Supporting young carers from hidden and seldom heard groups:
A literature review

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July 2020

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Contents

Introduction

Background

As part of its commitment to the Carers Action Plan 2018-2020 'Supporting carers today', The Department of Health and Social Care (DHSC) funded The Children's Society to undertake the project 'Supporting young carers from hidden and seldom heard groups' focusing on young carers from disadvantaged and seldom heard groups. The overall aim of this project was:

> To evidence whether and how increased identification of young carers from disadvantaged and seldom heard groups can be achieved in order to support the authority in meeting the objectives in the field of young carers.

A steering group for the project was established which consisted of key stakeholders from the young carers sector, including The Children's Society National Young Carer programme team, Policy and Evaluation team, National Young Carers consultant Daniel Phelps, the DHSC Carers Policy Lead, and partner organisations Barnardo's and Carers Trust.

The Literature Review

The purpose of the literature review (carried out between February and May 2020) was to inform this project funded by DHSC. Its objectives were to review literature on (a) the hidden nature of caring and (b) cohorts perceived to be hard to reach.

Method

The following approach to the literature review was taken:

- A definition of the problem (the research question) was developed.
- A search strategy was developed.
- Inclusion and exclusion criteria were decided upon.
- Literature was selected and data extracted.
- The report was written up.

A. A definition of the problem (the research question) was developed

The following overarching research question was developed, informed by the steering group meeting:

> Whether and how increased identification of young carers from cohorts perceived to be 'hidden', 'hard to reach', 'seldom heard', or 'specifically disadvantaged' can be achieved?[1]

From this question three sub-questions were developed informed by the steering group meeting:

- What are the 'hidden', 'hard to reach', 'seldom heard', or 'specifically disadvantaged' groups?
- What are the barriers to identification and engagement for 'hidden', 'hard to reach', 'seldom-heard', or 'specifically disadvantaged' groups?
- How can we increase recognition and identification of young carers from the 'hidden', 'hard to reach', 'seldom heard', or 'specifically disadvantaged' groups? (solutions).

The term 'disadvantaged'

It was suggested to the steering group and subsequently agreed that the term 'disadvantaged young carers' in the context of the literature review would be problematic since it could be argued that all young carers are potentially disadvantaged. Therefore, the term 'disadvantaged' would only be included when it related to young carers with additional or specific disadvantages due to particular circumstances or being within a particular group.

[1] The wording used here has been modified slightly from that used in the project brief (see above) for the purposes of the literature review and following agreement to use the term 'specifically disadvantaged' by the steering group.

B. The search strategy

Scientific literature, 'grey' literature, and websites from organisations and professionals were all chosen to be included within the literature search. Search terms were then developed from the initial project objectives and from discussion at the initial steering group. These were subsequently informed by the steering group meeting.

Search terms

The following search terms were used in combination with the term 'young carer':

- hidden
- 'seldom heard'
- 'hard* to reach'; 'harder to reach'
- unrecognised
- not recognised
- stigma, stigmatisation
- disadvantage, disadvantages, disadvantaged
- barrier, barriers
- excluded
- fear
- secrecy, secret
- identify, identification, identified
- unknown
- not known
- invisible
- unidentified.

There were minor variations as to how these terms were used depending on the database that was being searched.[2]

Databases

The following databases were used:

- ERIC
- Education Source
- Child Development and Adolescent Studies
- APA PsycArticles
- APA PsycINfo
- Academic Search Complete
- PubMed
- Carer Research and Knowledge Exchange Network (CAREN)
- Google Scholar.

In addition, Carers Trust, Barnardo's, and The Children's Society websites as well Leu & Becker (2019) were searched using the search terms.

Literature was initially collated using Mendeley software.

C. Inclusion and exclusion criteria

Age of young carers

The age range used in the definition for a young carer within the Children Act 1989 (17ZA) was taken for the age range of young carers:

> '"young carer" means a person under 18 who provides or intends to provide care for another person (but this is qualified by section 17ZB(3)).[3]'

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[2] Variations in how search terms were used can be seen in Appendix 1.
[3] http://www.legislation.gov.uk/ukpga/1989/41/section/17ZA (retrieved May 2020).

Some literature however would be included relating to 'young adult carers' and 'adult carers' if it was considered to be informative in relation to the target age group of young carers (see criteria developed for the evaluation of studies and data extraction below).

Geography

While the focus for the review was England, other UK and international literature was included where it is particularly relevant to the research question (see criteria developed for the evaluation of studies and data extraction below).

Age of articles

Articles were prioritised that were published after 2010, although literature published prior to 2010 will still considered relevant where no newer similar alternatives were found (see criteria developed for the evaluation of studies and data extraction below).

D. Selection of literature and data extraction

Literature was initially collated based on meeting the search criteria and was then filtered based on the relevance of the title and abstract (or introduction/ equivalent where there was no abstract) to the overarching research question. The literature was then reviewed again, and a second level of selection was undertaken within Mendeley using the title and abstract and its relevance to either of the three sub-questions' themes:

■ What are the 'hidden', 'hard to reach', 'seldom heard', or 'specifically disadvantaged' groups?

■ What are the barriers to identification and engagement for 'hidden', 'hard to reach', 'seldom heard', or 'specifically disadvantaged' groups?

■ How can we increase recognition and identification of young carers from the 'hidden', 'hard to reach', 'seldom heard', or 'specifically disadvantaged' groups? (solutions)

The following factors were used to guide the second level of selection:

■ age of literature: priority given to 2010 onwards

■ age range: priority given to 0 to 17 years

■ geography: priority given to England.

Each factor was not considered in isolation with regard to how relevant the literature was. I Instead each factor was used as a guide while considering the literature as a whole.

Literature was scored either: 1 (most relevant); 2 (medium relevance); or 3 (lowest relevance) for each of the sub-questions.

Key information from the articles scoring 1 (most relevant) relating to each sub-question (or theme) was extracted and logged in an Excel spreadsheet. An additional five themes were developed inductively and a final spreadsheet of data with eight sections was developed and populated.

1. Young carers generally hidden

2. Current identification

3. Improving identification generally

4. **What are the 'hidden', 'hard to reach', 'seldom heard', or 'specifically disadvantaged' groups?**

5. Specific Issues for this group

6. **What are the barriers to identification and engagement for 'hidden', 'hard to reach', 'seldom heard', or 'specifically disadvantaged' groups?**

7. **How can we increase recognition and identification of young carers from the 'hidden', 'hard to reach', 'seldom heard', or 'specifically disadvantaged' groups? (solutions)**

8. Prevalence

(**Bold** indicates the initial three questions (themes) that were developed)

Competing interests

The author of this literature review declares that they have no competing interests.

Results

Phase	Literature
After initial selection of literature using search terms[4]	1138
After removal of duplicates	916
After initial filtering based on Title and Abstract	258
After secondary filtering based on title and abstract (total)	36 (including two abstracts only)
What are the 'hidden', 'hard to reach', 'seldom heard', or 'specifically disadvantaged' groups? [scored 1]	26
What are the barriers to identification and engagement for 'hidden', 'hard to reach', 'seldom heard', or 'specifically disadvantaged' groups? [scored 1]	25
How can we increase recognition and identification of young carers from the 'hidden', 'hard to reach', 'seldom heard', or 'specifically disadvantaged' groups? (solutions) [scored 1]	9

[4] It should be noted that a few additional articles were included at this stage that were previously known about and considered to be relevant to the research question.

