

# **Ghosts within the educational machine: Are hidden young carers going with their needs unmet?**

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## **Abstract**

Supporting children's emotional wellbeing and mental health is a top priority for the Department of Education (DfE). Young carers (YCs) are a particularly vulnerable group in the community who are at increased risk of poor emotional wellbeing and absenteeism (Becker & Sempik, 2019; Kaiser & Schulze, 2015; Robison et al., 2020). In the UK, there is a statutory duty to identify these children, assess their needs and appropriately support them (DfE, 2014; Pickup, 2021). Several factors make it increasingly difficult to recognise YCs; these children are hidden, akin to 'ghosts' in the education system, with needs that become magnified by their invisibility. Research in the field highlights that intervention could be similarly effective for YCs and for children experiencing Emotionally Based School Non-Attendance (EBSNA), with successful intervention focusing on providing emotional support, tailored support plans, building trusting adult relationships and a sense of belonging at school (Chian, 2022; Seddon, 2024; Woolfson et al., 2006). Several implications are explored, and various recommendations are made for educational psychologists' involvement, such as working on both a systemic and individual level to advocate for the YC. Gaining the voice of YCs is crucial to knowing how best to support them, and subsequently evoking change within educational policy.

## **Ghosts within the educational machine: Are hidden young carers going with their needs unmet?**

In the UK, the NHS classifies a child as a Young Carer (YC) if they are “under 18 and help to look after a relative with a disability, illness, mental health condition, or drug or alcohol problem” (NHS, 2021). YCs have also been defined as “those that carry out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility which would usually be associated with an adult” (Joseph et al., 2020). Becker (2007) helpfully describes a ‘caring continuum’, distinguishing between helping the family with everyday chores, typical of most children, and caring *for* someone (i.e., a greater level of responsibility such as specialised or intimate care), the latter requiring considerably greater time and accountability.

The definition used within a more recent national study of YCs also crucially recognised the *impact* of caregiving responsibilities (Cheesbrough et al., 2017). Despite the absence of an agreed definition, it is well documented in the literature that YCs are a vulnerable group who can be both hidden and ostracised (Gray & Robinson, 2009; Smyth et al., 2011; Stamatopoulos, 2015).

The true number of YCs in the UK is unknown. Research has estimated that between 2-8% of UK children in industrialised societies are YCs (Becker, 2007; Joseph et al., 2020), with another study specifying that 7% of children do ‘high amounts’ of caregiving, and 3% do ‘very high amounts’ (Joseph et al., 2019). However, a recent survey of 2175 children in the general population found that approximately 19% of respondents showed indications that they were in caring roles (Warren, 2023).

Reported numbers of UK YCs appear to be increasing. In the first census exploring YCs in 2001, it was reported that only 2% of UK children aged between five and seventeen were YCs (Joseph et al., 2019). A decade later, the 2011 census reported an increase to 18.7% in the number of identified YCs (Warren, 2023). Research has also indicated that there has been a change in YCs' caregiving responsibilities over time, with more demands being placed on children to provide emotional support to their caregiver, which are harder to define and identify than physical responsibilities (Dearden & Becker, 2004). However, as the research statistics are gained via parental self-report, a key weakness is the potential for recall bias (Szafran et al., 2016), inaccurately remembering past experiences or omitting details when reporting them, or social desirability, where respondents may provide answers which they perceive to be viewed more favourably by others. Both recall bias and social desirability bias could lead to an underrepresentation of YCs in published estimates. Many children and young people with caring responsibilities risk being not only overlooked in national statistics, underestimating the true scale of the unmet need of this population, but also individually overlooked by the local services designed to support them.

To be identified as a YC in the UK either the child or their parent must contact their local authority (LA) and request an assessment, where a social worker would explore what support is required (NHS, 2021). Caregiving responsibilities for UK YCs can include various tasks and demands that may not appear at all unusual for children and young people carrying them out. Research has described the types of care children might provide to include tasks which are physically demanding (e.g., heavy lifting), emotionally distressing (e.g., conducting intimate care) and time-consuming (e.g., childcare or domestic tasks; Henwood, 1994). The NHS guidance for YCs states "you may do extra jobs around the house such as cooking, cleaning, or helping someone get dressed... you may also be giving your parents

emotional support too” (NHS, 2021). As there are no definitive criteria for the *amount* of help and the level of *impact* these caring expectations have on children, this creates an additional barrier to identifying YCs, who may be missing out on the essential support they don’t easily perceive they need and for which they cannot easily ask.

