Welcome to the young carers research and practice forum

Monday 27 September 2021

#YCRResearchAndPractice
Agenda

1.00pm  **Opening remarks**
Andy McGowan – Caring Together
Dr Emma Maynard – University of Portsmouth

1.30pm  **Young carers and young adult carers research insight**
1.  *School-based support for young carers: Best practice, barriers and enablers*
   Dr Amy Warhurst – University of Winchester
   Dr Sarah Bayless – University of Winchester
2.  *‘But you know, it seems like a lot to ask for’*
   Young adult carers’ views on their experiences in higher education and support
   Catherine Quinn – University of Portsmouth
3.  *‘It’s making his bad days into my bad days’*
   The impact of COVID-19 social distancing measures on young carers and young adult carers in the UK
   Dr Kate Blake-Holmes – University of East Anglia

2.15pm  **Panel question and answer session**
Facilitator: Dr Emma Maynard

2.30pm  **Break**

2.35pm  **Break-out rooms**

3.00pm  **Feedback**

3.15pm  **Closing remarks**
Professor Saul Becker, University of Cambridge
Setting the scene
“It feels like no-one is listening or thinking about us. It’s like the ‘Clap for Carers’ on a Thursday – it says it’s for carers, but it’s not – it’s for people who work in the NHS. They have got a really hard job – I’m not saying they’ve not – but when their shift finishes, they can go home and switch off. I don’t have an off-button – I’m always on duty. I just don’t want people to forget about us.”
Setting the scene

James, member of @NorfolkYCForum was on @TimesRadio this morning (at 11.40), discussing life as a young adult carer for #YoungCarersActionDay. James shares the impact on young carers, one year on from the first COVID-19 lockdown. Catch up here:

On #CarersWeek I paid a tribute to @CaringTogether and @holtyouth for the wonderful work they do to help our young people. Young carers have suffered disproportionately during the pandemic and they must be prioritised with support to catch-up. @andy_mcgowan
YOUNG CARERS: A WHOLE FAMILY STORY

DR EMMA MAYNARD, EDD, CPSYCHOL, SFHEA
SENIOR LECTURER IN CHILD & FAMILY STUDIES
UNIVERSITY OF PORTSMOUTH
YOUNG CARERS: A JOURNEY

• 1996-2006 “Young Carers”
• 2006-2010 “Early Help”
• 2014-2021 “Family Research”

• When we work with children and families, we work with young carers

• The language, lens and perspective shifts
• Narratives are politicised, and subjective
• In my research with 24 families and 28 school leaders, not one of them mentioned Young Carers.
• Yet, every single one of them did.
In 1997 a certain school wrote back to my enquiry as to whether they were aware of any young carers in their school. They said “We do not have any young carers here”

In 2021 I visited the same school as part of a research project – talking about how schools responded to the needs of families with complex needs. They said “School never closes a case”

In 24 years (!!!) perhaps things have changed!

But my data suggests that family narratives and language about care

...and perceptions of gives and receives care, are complex and deeply entwined in family experience
FAMILY STORIES

• Doctoral and post doctoral research (some papers out, some under review)
• 24 parents in 2 phases
• 28 school leaders
• Qualitative, inductive, dialogic research methods – “their story” (IPA and Reflective Thematic Analysis)
• About how they sought and accepted help, their journey to needing help, and their recovery from that time
KEY FINDINGS —

- **A symbiosis of mental health needs** “we both spiralled together”, from day to day mental distress, escalating to suicidality.

- Parents sustained recovery from mental distress was connected to their children’s state; “we can’t go back there again” as a motivator for keeping them both well and functioning.

- Parents’ mental health directly influenced their ability to cope with children’s complex needs.

- Parental disability was discussed without any reference to the impact on the child (MS, MH, Wheelchair user). Some struggled to share possessions, experiences or emotions with their children.

- STIGMA, about services, from community, and family, dramatically impacts mothers’ engagement with parenting, parenting self efficacy, & mental health.

- Schools are aware of, and embrace whole-family approaches and consider they are increasingly expected to act as HUBS of family wellbeing and intervention.
CARE.. IN THE COMMUNITY

- Community environments appeared key in parents’ mental health
- It seemed impossible to separate out “a care giver” and “a care receiver” - children’s own needs were very apparent through behaviour positioned as challenging / disruptive
- Schools now placing themselves as key in family support...
BIBLIOGRAPHY


• Freire, P. (2005) *Teachers as Cultural Workers; letters to those who dare to teach.* New York; Routledge


Background and Context

• Resources and guides for teachers on supporting young carers focus on key actions: Invite conversation, raise awareness, provide pastoral care, academic support and signposting outside support (Carers Trust & Children's Society, 2017).