Part A: Legislation and policy context

The Children and Families Act 2014 (by amending the Children Act 1989) and the Care Act 2014, which came into force in April 2015, introduced new rights for young carers, where a 'young carer' means "a person under 18 who provides or intends to provide care for another person". The legislation places a duty on local authorities to take "reasonable steps" to identify young carers in their area who have support needs. Carers Trust and the National Centre for Social Research (NatCen) (2019, p.14) remind us that "while the duty sits with local government, the Care Act 2014 also places a duty on education and NHS bodies to co-operate with local authorities in its delivery."

Under this legislation, young carers now also have a right to a young carer's needs assessment irrespective of the type or level of care they provide. There is no requirement to request the assessment which must determine whether the young carer has needs for support and whether it is appropriate for the young carer to provide, or continue to provide, care. Local authorities must decide whether a young carer's needs can be met by services and whether or not to provide such services (HM Government., 2014). The Care Act makes provision for a so called 'transition assessment' for young carers (a 'young carer's assessment') to assess whether a young carer is likely to have needs for support after becoming 18 and, if so, what those needs are likely to be.

Carers Trust and NatCen (2019, p4) state that "the intention of the legislation was to improve identification and support for young carers by enhancing the rights of young carers, young adult carers and their families" and that "in the process of identifying young carers and assessing their situation, local authorities, and other agencies are encouraged to take a 'whole family approach' so that the needs of all family members are addressed through clear support pathways and with the principle of 'no wrong door'". They highlight that for these rights to be met, children and young people with caring responsibilities must first be identified, that early identification is particularly important, and that assessments (despite not necessarily leading directly to support) will ensure "that a young carer is on the radar should they require support if the need occurs at a later stage" (p4).

The latest Carers Action Plan 2018-2020 (Department of Health, 2018) has a particular focus to improve the identification of carers and young carers through for example:

- supporting health and social care professionals to be better at identifying, valuing, and working with carers
- improving the identification of and support for carers in relation to end of life care and bereavement
- identifying exemplar models for identification of and support for carers of people with dementia
- developing a more person-centred and integrated approach to identification, assessment, and support
- a young carers identification project to deliver a 'train the trainer' model to support local areas to identify potential young carers

- better information sharing across agencies to identify children who are young carers
- a focus on young carers from disadvantaged and seldom heard groups, to increase the timely identification of particularly hidden young carers and to support better identification among Black, Asian and minoritised ethnic families.

This literature review is informing the project funded by DHSC focusing on young carers from disadvantaged and seldom heard groups.

Status of identification

Identification: Looking back

Ronicle (2011) reminds us that the refreshed carers strategy for England 'Recognised, valued and supported: Next steps for the Carers Strategy' (Department of Health, 2010) suggested "that more should be done to identify and support young carers and that services should be more 'carer aware'" (p9). In fact, "supporting those with caring responsibilities to identify themselves as carers at an early stage" formed part of one of the Government's four priorities (Department of Health, 2010, p6). The strategy stated that "many young carers remain 'hidden' from health, social care, and education services – partly as a result of those services needing to do more to identify them but also because of family fears that they will be taken into care or because the young people themselves are concerned about the reactions of others and bullying by their peers" (p9).

However, their report on family focused models of support (Think Family Pathfinders). Ronicle (2011) highlighted that difficulties faced by young carers were not being identified early enough by services and that many young carers remained 'hidden' from health, social care, and education services. Barnardo's reported that there was variation with how schools were identifying young carers (Barnardo's, 2006). They reported that it was "hit and miss as to whether schools are aware of the reality of their [a young carer's] situation" and that agencies (GPs, adult social services, and parental mental health services) were missing opportunities to identify these children and young people.

Further evidence of young carers being hidden came from The Children's Society, which despite finding strong associations between socio-economic factors and being a young carer (by analysing data from the Longitudinal Survey of Young People in England (LSYPE)) found a weak relationship between young carers and their level of contact with support services in areas where strong associations would be expected (The Children's Society/Hounsell, 2013).

Referral routes

Young carers are identified and families are referred to services via a variety of routes. Ronicle (2011) found the families in their study were most likely to be referred to young carer projects by social care (32% of referrals), schools (20% of referrals), or other voluntary or community organisations (13% of referrals). They posited that this reflected both families' level of need and the key partners working with these families. They found 10% of referrals were from health professionals, 8% from mental health services (adults and children), and 3% from drugs or alcohol agencies.

Current status of identification: Post-legislative changes

Following the new duties on local authorities to take 'reasonable steps' to identify young carers living in their area, research by Barnardo's found that the right to an assessment within legislation had raised the profile of young carers and awareness of their needs with commissioners and other agencies. They also found that the numbers being assessed and identified were increasing (although in some areas this had led to a reduction in support (James, 2017)). However, James also reports that many young carers were still being failed by the numerous agencies they came into contact with, including not being identified and not receiving the targeted and consistent support they needed. Furthermore, their research found that there was ambiguity about where the responsibility for identification and referral lies within the local authority.

The report by the Children's Commissioner for England reported that "not all local authorities are taking steps to identify children who may be providing care in their area" as well as suggesting that 80% of young carers may not be receiving support from their local authority (Children's Commissioner, 2016, p5). The report states that "additional steps must be taken to improve identification". These findings were reflected in a local study in London where it was found that adequate and reasonable steps were not being taken to meet statutory duties and identify and assess young carers (Waters, 2019).

More recently still, Carers Trust and Natcen (2019) report that there remains a lack of awareness in both the public and professional arenas of who young carers are, their prevalence and their rights. They conclude that "since these laws were enacted, it is evident that practice has evolved in some areas to create effective multi-agency relationships across social care, health, education and the voluntary services which allow young carers to be identified early on. However, these examples of effective and good practice are patchy and inconsistent" (p64).

They also report that GPs lack confidence in asking certain questions about family-based issues due to not receiving training about identifying young carers. Although not focusing on young carers, Carduff et al. (2014) propose that the problem of identifying carers is two-fold: firstly, general practices are not legitimising the wellbeing of carers nor identifying them; and secondly, carers are not self-identifying in their own surgeries. The lack of awareness of young carers by healthcare professionals is also highlighted by Rahman et al. (2019).

Referral routes

The Barnardo's research with young carer services and young carers found that over 22% of young carers were referred by a parent and while referrals from adult services were still limited, most opportunities to identify young carers by GPs were not being taken. Services in their study reported very low numbers of GP referrals and only 5% young carers themselves had reported being referred by a GP (James, 2017). Clay et al. (2016) found young carers typically accessed young carers' services via referrals from adult/children's social care, schools, or adult/children's health services, but also found smaller numbers were referred from healthcare professionals.

The Making a Step Change report of the evaluation of how six trailblazer areas in England were implementing the duties required under the Care Act 2014 and the Children and Families Act 2014 with regard to young carers and their families states that self-referral is growing in importance as a referral method (Carers Trust and The Children's Society, 2016). It was found that in Devon "40% of young

carers referred themselves, often after an assembly or awareness raising event in a school" (pp19-20). However, their analysis found that self-referral was "still dwarfed by other referral methods" and that referrals came predominently from children's services.