Education settings also have a role in identifying and supporting young people with their mental health (Cox & McDonald, 2020), with the 2017 green paper outlining steps to ‘transform’ young people’s mental health provision (DfE, 2017, p.2). To be identified as a YC at school, staff are required, in line with the Children and Families Act (DfE, 2014), to look out for signs of caring responsibilities as part of their duty of care, ensuring appropriate intervention is implemented. However, a limitation of this approach is that teachers find it more challenging to recognise children with emotional difficulties than behavioural problems and find it harder to recognise internalised distress (Loades & Mastroyannopoulou, 2010). YCs can also be reluctant to be identified as such, with many feeling misunderstood and experiencing negative social judgements and attitudes (Rose & Cohen, 2010).

Even those YC who are identified as such can fall “into the gaps between social services and education, and between health and social care” (Kaiser & Schulze, 2015), and may not themselves recognise their own responsibilities as at all unusual. With no reference point for ‘normal’ expectations of children’s household responsibilities, such that there is even no agreed definition of YCs, identifying children and young people as YCs is eminently difficult, and a particular group of YC risk going entirely unseen and their needs unmet (Smyth et al., 2011; Stamatopoulos, 2015). Consequently, the current method of assessing the need of YCs may well be resulting in a group of young people in need who are totally hidden from the systems and services that would otherwise support them, ‘ghosts’ in the educational machine (Hounsell, 2013).

Perhaps both contributing to and a consequence of being hidden from view, YCs are at risk of absenteeism due to their caring responsibilities (Kaiser & Schulze, 2015). UK statistics highlight that of those who identified as a YC, 66% cared for a parent, 31% for siblings, 5% for grandparents, and 1% for wider family (Hounsell, 2013). In addition, 6% were aged 5-7 years, 7% aged 8-9 years, 41% aged 10-14 years and the remaining were aged 15+, with caring responsibilities ranging from a few to over 100 hours a week (Hounsell, 2013; Warren, 2023). YCs' attendance can be irregular and unpredictable, with numerous factors impacting on their reasons for staying at home, such as not wanting to leave a parent who is poorly or suicidal (Kaiser & Schulze, 2015). Research has also highlighted that being a YC can negatively impact the carer's wellbeing, with approximately half of those surveyed reporting increased stress and mental health difficulties (Becker & Sempik, 2019).

YCs staying home to manage their emotions and to continue their caring roles can become hidden further through emotionally based school non-attendance (EBSNA). The term EBSNA is used to describe young people who struggle to attend school due to complex emotional factors (Higgins, 2022). It is estimated that 1-2% of UK children experience EBSNA (Halligan & Cryer, 2022). Poor school attendance is linked to several negative outcomes such as reduced academic performance (Gottfried & Kirksey, 2017; Ingul et al., 2019), with chronic absenteeism being a predictor of worse lifetime health (Henderson et al., 2014) and poorer socioeconomic outcomes (Gottfried, 2014).

Evidence within the literature indicates that the reasons YCs struggle to attend school may not be too dissimilar from children who struggle with EBSNA generally. Research has highlighted that partial absence, anxiety, and depression are all 'early signs' of emerging school avoidance (Ingul et al., 2019). Similarly, guidance provided to professionals for identifying YCs outlines potential 'signs' such as "regular lateness, low attendance, low

mood, anxiety, withdrawn behaviour” (Action for Carers, 2020). Qualitative research has explored the views of children experiencing EBSNA in a small-scale project, where all participants also identified as YCs, finding that being a YC was a contributing factor to their attendance issues (Shilvock, 2010). The evidence points to the importance of recognising the needs of YCs who find it difficult to attend school and may be experiencing EBSNA, with the emotional difficulties at that intersection greater than the sum of their parts.