• The main project aim is to understand how these key actions are implemented, what barriers exist and how the experiences vary.
Guiding literature

- YC are known to be disadvantaged economically and socially, and experience restricted educational opportunities (e.g. Kaizer & Shulze 2015)
  - Absenteeism and caring role interfering with school days (Sempik & Becker 2013)
- Bullying in school (Moore et al 2009)
- YC identify own support needs as respite opportunities, ability to take part in community life and attend school (Moore & McArthur, 2007) and identify the need for better support for their cared for relative.
Guiding Literature

• Increased resilience (Svanberg et al 2010) and maturity (Fives et al 2013)
• The experience of being a YC is very varied, and as such there is no single definition of young carer (Aldridge, 2018)
• Joseph (2020) conclude an interdisciplinary approach and broad definition of “carer” is needed to reduce the burden of care and support.
Aims

1) identify barriers in regional schools,
2) identify good practice and how this can be shared between schools,
3) to increase communication between feeder schools.
Methodology

• Invited 470 Hampshire schools by email to take part in a one-hour interview about their experiences of identifying and supporting young carers
• Semi-structured interviews with 18 primary and secondary schools
  • Experiences of young carers in school
  • Magic wish question
  • Barriers to supporting YC (not financial/resource)
  • What can schools do despite these barriers
  • Additional questions
Initial findings

• Thematic analysis applied to the transcript, resulting in an initial set of over 300 codes.
• Some key themes:
  • Difficulty of identifying YC
  • Nature of YC roles
  • Policy/action plan
  • Types of support offered by school
  • Communication with parents/family
  • Referral to outside agencies
  • Social/emotional needs
  • Academic needs/challenges
Initial Findings

• The nature of support varies from school to school
  • Due to staff availability
  • Due to level of resource (practical or financial) / size of school
• Communication/trust/relationship building with families is essential
Identifying YC (“qualifying” as YC)

“And there are certain things that like if you’ve got low attendance, poor punctuality, if you’re never doing homework: those are issues that might make me or a head of department question whether that person is a young carer, but if you manage to keep on top of all those things, it's not easy just to spot a young carer”

“It becomes part of a set of circumstances really that you pick up on, and once you go to the mash team you get signposted around to all the people that can help. That’s usually when young carers or, you know, we pick up on the fact that they are a young carer and that we can help them through the young carers. But yeah, it’s kind of is a joint agency, a multiagency approach.”

“I mean externally, if it is known that somebody in the family is claiming money to be a designated carer, it would be really nice if that alerted the schools so that we could maybe pick students up. So you know if there is a recognized carer in the family home, the schools then get notified, because then that would help us without us having to do digging and overcome that embarrassment. ”

"we had a look at their [outside agency support for YC] policies on their website and the kind of identifiers they use for children to be able to attend their groups. But they have specific kind of requirements"

“I think any ideas to help us identify them would be so welcome, because if they don’t come forward I don’t know how else.”
Restricted educational opportunities/need for support

“It's also that understanding [...] So actually if there is a young carer who hasn’t done their homework, that we have that understanding and we don't necessarily apply the normal sanctions that we would because we recognize that kind of vulnerability that they have.”

“On average a young carer will achieve one grade less than their non-caring peers at GCSE, and that can be really significant. That can mean they don't get the college course they want, and normally there is the option to do it an extra year but most kids want to finish College in two years, so they are more likely to then change their studies. And as I said earlier, a disproportionate amount of young carers go in to the caring professions so that makes it really difficult for them going forward.”
Schools support YC

“So the support that we put in place for the young carers here is that we recognize that their responsibilities as carers can affect their education in their school work.”

“I suppose it's a school ethos, you know, we're here not only to educate the children, but to support the families.”

“I think it's totally dependent on the individual and it's knowing that individual, which we’re good at. We get to know the individual, we get to know their needs, we talk as a whole staff, and we can put support in there.”