Most recently, the survey carried out by Carers Trust and NatCen (2019) found that 98% of services responding received referrals from children's social services (61% from adult social services, 73% from health services, and 96% from schools). They concluded that "there remains a limited number of adult social services identifying young carers through their engagement with families" (p17).

Early identification?

The literature reveals concerns that young carers are not being identified early enough. Frank & Mclarnon (2008, p4) highlighted their concern that "young carers and the needs of the person for whom they are caring may only be identified when there is a crisis". And while Carers Trust and NatCen (2019) highlight the importance of identifying young carers as early as possible, the Barnardo's Hidden Lives report states that "many [young carers] spend years unidentified, unsupported, and isolated in their caring responsibilities."

Their research found young carers had spent four years on average (and 10 years in some cases) in caring roles before being identified for support (Barnardo's, 2006). Phelps (2019) found in their evaluation of young carer services within Hampshire, that over half the young carers in their study had been caring for three or more years before being engaged with their projects. Ronicle (2011) concludes that "LA-wide early intervention systems that prevent inappropriate caring roles are yet to be fully established" (p58).

Prevalence of young carers

The last census in 2011 identified 166,000 young carers in England and Wales between the ages of 5 to 17. However, these figures are believed by some to be under-representative of the true number of young carers for several reasons. The Children's Society (2013) posits the reasons for a lower figure is that it is parents, not children, who complete the census, and that the census questions do not specify the range of conditions of those who are cared for such as mental ill health, HIV, and substance misuse. They state that "many young carers come from hidden and marginalised groups, including children caring for family members with mental illness or a substance dependency. This group of young carers was not captured in the latest census" (p4).

Similarly, James (2017) claims the census did not include those who care for family members with drug and alcohol problems and also highlights that numbers rely on families to self-declare, which is problematic since the term 'young carer' may not be familiar or understood by families, or because families fear disclosing that a child is a carer. Vizard et al. (2019) express similar concerns and assert that under-reporting can be a concern where adults respond to social survey questions on behalf of children.

Recent research by the University of Nottingham for the BBC, suggests that more than one in five children in England carry out some care for sick and disabled family members. If these findings were reflected across the country, they would point to a figure of over 800,000 secondary school children (aged 11 to 16) in England (Joseph et al., 2019a). Similar research by the BBC in 2010 pointed to a figure of 700 000 young carers (8% of young people) in the UK (BBC, 2010). However, it should be noted that others take a more conservative view on the

numbers of young carers. Aldridge (2018) raises concern over the reliability of anonymised questionnaire surveys and census surveys that use a limited number of questions to determine the caring status of children. They question specifically the findings of the BBC (2010) study and point to a national omnibus survey of young carers in England where 420 young carers were identified out of 79,629 households – giving a figure of just 0.5% young carers in the general population (Cheesbrough et al., 2017).

Conclusion, Part A: Legislation and policy context and status of identification of young carers

This review has found that the identification of carers, including young carers, has been a focus of policy for a significant number of years. The Government's carers strategy of 2010 recognised that many young carers remained hidden and supporting them to identify themselves was one of the Government's priorities. Ten years on, the Carers Action Plan 2018-2020 maintains the focus of identifying carers and young carers through more nuanced actions, including focusing on the identification and support of hidden young carers from disadvantaged and seldom heard groups. Despite some improvement in recognition and awareness of young carers following the introduction in 2015 of duties on local authorities to identify young carers, there appears to be some way to go in order to achieve consistent, effective, early identification of young carers across all sectors and in particular through health services and adult social care.

There remains scepticism and uncertainty about the numbers of young carers officially identified by the census (with many believing this to be an underestimate of the true number) but also from others who question the reliability of research that has indicated significantly higher numbers. Achieving a prevalence that can be agreed upon - although helpful – remains challenging. With census data coming only every ten years, other ways of achieving this could also be pursued, including determining the numbers of young carers more locally at local authority level, using other national surveys, and making comparisons with the prevalence of young carers found in other similar countries.

Part B: Young carers: generally a hidden and invisible population

Although terms such as 'hard to reach' and 'seldom heard' are found associated with young carers, the literature is replete with the terms 'hidden' or 'invisible' to describe young carers generally. The use of these terms is not restricted to particular sub-groups of young carers and therefore it is necessary to begin this review with regard to the young carer population as a whole.

Since research on young carers emerged around thirty years ago, this group of children and young people has consistently been described as a 'hidden' population (for example Aldridge and Becker, 1993; Warren and Ruskin, 2008; Stamatopoulos, 2015) and this remains the same today (e.g. James, 2017; Astrup, 2019). As Joseph et al. (2019b) state "in many families in the UK and internationally, the caring roles of children and young people are hidden and remain a "private" family matter rather than an issue for public policy intervention". This is despite awareness having increased in the UK about the issues of young carers and who they are, thanks to media attention, local and national awareness raising, campaigns such as the annual Young Carers' Awareness Day initiated by the charity Carers Trust in 2014[5], and the introduction of new legislation in England that defines young carers (HM Government, 2014).

'Seldom heard' and 'hard to reach' young people

In their literature review of best practice for promoting the participation of 'seldom heard' young people, Kelleher et al. (2014, p.53) assert that:

> "The term 'seldom heard' is an umbrella term which is used to denote young people from an extensive range of backgrounds and life experiences whose voices typically are not heard in decisions that affect them and who tend to be underrepresented in consultation and participation exercises, both as individuals and as groups."

Their review also outlines that seldom heard young people may be difficult to identify and are not a homogenous group. They highlight that terms such as 'hidden', 'invisible', and 'hard to reach' are used interchangeably and that terminology is important since it can be stigmatising. The term 'hard to reach' is specifically highlighted as being stigmatising and problematic and (rather than placing the responsibility on services) places responsibility for involvement on the group members themselves (for example, Cook; Begum, cited in Kelleher et al., 2014). Their review found that 'seldom heard' young people, "may exist within wider 'seldom heard' groups such as ethnic minority groups or as groups in their own right such as young carers or young parents" (p25). Kelleher et al. (2014) discuss the complexity and hetrogeneity that is found within seldom heard groups, as well as commonalities (such as language or communication difficulties or low confidence) that limit their involvement.

Turkie (as cited in Kelleher et al., 2014) specifically notes that there are common rationalisations for not including seldom heard groups, citing young carers being

too tired as a particular example. Smail (as cited by Kelleher et al., 2014) asserts that children and young people may be 'hard to reach' due to practical difficulties, their particular vulnerability (as in the case of young carers), cultural reasons, and/or geographical reasons. Smail also reports that young carers are one of the groups most frequently identified as 'hard to reach'. The term 'seldom heard' is used by Carers Trust and NatCen (2019) as an umbrella term for groups of young carers that present particular challenges to identification and support and by Martinsen et al. (2019) in relation to young carers who need to be recognised and given a voice.