Thambirajah and colleagues (2008) provide a helpful framework for understanding school avoidance. A key strength of this model is its clarity; its application to school contexts is straightforward. Thambirajah argued that avoidance occurs “when stress exceeds support, when risks are greater than resilience and when ‘pull’ factors that promote school non-attendance overcome the ‘push’ factors that encourage attendance”. Individual differences, as well as an interaction between the child’s environment (e.g., school and home) and within-child factors (e.g., sense of self-esteem and resilience) make it more difficult to comprehend each child’s perceived ability to cope. EBSNA is a heterogeneous concept; children have ‘pull’ factors pulling them towards home (e.g., staying with a sick parent), and ‘push’ factors pushing them towards school (e.g., meeting a friend). Children also have varying risk and resilience factors for developing EBSNA, and being a YC is one of these risk factors (Kaiser & Schulze, 2015). The literature highlights that children experiencing EBSNA have significant mental health needs and experience increased emotional distress going to school (Halligan & Cryer, 2022). Findings are consistent for YCs, indicating that their emotional wellbeing and mental health is poorer than non-carers (Robison et al., 2020), also that they report less happiness with their lives than non-caring peers (Lloyd, 2013). Thus, YCs, especially those experiencing EBSNA, are more likely to struggle attending school, and at increased risk of poor emotional wellbeing.

Research highlights that the most common LA provision (67% of LAs) for YCs is a referral to YC services such as support groups (Phelps, 2021). These provide an outlet for YCs to have a break from their caregiving responsibilities and socially interact with other young people in similar positions. However, the evidence also suggests that as many as 80% of YCs may not actually be receiving support from their LA (Children's Commissioner for England, 2016). This is a problem; not only are hidden YCs not being picked up by the system, but children who *are* identified as YCs are also not receiving adequate support from their LAs. Experts have articulated that without support, being identified as a YC may feel “meaningless at best, and harmful at worst” (Nap et al., 2020). It is a legal requirement for LAs to take ‘reasonable steps’ to identify YCs, and for YCs to be supported to get the help they need (DfE, 2014). It is therefore unacceptable that a vulnerable group in the community are slipping through the net.

There are some more successful interventions that could help even these more hidden YC populations. Phelps (2021) aimed to evaluate the support on offer for UK YCs, using the Hampshire YCs Alliance (HYCA) which encompassed 10 years of YC services provided. YCs self-reported that they needed: emotional support, time away from caregiving, support with/understanding of their caring role, and awareness that they are not alone (Phelps, 2021). This qualitative research found that overall YCs liked attending projects because it made them feel valued and ‘normal’. YCs felt these sessions were most successful because the staff running them were compassionate, kind, and loyal, as well as knowledgeable, which enabled them to understand the individual needs of the children. In addition, the type of support offered was consistent over many years, tailored support was offered in a responsive and flexible manner, and confidentiality was upheld, meaning YCs felt it was a safe environment to share sensitive information.

Phelps (2021) found that a ‘3-pronged’ support model (offering respite activities, family support, and school support) was a successful model for rolling out country-wide service support, with cohesion of support implementation between home and school. YCs reported that these projects offered them emotional support to help them navigate feelings such as stress, anxiety, or ‘feeling down’. Vitally, children were offered tailored, individualised emotional support, and an environment where they could feel safe. Research exploring successful interventions to support EBSNA has similarly highlighted that a sense of belonging and social connectedness, family support, and a bespoke, individual support plan (with a person-centred approach) are all beneficial for a successful reintegration to school (Chian, 2022; Woolfson et al., 2006). Additionally, research has highlighted that for children experiencing EBSNA, building trusting relationships with staff, feeling listened to by school, and having emotional support from teachers were all helpful methods of support (Seddon, 2024). Both children who are experiencing EBSNA and YCs who are struggling to attend school would benefit from similar interventions; a joined-up approach between home and school with individualised emotional support is key.

As evidence highlights that YCs are at an increased risk of poorer emotional wellbeing (Dharampal & Ani., 2020), and more at risk of school absences (Kaiser & Schulze, 2015), the HYCA service is an example of a successful intervention with high ecological validity, which listened to the specific needs of the YCs, and enabled them to feel heard and valued. However, the research findings (Phelps, 2021) must be interpreted with caution, as a sample size of 24 may not be representative of the wider population of YCs, especially hidden YCs. More research needs to be conducted to explore the emotional difficulties of YCs, which mirror the difficulties of those children experiencing EBSNA, to foster the early identification of these vulnerable groups.