“I think it comes down to having those really important, consistent relationships where the child realizes that you as the adult actually care, you're not just passing the time of day. You actually care, you want to know and you want to support, and I think that's what's really beneficial with any child is those relationships.”
Need a culture of celebrating YC achievements

“I'm just proud of how we see so little bullying around young carers, and when I go to young carers events it’s always raised by people as a concern. You know, young carers are experiencing bullying and stuff like that and I always really try not to look too smug when at the back of these rooms. But yeah, I'm always really proud that we don't experience it and I think that partly is because we do constantly talk about how inspirational these young people are.”

“We really started beating the young carers drum so loudly. [...] they all would have had those conversations about where they were going and why and they are a young carer and who they cared for, and I was incredibly proud then, because it really showed that we had imbued in them a sense of pride in what they do as well.”
Resilience/Maturity

Often cited in the literature, but was hardly mentioned

“I think a lot of them [YC] seem to be a lot more mature than their peers.”

“And I've noticed that a lot of our young carers seem to be very mature for their age.”
Potential enablers

• **More staff:**
  “You know, maybe have a dedicated team for young carers because we have 30 of them, that is quite a lot, and there’s only a couple that don’t engage with us, they don’t wanna know, they don’t want the help, they don’t want to support. So that’s a lot of students that probably don’t get the time that I think they’re entitled to”.
  “and more capacity in terms of people. So I think you’d have more people available to do one-to-one or small group relationship building, self-esteem work and listening.”

• **More opportunities for normal experiences:**
  “You know these young people they’re missing out on their childhood, so they need to have a bit more fun I think.”
  “Obviously we get a small allowance to buy the resources for the club. But if we wanted to take them on a social trip, or ice skating, something that would support them emotionally and socially.”
Potential Enablers

• Recognition for Funding (pupil premium)

“At the moment, they’re a group that’s talked about in very nice terms and with lots of sympathy, but they don’t have enough I don’t believe, and identifying them as pupil premium would be a real big step forward.”

“I think there has been an ongoing push, maybe not quite a campaign, but ongoing push since I’ve been involved with young carers, to have young carers recognized as pupil premium.”

“In an ideal world, I would love for young carers to fall under the Pupil Premium banner because I feel like this would give the chance for it to be recognized as something that’s important, so I feel like not only would it give them the funding, which would be helpful, but it gives them the recognition that they need.”
Next steps

• Sharing best practice
• Magic wish questions – what would really make a difference to the support schools can offer?
• Who else should be providing support for YC?
Thank you for listening

• Thank you to our RA Eleanor who carried out interviews, and our RA Jade who helped with recruitment of schools. Thanks also to Daniel Phelps who was involved in the initial discussions around this study.
"But you know, it feels like a lot to ask for.”
Young Adult Carers’ views on their experiences in Higher Education and Support

Catherine Quinn
MRes Research Project

#YCRResearch&Practice
Context
Objectives

- To examine the lived experience of YCs and YACs in anticipating a move into HE.
- To examine the priorities of YACs in making decisions about HE.
- To examine YACs' expectations and experiences of support while at university.
### Master Themes

#### Theme 1: Awareness/Understanding
- Peers
- Lecturers
- Flexibility
- Better training about YACs

#### Theme 2: Support
- Visibility of support available is poor
- Not always support available specifically for YACs
- Found support application process/accessing support difficult

#### Theme 3: Caring Role
- Sense of guilt about leaving home for university
- Balance of either neglecting studies or caring
- Identity of being a YAC
- Impact of caring role on choice
<table>
<thead>
<tr>
<th></th>
<th>YACs Co-produced Recommendations for HEIs</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Transition to university</td>
</tr>
<tr>
<td>2</td>
<td>Awareness in university community</td>
</tr>
<tr>
<td>3</td>
<td>Accessibility of support</td>
</tr>
<tr>
<td>4</td>
<td>Visibility of support</td>
</tr>
<tr>
<td>5</td>
<td>Flexibility of coursework/attendance</td>
</tr>
<tr>
<td>6</td>
<td>What they would like future support to look like</td>
</tr>
<tr>
<td>7</td>
<td>YAC policies</td>
</tr>
</tbody>
</table>
Recommendations
Please do get in touch if you want any further conversations about my research study.