Reasons why young carers remain invisible and hidden

The Children's Society (2013, p.4) reports that there are "a host of reasons, including family loyalty, stigma, bullying, not knowing where to go for support" for why young carers remain hidden. However, despite there being many different barriers to identification found within the literature, there are some very consistent themes. Carers Trust and NatCen (2019) outline the following four key barriers to identification and support: the focus on the person with care needs; information sharing; signposting and referral; and financial resources. They also highlight the vagueness of the NHS duty to identify young carers and the limited awareness of duties within legislation as factors preventing the identification of young carers by GPs.

Self-identification by young carers and families

One key barrier to the identification, engagement and support of young carers and their families that has been, and still is commonly identified throughout the literature, is that often they do not self-identify. What is also commonly found in the literature are several key reasons as to why young carers and their families do not self-identify.

The caring role and the term young carer

Firstly, young people (or their families) do not always recognise themselves as carers. This may be because their caring role does not fit an archetypal caring role; they may primarily be providing emotional support, for example, or they may feel they do not qualify as a carer because of the particular health condition of the person they care for (Carers Trust and NatCen, 2019). It has been found that adult carers can be ambivalent about their own needs or too preoccupied with caring to recognise their own care needs and identify themselves as a carer with support needs (Carduff et al., 2014), which may be a reason why some young carers also do not self-identify.

Secondly, it is reported that young carers do not always identify with the term 'young carer' in order not to be recognised as different (for example, Aldridge and Becker, as cited in Christie 2010; Morrow, 2005) and moreover that some families are not familiar with the term (Astrup, 2019). Carers Trust and NatCen (2019) report that terminology can be a barrier to identification and the importance of considering language carefully when raising awareness. By contrast, Clay et al. (2016) found the young carers in their research who were accessing local support services, recognised and were familiar with the term 'young carer' and acknowledged it in their own lives. However, they did find that while many young carers were proud of their role as a carer, older young carers were more sensitive about the use of the term and therefore avoided disclosure so as not to be treated differently by pupils and staff in school.

Parents may also be uncomfortable with the term 'young carer' and may feel that it puts them in a position of dependency or inadequacy (Newman, as cited in Joseph et al., 2019b).

Concealment of the caring role

A second predominant reason for why young carers and families do not self-identify that runs throughout the literature to the present is that it is common for young carers (and their families) to deliberately conceal their caring role. This is because they are concerned about or are fearful of the consequences of making themselves known to services or of the potential negative reactions that they may receive from their peers (Carers Trust and NatCen, 2019), or because they are embarrassed (Frank as cited in Christie2006). There is a 'culture of secrecy' adopted by families and young carers themselves for different reasons (Barnardo's, 2006). The literature asserts that young carers fear a lack of confidentiality (Underdown, as cited in Christie, 2010) and do not trust social workers, and families commonly do not wish to disclose their situation because they fear social service intervention and their families being broken up (for example, Barnardo's, 2006; Clay et al., 2016).

As well as not wishing to identify themselves to services, young carers also conceal their situations to peers because of loyalty and fear of consequences including disruption of friendships or being bullied (for example, Barnardo's, 2007, as cited in Butterworth, 2014; Carers Trust and NatCen, 2019). A common underlying reason why young carers and families refrain from identifying themselves is the fear of the stigma associated with caring generally and the stigmatisation of young people (for example, Clay et al., 2016; Carers Trust and NatCen, 2019). Furthermore, the 'silence' from young carers due to a perceived stigma associated with a parent's health condition is discussed by Christie (2010) who cites the recognition of this issue from several decades ago in the sixties and seventies and more recently in the young carers' literature from the nineties. Hughes (2016) sets out five different 'categories' of stigma that affect family carers and reports that the effect of stigma is to evoke fear of discrimination such that family carers may not identify themselves. Hughes also states that there is relatively little research on the impact of stigma on family carers.

The parents of young carers may act as a block to identification and referral of support for their children, or as Christie (2010, p86) puts it "parental contribution to hidden-ness". Young carers may not identify due to parental pressure and parents not wishing to be 'outed' as needing care (Hughes, 2016) and parents' or families' resistance may deter young carers from self-identifying or preventing the process of referral by withholding consent from services being able to make referrals (Carers Trust and NatCen, 2019). The literature commonly talks about caring being a private issue in some families and that it is 'family business'. Carduff et al. (2014) propose that the relationship between the carer and the cared-for person could affect the carer's willingness to seek support.

Onset and impact of caring role

For some young carers, their caring role maybe be something that they have simply become used to. Becoming accustomed to caring and its contribution to the 'hiddenness' of young carers has been overlooked in the literature according to Christie (2006). This reflects one of three barriers posited by Carduff et al. (2014) who assert that taking on the care of another peson is often a gradual process. The second barrier which they put forward is that over time the caring

role becomes all-encompassing and carers prioritise the needs of those they are caring for at the expense of their own needs.

Awareness of support available

Another common reason found in the literature as to why young carers and families do not come forward and identify themselves is as Astrup (2019, p15) states "often these families simply don't know that the support is out there…" and if they are aware of support, parents do not necessarily understand its nature or its efficacy (Clay et al., 2016; Carers Trust and NatCen, 2019). Barnardo's previously found that only a low percentage of young carers were informed about help available through social services and even less about school support. They also found that teachers were not aware of external support for young carers and therefore were not able to advice on this (Barnardo's, 2006).

Professionals lack of awareness, recognition and acknowledgement of young caring

A second key barrier to the identification, engagement and support of young carers that the literature identifies is a lack awareness, recognition and/or acknowledgement of young carers and their role by professionals who are in a position to identify young people with caring responsibilities. As a result, many professionals fail to recognise the potential 'triggers' for young caring (Aldridge and Becker, cited in Warren and Ruskin, 2008). While this issue is longstanding (Christie (2010) cites several references from the nineties), recognition and identification by professionals is still not always happening, and this may occur for example when the caring role that a young person is undertaking is an emotional one (Carers Trust and NatCen, 2019). Ronicle, (2011, p46) states that "practitioners across adult and children's services do not always have a clear understanding and awareness of young carers and how their caring role impacts on their lives". With regards to health professionals (although not specific to young carers) Carduff et al. (2014, p1) found "there was ambiguity about the role of primary care professionals in identifying and supporting carers" whereas, Ronicle (2011) reports a finding that in the borough of Islington it was felt that the number of young carers who had been referred to the young carers service from Children in Need teams was low.

System barriers

Other barriers to the identification of young carers and their families identified within literature, although not as commonly reported as those described above, include limited resources (for example, Carduff et al., 2014; Carers Trust and NatCen, 2019). The recent resource from Carers Trust and NatCen (2019) that is aimed at local government, sets out barriers to identification that were identified across different sectors (statutory services, health services, school, and the voluntary sector). Several barriers were highlighted relating to ineffective systems: joint working and cooperation across sectors, technology, the clarity of roles and responsibilities of professionals, and capacity issues. A knowledge and skills gap related to understanding young carers and how to support them was also put forward, which suggests something lacking with workforce development (as does a lack of clarity of roles and responsibilities). The research highlighted the vagueness of duties for the cooperation of health and education, the lack of a duty to identify young carers in schools, and financial constraints as being fundamental issues.