Frank and McLarnon (2008) stated that “YCs and their families are experts on their own lives and as such must be fully informed and involved in the development and delivery of support services”. There is evidence to suggest that the most successful intervention for YCs comes from working in collaboration with them, listening to their needs, and using their voices to help inform policy and guide practice (Phelps, 2017). Being an advocate for the voice of the child is a key role of EPs (Doutre et al., 2013). Thus, it can be argued that EPs could work with YCs on an individual level: to listen without judgement and feed back to school staff how the child could be better supported (e.g., reduced timetables or greater curriculum flexibility; Adams, 2013). Taking into account the limited capacity of EP workload, EPs could teach schools to recognise the signs of young carer responsibilities through training, and help to evoke change at higher levels to ensure that there are policies and processes in place to meet the children’s needs. EPs could collaborate with local authorities to actively lead or contribute to working groups which are dedicated to supporting this vulnerable group, to ensure they receive the necessary attention, driving meaningful change. EPs could also use their knowledge of psychological theories and frameworks (e.g., principles of personal construct psychology) to help the YC better understand their sense of identity, fostering a sense of autonomy and increased self-esteem (Pickup, 2021).

Although research has suggested that EPs may not ordinarily come into direct contact with YCs unless they have special educational needs (Williams, 2016), there is an increased likelihood of their paths crossing if the child is experiencing emotional and/or behavioural difficulties. EPs have the opportunity to work on a more systemic level with schools, parents, and other agencies to provide a collaborative approach to supporting the needs of YCs (Adams, 2013). The evidence indicates that early identification of YCs is a necessity (Hoefman et al., 2020), and another key role of EPs is to provide early intervention and

prevention work (Williams, 2016). Thus, EPs should allocate time to helping schools better identify YCs, and signpost children to appropriate charities, projects, and agencies of support. Additionally, EPs could deliver whole-school training to raise awareness of the impact of being a YC, to challenge the ethos of schools and negative perceptions, creating a more supportive school system overall (Adams, 2013). As an example, EPs could explain the Piper Model to staff (see Appendix A) as a helpful mental health framework to foster a holistic view of YCs, leading to the creation of personalised provision maps (Piper, 2017). EPs could also conduct qualitative research exploring YCs' experiences, and aim to publish their work as a way of sharing YCs' voices, so that they are more likely to be heard by those who determine educational policy.

In summary, although there is a statutory duty to identify YCs in society (DfE, 2014; Pickup, 2021), several factors make their identification difficult. The profile of a YC looks different for individual children; the age of the carer can differ, the person they care for could be anyone within their immediate microsystem, and the nature of their caring responsibilities can vary considerably in terms of time commitments, as well as the form of care. To make matters harder, there are multiple barriers to the identification of YCs in the UK, resulting in many YCs remaining hidden due to fear of stigma and family loyalty (Hounsell, 2013).

Many YCs struggle with poor emotional wellbeing and mental health (Becker & Sempik, 2019; Robison et al., 2020), and YCs are more at risk of absenteeism than non-carers (Kaiser & Schulze, 2015). The intersection between YCs and children experiencing EBSNA argues that these vulnerable groups may be experiencing overlapping challenges greater than the sum of their parts and would therefore benefit from holistic support. Intersection invisibility may explain why YCs are not receiving the emotional support they need, as their YC label is unhelpfully categorising them into a taxonomic box, ignoring a complex interplay

of difficulties (Purdie-Vaughns & Eibach, 2008). Successful interventions supporting children experiencing EBSNA and YCs promote building trusting relationships with adults at school, increasing a sense of belonging, having tailored support plans, and increasing emotional support from teachers (Chian, 2022; Phelps, 2021; Seddon, 2024; Woolfson et al., 2006). EPs can support YCs on an individual and systemic level and YCs' voices could be amplified to inform educational policy. More research is needed to better understand YCs' complex needs, and to make visible the 'ghosts' within the educational machine.