Thank you for listening!
The impact of COVID-19 on young carers – a rapid response study

Young carers research and practice forum
Sept 2021

Dr Kate Blake-Holmes
Background to the study
April – June 2020

❖ Developed in collaboration with Caring Together and University of East Anglia

❖ Aims
  ❖ Increase the recognition of young people providing care – promote awareness across services of the impact the changes in H&SC services would have on young carers
  ❖ Capture the views of young carers about their current experiences
  ❖ Consider whether any child with a long term physical health condition, disability or mental ill health is consider as a young carer throughout the pandemic.

❖ Methods
  ❖ Study designed in consultation with Norfolk Young Carers Forum
  ❖ Semi Structured Interviews with 20 participants – 8 young carers, 5 young adult carers, 3 parents and 4 youth workers
  ❖ Questionnaire – April 2020 – March 2021 – 177 respondents
Complexity of Care
Increase in Caring role

**Siblings**
- Caring for younger siblings
- Impact on young siblings with additional needs

**Parents**
- Impact on parents care needs
- Impact on parents coping strategies

**Family**
- Caring for other family members
**External support**

**Statutory**
- Health and social care
  - GP appointments, specialist services, community mental health services
- Assessments
  - Both for the young carer & and the person they are caring for

**Informal**
- Private arrangement
  - Cleaning, shopping delivery & and child care
- Family and friends
  - Emotional support, checking in and respite

**Crisis planning**
- What would happen if I become unwell
Education

- Teaching siblings
- No quiet space
- Overwhelmed and unmotivated

- Will I be behind?
- Will teachers understand?
- How can I do this safely?

- Respite
- Safe space to focus on self
- Teachers able offer emotional support

Going back

Home learning

Respite
Mental health & Managing Stress

“No breathing space
- Pressure is building
- No respite
- No access to coping strategies

Increase anxiety
- Vulnerability of parent: real & perceived
- Own mental health needs

Parental mental ill health
- Increase in symptoms
- More exposure to symptoms
- Reduction of support

Can’t complain
- Try to be independent
- Other people do more
- Its much worse for the person I am caring for

“It’s making his bad days into my bad days
Key themes – inter-related need for respite

Reduced respite for family member
- No time to recover

Reduced respite for young carer
- No time to breathe
Whole family approach

'It's making his bad days into my bad days': The impact of coronavirus social distancing measures on young carers and young adult carers in the United Kingdom

Kate Blake-Holmes 1, * | Andy McGowan 2

1 School of Social Work, University of East Anglia, Norwich, UK
2 Caring Together, St Ives, UK

Correspondence
Kate Blake-Holmes, School of Social Work, University of East Anglia, Norwich Research Park, Norwich, Norfolk NR4 7TJ, UK.
Email: kate.blake-holmes@uea.ac.uk

Abstract

The lockdown measures put in place in March 2020 in England to counter the spread of the coronavirus have had significant implications for the lives and well-being of young carers and young adult carers. In such unprecedented times, little was known about the potential impact on this group and their specific experience of the Covid-19 lockdown restrictions. A rapid review was conducted, 28 young carers responded to a survey and an additional 20 participants were interviewed in January 2021; the survey was repeated with a further 149 responses. Findings show that the level of care that young carers are required to provide had increased as external agency support for their families had been withdrawn while their own coping strategies had been challenged. In particular through school closures. These restrictions had a significant impact on every aspect of their lives, from their ability to meet their own mental health needs to managing the requirements of home schooling. The needs of young carers should be acknowledged within the political agenda, especially at times of crisis. It is crucial that health and social care services increase their capacity to identify and support young carers and that work is done within educational settings to provide a flexible response to individual needs.

Keywords

Coronavirus | Policy | Young adult carer | Young carer

Kate.Blake-Holmes@uea.ac.uk
Panel question and answer

Please put your questions in the chat, or raise a virtual hand if you have a question to ask.
Five minute comfort break

When you return, you will be in your break-out rooms so make a note of the questions
Break-out rooms

1. What are the key issues currently being identified for young carers and their families (from a practice and research perspective)?

2. Are there any identified gaps/opportunities in relation to young carers research?

3. How can we improve and increase ongoing collaboration between young carer organisations and researchers?
Feedback from break-out rooms

1. What are the key issues currently being identified for young carers and their families (from a practice and research perspective)?

2. Are there any identified gaps/opportunities in relation to young carers research?

3. How can we improve and increase ongoing collaboration between young carer organisations and researchers?
Closing remarks

Professor Saul Becker
University of Cambridge
Thank you for attending

andy.mcgowan@caringtogether.org

caringtogether.org

#YCRResearchAndPractice