Hidden and less supported

The study by Warren and Ruskin (2008) classified three different groups of young people: (a) 'non young carers' ('non-caring'); (b) known young carers; and (c) children 'showing signs of caring' (but who appear not to have been identified/recognised as carers. The study found that those showing signs of caring had less support from health and social care services – despite sometimes undertaking more tasks and having greater responsibilities than known young carers. The authors state that this group of young people were unsupported since their caring roles remained 'hidden'. Similarly, Clay et al. (2016) report that as a consequence of parents and children being concerned about disclosure of their situation, children can go unrecognised and unsupported.

Conclusion, Part B: Young carers: generally a hidden and invisible population

While one focus of this review was to identify the 'hidden', 'hard to reach', 'seldom-heard', or 'specifically disadvantaged' groups, the literature clearly describes young carers generally with such terms and uses them interchangeably. Despite their recognition having increased over the years, young carers still remain a hidden population today, three decades after their hiddenness was highlighted. Literature highlights that despite sharing commonalities with other seldom heard groups, young carers are a heterogeneous group with different circumstances and different needs.

Multiple and commonly reported barriers are found in the literature as to why young carers may not be identified. These can be viewed as falling under three categories: lack of self-identification; lack of professional awareness and recognition; and systems that are lacking. It is evident from the literature that these barriers are (as Carers Trust and NatCen (2019) assert) interconnected and interdependent. It would be helpful therefore to consider how these barriers interrelate when considering solutions to these barriers. The link between remaining unidentified and remaining unsupported (and not having their rights as young carers met) is evident from the literature. This fact should drive the need to better understand the reasons why these children and young people are remaining unidentified.

Part C: Improving identification for young carers

There are numerous and varied recommendations and research findings found within the literature related to improving or enabling the identification and engagement of young carers. These relate to both practice and strategic levels, as well as local and national levels.

Strategic and systems level

The report by Carers Trust and NatCen (2019) summarises a wide range of enablers that they identified to improve identification, beginning with acknowledging young carers as a priority, securing relevant partners' commitment and transforming services to ensure young carers are identified and routed through to support. The report emphasises that these enablers - although separate - are interconnected. The report also puts forward a number of recommendations for improving young carers' identification including a "commitment from multiple agencies and a fundamental change in organisational culture" (p66). It asserts that such a culture change, along with senior statutory leadership and integration into wider identification and support mechanisms, is necessary to bring about effective whole system and whole family approaches. Oversight and scrutiny are also highlighted, including improving data collection mechanisms and identification of young carers by Ofsted. The report concludes by recommending the transformation of systems (referral, case management and review), prioritising and investing in young carers, and developing the workforce across all sectors at both national and local level.

Practice level

Multi-agency working: coordinated, 'whole family' support, and effective pathways

Multi-agency working and a coordinated and holistic or 'whole family' approach to support has been upheld as the best way to support young carers and their families for a many years (for example, Frank and Mclarnon, 2008). The Social Care Institute for Excellence (SCIE) (cited in Butterworth, 2014, p10) encouraged the development of an "open door into a system of joined-up support at every point of entry". Joseph et al. (2019b) highlight the need for "interdisciplinary and multiagency working" as do Warren and Ruskin (2008) who conclude that effective collaborative practices will help ensure young carers and families access support. Social care, health and education professionals all have a crucial role in the identification and assessment of young carers (Clay et al., 2016) and should work together (Barnardo's, 2006) also in collaboration with the voluntary sector (Carers Trust and NatCen, 2019). James (2017) however found that practitioners in their study thought that adult services, mental health, and drug and alcohol service needed to improve their identification of young carers. The literature also repeatedly highlights the need for clear, effective and accessible pathways to support for young carers and families (Carers Trust and The Children's Society, 2016; James, 2017; Carers Trust and NatCen, 2019)

Early intervention

A further consistent message from the literature is that early intervention and being proactive is key (for example, Clay et al., 2016) as is the critical role of holistic assessment by all services. Previously, the Common Assessment Framework (CAF) was upheld as an enabling mechanism for this (for example, Frank and Mclarnon, 2008) but now the Early Help Assessment Tool (EHAT) (which replaced the CAF) has been highlighted as being an effective way of early identification and assessment through a coordinated approach (Carers Trust and NatCen, 2019). Christie (2006) highlights the need for professionals to be "vigilant to potential signs and cues" (p.92). In addition, the use of checklists and assessment tools to support identification have been recommended (e.g. James, 2017; Carers Trust and The Children's Society, 2016).

Awareness raising and workforce development

The UK is the only country to be classed at the Level 2 (Advanced) of the classification of countries according to their level of awareness of the issue of young carers and their policy response (Leu and Becker, 2016). Despite being the highest ranked country internationally, with "widespread awareness and recognition of young carers amongst public, policy makers and professionals", the importance of raising the awareness of young carers remains a common theme in the literature. This is however problematic because of the controversial nature of the label of young carer Joseph et al. (2019b). Carers Trust and The Children's Society (2016) conclude in their Making a Step Change report that awareness is key to identifying young carers but that this requires time and persistence. The awareness and understanding of professionals needs to be increased about the needs of families as well as support services available for young carers (for example, Clay et al., 2016). Teachers in particular need training to raise their level of awareness and understanding (for example, James, 2017; Clay et al., 2016). Furthermore, schools should raise awareness about young carers with other pupils (James, 2017) and use the national Young Carers' Awareness Day to raise awareness (Carers Trust and NatCen, 2019).

Schools

Ronicle (2011, p47) states that "schools play a vital role in both early identification and in the provision of support for young carers and their families" and many recommendations have been put forward in the literature to facilitate identification including shools having a young carer strategy and teacher training on young carers issues (for example, Barnardo's, 2006), establishing a School Lead for young carers (for example, Carers Trust and NatCen, 2019), providing opportunities and activities for young carers to identify themselves (for example, Carers Trust and The Children's Society, 2016) and "encouraging a culture where young carers can ask for help without fear of bullying or stigma and where other pupils are aware of the issues they face" (for example, Barnardo's, 2006, p11).

Promotion of available support

The need to promote support and support services is highlighted in the literature and access to support services has been found to be dependent (among other factors) on families having a good awareness and understanding of available support services (Clay et al., 2016). For example, "early and effective communication between professionals and families helped to allay parental concerns about the consequences of requesting/accessing support, and helped to facilitate access to young carers' projects" (Clay et al., 2016, pp9-10).

Barnardo's (2006) recommends that local authorities should use publicity materials that advertise local support.

Conclusion, Part C: Improving identification for young carers

The literature reveals numerous and varied ways that identification and engagement of young carers could be improved at both a policy and at a practice level. Foundational to any improvement is the need for investment at both local and national level to actualise effective whole family, multi-agency, and 'no wrong door' approaches that are underpinned by legislation. It is clear that early identification is key and using early trigger systems such as the EHAT can enable this. Awareness raising and workforce development are also seen to be key areas for development, as is the important role that schools must play in identifying and triggering support for young carers and their families. An investment in the ongoing promotion of the support that is available is clearly needed to ensure young carers and families know help exists and how to access it. In order to effectively develop these different strands however, a coordinated and strategic approach would appear vital.

