person struggles with confidence issues this is an amazing thing to see.”*

Cindy explained that three residential brought new group experiences including *“Bell Boating”* which involves a group of people canoeing on twin-hulled open canoes. Cindy said, *“I loved it. It was such a good activity to get to know everybody including the staff working at the centre and with us.”* She also had a go at rock climbing. Cindy lives in a rural area so the second residential was a significant contrast. *“Being in the city was a big change for me, we went on a walk around the surrounding area it was beautiful!”*

At the third residential, a disco provided Cindy with the opportunity to *“let go and stand out from the crowd with all the amazing people I’ve met on this journey.”* She also took the opportunity to swim in the sea. *“Everyone thought I was crazy, but I loved it. A chance to show everyone what I do and what I love doing! It’s a time to chill and feel everything around you and be at ease!”* The final residential also provided an opportunity to reflect, look back on what was been achieved and consider what happens next. Cindy feels that the programme has helped her in several ways:

*“I am a new person, a lot happier, upbeat, with it and focused! It has given me the chance to meet more young carers and some amazing people! I am a lot happier now and without this programme I probably wouldn’t be where I am today!”*

One of the achievements she is most proud of is starting to get on with her family again; she is happier; she thinks she has finally grown up; she now knows she is not alone; she can see her future: *“it’s not clear but I can see it’s there.”* Cindy hopes to stay friends for a long time with the other Young Carer Health Champions she has met.

*“I am so thankful that I got signposted to do it because it was so much fun and inspiring but most of all it has led me to sign up do volunteering at the Young Carer’s Festival which I would not have known was a thing if I didn’t do this programme!”*

As a Young Carer Health Champion Cindy has been involved in writing a report on the services available to young carers near her home. She has considered issues such as public information; accessibility of services; how visible young carers are in publicity materials; policies, charters and pledges to young service users. She has written a report highlighting the need to improve local services, ensuring that young carers do not get lost in the system. She has

identified that key areas for system change include a focus on identification and referral pathways. Cindy says that she could “*go on for England*” about how young people like her could be better supported because the system really needs changing. As soon as health care professional diagnoses a person with a long-term condition, it should flash up on their computer that this person has young people at home with them and lead to a conversation about who could be, or might end up, caring for them. It then should be the professional’s job to get permission to refer the young person for support.

Cindy’s Support Worker advises that improvements in support for young people like Cindy during their transition to adulthood, will lead to benefits seen later when young carers and young adult carers have the confidence and skills to become a functioning member of the community. Key principles for other services that aim to support young people like Cindy to bear in mind include

- Keeping services young- person focused; tailoring support to the needs and aspirations of individual young people
- Enabling young people to shape activities and support groups
- Embedding peer support within the service
- Ensuring that the service provides a platform for young people to be heard and influence.

Cindy’s support worker has no doubt that Cindy has the drive and the initiative to get where she wants to be. Cindy is very passionate about *Organic Farms*. She explained that she has been to some amazing places whilst learning more through volunteering, loves being outdoors and is extremely passionate about a future farming career.

### *Hope’s Story*

Hope is a young woman who divides her week between attending university in a city away from her family home, and traveling home to help to care for a sibling who has complex disabilities. Hope became involved in the Young Carer Health Champions Programme after her mum pointed out an advertisement on a Young Carers social media page. Initially Hope did not understand that she was a carer, comparing herself to her younger sister who lived at home every day.

It became clear that Hope would benefit from the Young Carer Health Champions programme. She was encouraged to apply by a Carer’s Trust Support Worker who supports young people close to Hope’s family home. The Carer’s Trust had been providing weekly support to Hope’s younger sibling for some time but Hope’s engagement with the Carer’s Trust had been limited so her Support Worker felt that the Young Carer Health Champion’s Programme would be an opportunity “*right up her street*”. It took a while for Hope to give herself a “*pat on the back*” and recognize that she is a carer too.