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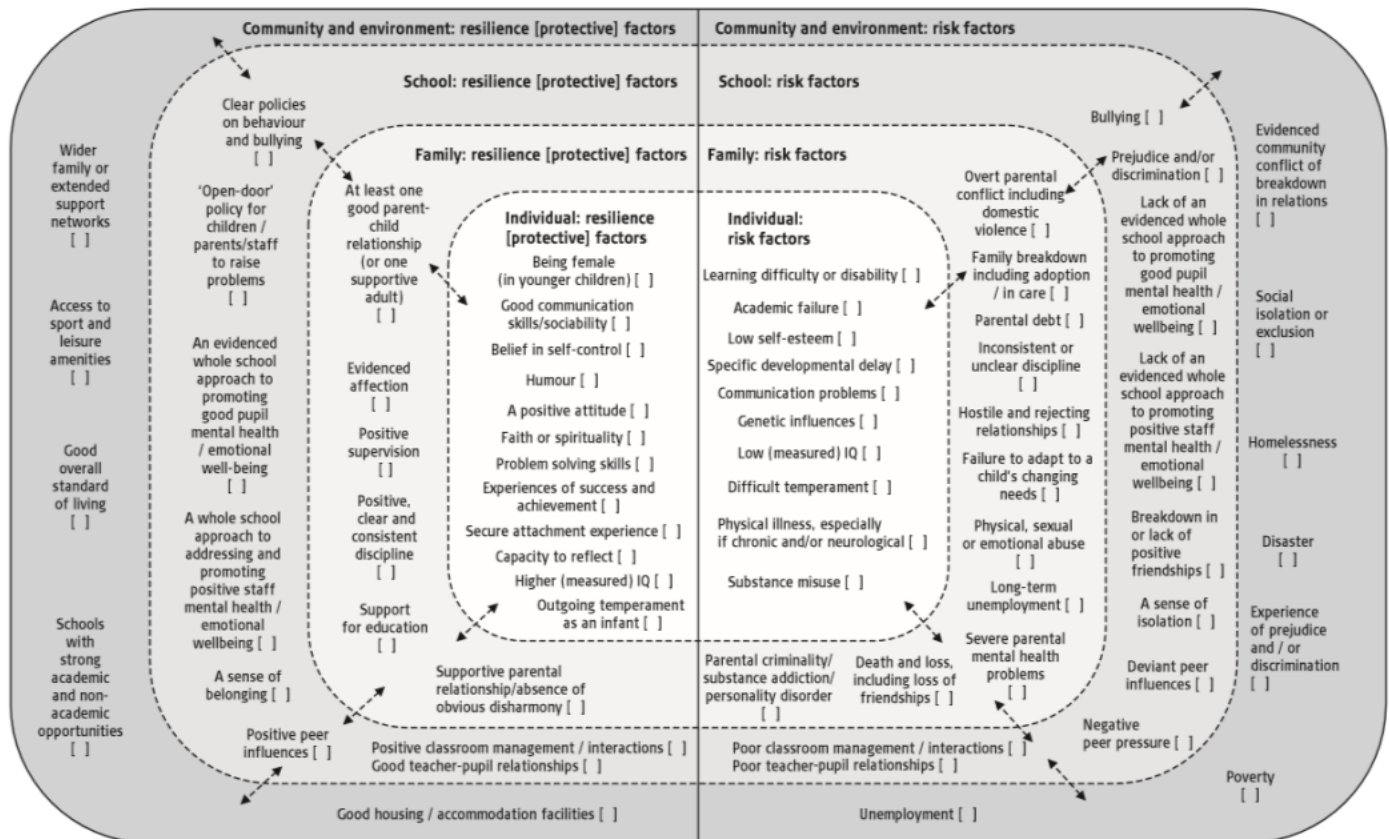
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## Appendix A. EBSNA Risk and Protective Factors

### EWB/Pupil profiling based on risk and resilience [protective] factors – using an interactive four-field EWB map



Piper, D. (2017). *The piper model: personalised interventions promoting emotional resilience in children with social, emotional and mental health needs*. Routledge. March 6, 2024.