Part D: Particularly hidden groups of young carers and barriers to identification and support

Brackertz (as cited in Kelleher et al., 2014) asserts that it is a young person's particular circumstances that determines the extent to which they are 'hard to reach' and the practical challenges of engaging seldom heard young people. Indeed, although the literature reveals that young carers are generally viewed as being a 'hidden' or 'invisible' group of young people, it also highlights that there are particular groups of young carers who because of their individual circumstances are especially likely to be 'hidden', 'invisible', 'hard to reach', or 'seldom heard'. For example, Carers Trust and NatCen (2019, p4) state that "'seldom heard' groups are at a higher risk of not being identified" and Ronicle (2011, p10) reports that "there is a recognised need to identify the many hidden young carers, particularly in families with relatively complex levels of need and where mental health and substance misuse issues may be a concern".

A number of different groups and communities have been identified as requiring special attention:

"It is important that special consideration is given to specific groups to ensure inclusive working practice, especially when undertaking an assessment of needs. For example: black and minority ethnic groups; refugees and asylum-seekers; parents dependent on drugs or alcohol; parents with mental ill-health; parents with HIV/AIDS; families in rural areas; very young carers." (Frank and Mclarnon, 2008, p5)

There has been consistency as well as variation in the particular groups that have been highlighted. For example, 'hard to reach groups' listed by Phelps (2012) include:

"BAME communities; refugee and asylum seeker carers; travellers; younger carers (aged 5–10 years); young adult carers (aged 16–24 years)[6]; young carers from rural areas; children caring because of parental mental illness, substance misuse and other stigmatised condition such as HIV; young carers who have offended or are at risk of offending; young carers with special educational needs and disabilities; sibling carers." (Phelps, 2012, p.20)

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[6] Although only briefly mentioned within this review due to the literature selection, young adult carers have been highlighted in depth within literature in recent years and recognition, awareness, and support for this group has increased.

And 'seldom heard' groups listed by Carers Trust and NatCen (2019) include:

> "Black, Asian and minority ethnic backgrounds, those identifying themselves as lesbian, gay, bisexual, transgender, questioning and intersex[LGBTQI], those living in rural areas, those caring for someone with a mental health condition and/or those caring for someone who misuses drugs or alcohol." (Carers Trust and NatCen 2019, p8)

The literature describes the different and particular circumstances of young carers from a range of different groups, and why and how these can act as barriers to their identification and subsequent engagement with support.

Particular stigmatised conditions

As previously discussed, a significant underlying reason why young carers and families do not self-identify is because of the fear of the stigma associated with caring in general. The literature commonly stresses however that such fears and associated difficulty with self-disclosing are even more prevalent when young people are caring for someone with particular illnesses or conditions that are perceived as being stigmatising, such as mental ill-health and alcohol and substance misuse, as well as with certain physical conditions such as HIV/AIDS (for example, Stafford, Frank, and Alexander (as cited in Christie, 2006); Hill (2012); and Carers Trust and NatCen (2019)).

Parental alcohol misuse, parental substance misuse and parental mental health

Young carers within families where there is parental alcohol or substance misuse or parental mental health have been consistently recognised in literature as being particularly hard to reach and potentially hidden as a consequence of increased stigma associated with drugs or alcohol misuse (for example, Frank and Mclarnon, 2008; Phelps, 2012). Frank (as cited in Christie, 2006) concluded that more children caring for parents with a visible illness were identified than those caring for a parent with a mental-health condition, or a drug or alcohol related illness.

Terms including shame, stigma, 'family secrecy', 'a taboo subject', and 'family business' have been used in relation to why young carers keep silent about their family situation and remain unidentified. Carers Trust and NatCen (2019) found that service providers highlighted mental health issues and substance misuse as being particularly linked to stigma; however they found young carers did not hold this distinction between mental and physical illnesses.

In discussing the identification and engagement of young carers, the literature often discusses parental alcohol and substance misuse and parental mental-ill-health together:

> "Families may also fear that their children could be taken into care or are concerned about the reactions of others if they disclose mental health and/or substance misuse issues. As a result many young carers remain 'hidden' from health, social care and education services." (Ronicle, 2011)

'Condition stigma' is one of five types of stigma listed by (Hughes, 2016) in their overview of stigma experienced by family carers. Hughes includes 'self-inflicted conditions' within this category and provides drug and alcohol abuse as examples. A recent Swedish study found that young carers developed purposeful strategies to normalize themselves within their social circle and become 'invisible' (Hagström and Forinder, 2019). Similarly, Gillan (as cited in Hill, 2012) found in a Scottish study in 2009 that "guarding secrets about parental harmful drinking was important to children because of the stigma associated with it" (p180). The same study also highlighted the concern by counsellors that where children were from professional, middle-class families, social stigma and secrecy were a specific concern.

Parental barriers

Furthermore, Hill (2012) in discussing an international review of prevention programmes for children of problem drinkers, outlines the additional ethical challenge of recruiting children to such programmes and obtaining parental consent. Carers Trust and NatCen (2019) found that whereas parents or family members not recognising or accepting that they have a health condition or disability was a general barrier to the identifcation of young carers, this was more pronounced when caring was for someone with more hidden or stigmatised conditions (such as mental ill health and/or substance misuse). They also raise the issue of parents dissengaging from specialist services such as a drug and alcohol services if they are questioned about their children, with the result of children being unsupported and at risk.

The variability of caring and identification

Reflecting earlier research by Aldridge and Becker (2003), Clay et al. (2016) discuss how young carers caring for parents with mental health conditions report the unpredictability of how the condition affected their parents and the fluctuation of their caring responsibilities from very minimal to high levels of care. The study also found that support services were not always available when needed due to the unpredictability of the caring role. The unpredictability of caring responsibilities for some young people has implications for the timing of assessments and potentially missing the identification of some young carers - if assessment takes place when caring roles at at a low level.

HIV/AIDS

Children caring for someone with HIV/AIDS has also arisen significantly in the young carers' literature in the context of being a stigmatised condition that can act as a barrier to identification and engagement.

Prevalence

The number of HIV-affected children (those living in families where one or more members has been diagnosed with HIV) in the UK is unknown, but was estimated some years ago at between 15,000 to 20,000 (Conway, as cited in Becker and Evans, 2007). Furthermore, Cree and Sidhva (2011) reference several sources that report that since 2000, epidemiologists believe that the global percentage of people living with HIV has stabilised.

Caring roles of young people caring for someone with HIV

Becker and Evans (2007) report that children in families affected by HIV/AIDS in the UK "had significant, regular responsibilities for household chores,

including cooking, cleaning, washing dishes, laundry, shopping" (p5). They also report, however, that due to the fluctuating nature of HIV caring roles fluctuate in intensity. As previously discussed, this has implications for the assessment of families and young carers.

Stigma and discrimination

Cree and Sidhva (2010) state that "children who are infected with, and affected by, Human Immunodeficiency Virus (HIV) are living with an illness that, throughout the world, brings with it stigma and discrimination" (p1587). They also report that the wide-spread ignorance about HIV has changed little over the years. Whilst Hughes (2016) categorises the stigma associated with HIV/AIDS under 'condition stigma', Becker and Evans (2009) outline three types of stigma and discrimination experienced by families as being 'enacted stigma' (experience of discrimination from community and family members), 'perceived stigma' (fear of stigma), and 'self-stigma', where stigmatising labels are imposed on oneself.