Hope explains that the Young Carer Health Champion programme enabled her to meet other young people who face similar challenges, particularly in higher education. It helped her to discuss issues, recognizing the potential impact a collective voice can have. For Hope the best thing about the NHS England Young Carer Health Champion programme is that “*It provides a channel for Young Adult Carers to meet in a productive and inclusive way.*”

The first residential was an opportunity to meet the rest of the Young Carer Health Champions for the first time, discuss the previous group’s work and set objectives for the coming year. Hope enjoyed team-building activities, which included rock climbing, time challenges, boat activities and campfire songs. She also participated in a personal confidence and public speaking session, which developed projection of voice, body language, and eye contact. Hope says

*“The Health Champion Programme has increased my confidence in travelling long distances independently.”*

The downside for Hope was that the journeys were exhausting. Another major challenge was the lack of mobile phone signal at some of the residential weekends, which made it more difficult to contact home.

The second residential included sessions facilitated by a Youth Worker to explore healthy living, personal image and celebrity endorsement. Hope and the other young participants also created an “*Elephant*” to represent their overall goals, broken down into “*manageable chunks.*”

Hope feels that her greatest achievement in the programme was creating strong networks with the other Young Carer Health Champions, discussing solutions to common concerns and sharing examples of good practice in their local areas. Hope has taken a lead in her university to inform the development of support for students who are young adult carers. She highlights that it is particularly difficult to enter the world of work whilst caring so providing inexperienced young carers with tools such as job searching, CV writing and using LinkedIn are particularly important too. Her own next steps are to complete her degree and continue to advance the views of carers in the two areas in which she lives.

Hope has been able to share her experiences to inspire others to raise awareness of how to recognize young carers and their support needs. It is important for Hope that young people are consulted more widely on national issues, including more support for those who wish to pursue higher education. Hope values the commitment to continue to develop the Young Carer Health Champions programme concluding that

*“As a dynamic and developing project, the reception to feedback has been phenomenal. It is great to see that the Health Champions can have a great impact both internally and externally. I cannot wait to see its progression and expansion in future years.”*

Hope's mum recognizes that the Young Carer's Health Champions programme provided Hope with a new opportunity to travel across the country and socialize with other young adult carers, sharing her story as "*both one of difficulty and empowerment.*" It allowed Hope to be a "*normal young adult*" by providing some respite from being a successful student and a young adult carer. Hope's mum explained that Hope has always been determined to make positive changes and was very clear on her intentions, but the Young Carer Health Champions programme fueled her passion. Leading change within the programme meant that she strived for change outside of the project too. Hope has had a great deal of success and her mum explained that she is strong, independent and passionate so she was always going to overcome any issues:

*"Hope makes me proud every day. In her final year of her university journey Hope has increased her grades whilst managing fourteen job roles within her university school. She has adopted the role of Student Carer Champion and has developed an entire system of support for young adult carers at the university. This support has been consolidated in a Student Union policy as well as a Learning Support Plan, Carers Open Day Guide and two Advisors funded by a grant which Hope encouraged the Vice Chancellor to provide."*

Hope is comfortable in her decision to stay at university and is now in the process of completing her degree and applying for jobs to determine her next steps. Hope's mum recognizes that there are further opportunities to extend support for young adult carers entering into further and higher education. They would benefit from support to negotiate their own goals independently. She argues that the specific needs of young adult carers should be recognized. More Case Studies would promote broader understanding of the need to identify young adult carers who step into the caring role after the age of 16. There should be an open door approach to engaging young adult carers through social activities as assessment interviews can be off-putting. Their collective voice as Health Champions is important so all opportunities to consult with them should be taken up and involve representation of a wide range of views.

Hope's support worker is proud of Hope's achievements ("*so many it is hard to keep track of them*"). Hope is good at juggling challenges. Once she has an idea she will run with it and push for what she thinks is right and she does not give in. The Young Carer Health Champion programme has helped her to move forward and get to a place where she is happy. Sometimes it has been hard to keep up with the impact that Hope has had on raising the profile of young adult carers at her university and her support worker would have liked to be able to offer more support, celebrate with her and give Hope the recognition she deserves. The NHS England Young Carer Health Champions Programme has a "*domino effect*" encouraging young people and motivating them to go back and make positive changes themselves. Most importantly they recognize they are already doing things that are worthy of celebration which makes them proud to be a young carer.