Disclosure

Becker and Evans (2007) report that in their study "although direct experiences of discrimination were not mentioned by children in the UK, the secrecy surrounding HIV significantly affected their ability to talk about their parents' illness and seek support from family, friends, neighbours, school teachers and other professionals" (pp9-10). Ely, Lewis, and Chinouya (as cited in Becker and Evans, 2007) found parents are reluctant to disclose their HIV status to their children due to the risk of disclosure outside the family and their children's reactions.

Cree and Sidhva (2011) pose the question that "if children and young people are advised by their parents not to tell anyone about HIV, how will they be able to access the help they need from mainstream services?" (p15). They conclude that this is a critical question for the future.

Caring for parents with dementia

Young carers caring for parents with dementia are a further hidden group found in the literature to some degree, although as Svanberg et al. (as cited in Hutchinson, Roberts, and Kurrle, 2014) put forward, there are noticeable gaps in the literature about outcome for these young people. Their article in the Australian Journal of Dementia Care discusses a research project recording the difficult journeys of young people caring for a parent with younger onset dementia. It outlines that the social stigma of having a parent with dementia leads to discrimination and exclusion for young people. The authors highlight the lack of understanding about how dementia impacts young people, as well as the fact that services and professionals focus on the person with care needs rather than the young people who are caring for their parents.

Caring for parents with Huntington's Disease

A study in 2015 in the USA found that children and young people caring for someone in their family with Huntingdon's Disease were a "little known caregiver population" (Kavanaugh et al., 2015, p12). It found that these young carers were often unrecognised and left isolated due to the stigmatising conditions of the disease and the "invisibility of their parents' disease and their caregiving role to others" (p13). As with dementia discussed above, Moore and McArthur (as cited in Kavanaugh et al., 2015) report that the focus is on the ill family member, and as a consequnce, the needs of the young person are overlooked.

Caring when a family member is in prison

Leeson and Morgan (2019) taking on a less common topic in their article 'Children with a Parent in Prison England and Wales: A Hidden Population of Young Carers' assert that children who have a parent in prison can take on significant physical and emotional caring responsibilities for their family. They argue that these children are a hidden population that experience structural inequality first-hand and that they are rarely eligible to be regarded as a young carer since the parent who they live with does not meet established criteria.

They cite many sources that report that stigmatisation can be a very real experience for families of prisoners. This they assert leads to families keeping their problems quiet for fear of being rejected, scapegoated, or looked down upon. Cherney and Fitzgerald and Phillips and Gates (cited in Leeson and Morgan 2019) report that children create a cover story which isolates them further, preventing them from confiding in friends or seeking help. Leeson and Morgan conclude that the lack of visibility of these children is enabling policymakers to continue to ignore their situation. Moreover, they argue that the same social acceptance and value placed on other young carers should also be afforded to these children and the eligibility of young carer organisations should be extended to them.

Black, Asian and minoritized ethnic communities (BAME communities)

Compounding issues to engagement and remaining hidden

The hidden nature of young carers from within BAME communities due to additional issues that they face, has been found in the literature for some years (for example, Frank and Mclarnon, 2008). James (2019, p6) asserts that that "BAME young carers continue to be even more isolated and hidden from services." The barriers to engaging these young carers with services have been described as being similar to those experienced by "their white counterparts, but compounded by racism, language, bullying, and lack of understanding" (The Children's Society, cited in Astrup, 2019, p15), or by various cultural and socio-economic factors (Bashford et al., 2002).

Prevalence

Analysis by The Children's Society found that "young carers are 1.5 times more likely than their peers to be from black, Asian or minority ethnic communities, and are twice as likely to not speak English as their first language" (Hounsell, 2013). James (2019, p13) highlights that "the Government's 2008 report Carers in the 21st Century states that although reports vary on numbers of BAME carers (young and adult), they are certain that a lot of them do not self-identify as carers due to cultural expectations." Findings by Warren and Ruskin (2008), if extrapolated across the UK, suggested a figure for young carers from BAME backgrounds being within the range of 309,000 to 619,000, although as the authors state further investigation is needed and the report does not claim that the findings could be more widely generalised.

Specific needs and additional vulnerabilities

The briefing by Barnardo's (Caring alone: Why Black, Asian and Minority Ethnic young carers continue to struggle to access support) highlights the specific and unique needs of this group of young carers, their particular vulnerabilities and

other inequalities that impact them, while acknowledging that these vary even within communities (James, 2019). Some of these specific issues faced by BAME communities include poverty and housing issues, racism, requiring (but not having) interpreters, undisclosed domestic abuse, language barriers, and stigma. Furthermore, Frank and Mclarnon (2008) propose that some of these groups are more likely to be excluded from school.

Cultural barriers to identification and engagement

The young carers' literature has also reported that there are many cultural barriers to the identification and engagement of young carers from BAME communities.

One barrier relates to the cultural understanding, acknowledgement and recognition of being a young carer and the unfamiliarity of the term. James (2019) reports that "the concept of being a young carer is alien to many communities and families particularly minority communities" (p13). Similarly, Bashford et al. (2002) reports that despite the recognition of mental health issues of mothers and possible impacts on children, community group respondents did not recognise children and young people as carers and moreover, for some it was found that there was a strong reaction against the notion of young carers.

Secondly, Carers Trust and NatCen (2019) report that in some cultures (more common in certain communities including black, Asian, Jewish, traveller and minority ethnic communities) there are embedded family and/or cultural expectations for children to care. The Children's Society (as cited in James, 2019) also highlight that in BAME communities there are cultural expectations for caring which can be gendered (such as the greater expectation for females to take on caring roles in Asian communities). James reports that some practitioners felt these expectations were difficult to challenge due to cultural differences.

Thirdly, according to Bashford et al. (2002) professionals working with families in one Asian community thought there was little understanding of mental health issues, as well as some conflict between western and Asian concepts of behavioural problems.

Further cultural barriers include: BAME families lacking trust in social services due to a fear of their family being split up and hence not wishing agencies to be involved (James, 2019); "perceived racism or lack of understanding within predominantly 'white' services" (Bashford et al., 2002, p65); boys and those caring for fathers being less likely to ask for help (The Children's Society, as cited in Astrup, 2019); and girls not being allowed to utilise support services on their own (Bashford et al., 2002).

The assertion by Warren and Ruskin (2008) should be noted that professional recognition and identification of young carers may be being impacted by myths and racial stereotypes associated with black and South Asian communities for example, because of extended family networks within these communities, families care for themselves.

Lack of engagement with communities and low awareness of support

Another barrier frequently highlighted in the literature is the lack of awareness of families of the support and services available (for example, James, 2019; Astrup, 2019) and being able to access culturally appropriate information (James, 2017).

The lack of engagement with communities is also reported by James (2019) and Bashford et al. (2002) who specifically mention older generations lacking this awareness.

Stigma and fear

In addition to the stigma-induced barrier to the identification of young carers generally, literature reveals that families within BAME communities can face additional forms of stigma and discrimination from within a community. Discrimination can be in relation to an unwillingness to understand or accept disability (Frank and Mclarnon, 2008) and there can be cultural stigma specifically around mental health (James, 2019). Warren and Ruskin (2008, p2) cite several sources to illustrate the assertion that "the perceived stigma associated with alcohol misuse, HIV/AIDS, mental illness, or caring more generally, particularly among young black and South Asian carers, may also affect families' openness about child care-giving". For minority communities, stigma can be a key barrier to seeking help and self-referring (James, 2019) and can inhibit service take up (Bashford et al., 2002).

Young carers who are refugees or are seeking asylum

The Children's Society's online Refugee Toolkit aimed at practitioners sets out some specific issues related to refugees and asylum seekers who are also young carers. The resource states that "young refugees and those from migrant communities can face severe and multiple disadvantages in their lives and have complex needs" (The Children's Society, 2020). It outlines the fact that many refugees or those who are seeking asylum have unmet health and care needs which can lead to them relying on children to care for them. It asserts that for these already particularly vulnerable young people, where language may be a barrier for their families, the additional burden of caring responsibilities may prevent them from integrating into their communities and having continuity of support. It puts forward the following reasons for this: (a) being unaware of support services; (b) a reluctance to involve agencies; (c) cultural views about caring; (d) young carers not recognising themselves as carers; and (e) the natural progression of a caring role by children over time.

Armed forces families

The Children's Society in their report on young carers from armed forces families sets out that these young carers are a particularly vulnerable group and that negative impacts are compounded because of "other factors linked specifically with military life" (The Children's Society, 2017, p9). For example, the report states that there are "significant barriers to recognition and identification of young carers" (p18).

Prevalence

Using desktop-based research and the latest census data, The Children's Society found there to be 521 young carers in armed forces families. These figures the report highlights do not include children of veterans or ex-service personnel and, since these comes from the census data, do not capture young carers caring for those with stigmatised conditions and disabilities. The report concludes that despite recognition of young carers in armed forces families "the scale of this issue remains unknown and the figures and statistics are piecemeal" (The Children's Society, 2017, p4).

Cultural barriers to identification and engagement

A key barrier highlighted in The Children's Society's report is the stigma of asking for help experienced by armed forces families. High stigma attached to illness in military communities could be due to the potential of health conditions impacting on promotions (Carers Trust and NatCen, 2019). This wariness of contacting military welfare services (and therefore not being identified) is also raised by Phelps and Keenleyside, 2012. Additionally, since young carers frequently have to move house and school due to deployment, this may lead to them not receiving timely support (Phelps and Keenleyside, 2012; The Children's Society, 2017).

Caring roles determining 'hiddenness'

As well as the illness, condition, or disability itself being a factor in the recognition and identification of children and young people, so too is the nature of the caring roles that they undertake.

For example, emotional support arguably represents the 'hidden elements of care' (Aldridge and Becker as cited in Christie, 2006). Similarly, Clay et al. (2016) in discussing the challenges of recruiting 'hidden' young carers to their study found that "the form and extent of caring in these families was less pronounced and harder to distinguish from children providing general support around the home (p86). Although Warren and Ruskin (2008) found that children and young people who show signs of being in a caring role (but not 'known young carers') sometimes performed more tasks and took more frequent full-responsibility than 'known young carers', they also found that this sub-group of young carers was also more likely than 'known young carers' to provide child care (sibling care) or emotional support.

Young carers caring for siblings and themselves

Young carers supporting alcohol-dependent parents have also been found to take on caring responsibilities for their siblings as well as caring for themselves (Hagström and Forinder, 2019) and this raises the question as to whether these caring roles were recognised by themselves, their family, or professionals.

Other barriers related to engagement of families and outcomes of young carers

Other barriers have also been highlighted in the literature that have impacts related to the engagement of young carers and their families and the outcomes experienced by young carers from particular groups. Carers Trust and NatCen (2019) report that service providers found it more difficult to support families who did not speak fluent English (for example, those with an additional language or where parents were deaf or hearing impaired). These families were less aware of the support available. They also report that the stigma perceived by families around engagement with social care was higher in areas where benefit uptake is perceived to be uncommon. Hounsell, (2013) assert that some young carers are as young as five years old, yet (Mills, Ashley and Phelps, 2010) in their resource for professionals working with younger carers (aged 5 to 8) report that many services only start working with young carers once they reach eight years old. The issue of poverty and young carers is also found in the literature. Vizard et al. (2019) assert that young carers affected by child poverty experience different outcomes than those who are not and highlight that their study raises important questions about the effectiveness of social protection for these young carers.

Conclusion, Part D: Particularly hidden groups of young carers and barriers to identification and support

The literature review set out to answer the questions 'What are the 'hidden', 'hard to reach', 'seldom heard', or 'specifically disadvantaged' groups of young carers?' and 'What are the barriers to identification' for these groups? The literature clearly reveals that all young carers are a 'hidden' population. However, it also reveals that there is additionally a significant number of groups and communities of young carers who because of their individual circumstances, are even more likely not to be identified and supported.

One of these groups are young carers caring for someone where there is perceived stigma attached to a health condition, disability or caring role. The resulting fear of prejudice, discrimination, and consequences of disclosure is a common and significant factor in young carers and families not self-identifying, as well as in actively concealing their family situations. Young carers caring for parents with mental ill health and/or substance misuse have been commonly identified as needing special attention. However, those whose caring is related to other stigmatised conditions/disabilities, including HIV/AIDS, dementia, Huntingdon's Disease, and young carers with a parent in prison were also highlighted within the literature.

A second group (or groups) of young carers are those from different communities who potentially have specific needs and vulnerabilities and may be facing additional cultural barriers. This review found that young carers from BAME communities were most commonly and thoroughly discussed in the literature. Other communities highlighted were armed forces families, refugee and asylum seekers, travellers, and the Jewish community. These additional barriers to identification and support faced by these young carers are specifically related to their communities and cultures and may be particularly challenging. They include stigma and fear within communities, communication and engagement barriers with services, and low awareness and understanding of young carer issues, certain conditions, and available support.

This review also found other groups of young carers (those who are very young, live rurally, are young adults, are at risk of offending, identify as LGBTQI, or have special needs or disabilities) who were briefly highlighted within the literature as being 'hidden', 'hard to reach', or 'seldom heard'. These groups, however, were not found through this review to be discussed in as much detail as some of the aforementioned groups. It was also found that the caring role itself may also determine how hidden a young carer is. Where caring is for siblings, for example, or is predominantly emotional in nature, young carers, families, and professionals may not recognise the role and identify a young person as a carer.

Furthermore, this review found a number of other factors identified within the literature that may impact the identification and engagement of young carers and families with support. Parental barriers, a fluctuating caring role, language barriers, poverty, social class, and professionals not recognising caring roles or focusing on the person who is ill or needs care have all arisen in the review as potentially inhibiting identification of young carers. These other factors, although they may have been identified specifically in relation to particular groups and communities of young carers (and be pertinent to these groups) are almost certainly not exclusive to specific groups. These factors will overlap with other circumstances and create for some young carers a complex mix of barriers that inhibit their identification and support.

Part E: Improving the identification of young carers from groups that are particularly 'hidden', 'seldom heard' or 'hard to reach'

As discussed, within in the literature there are many, wide-ranging recommendations for improving the identification and engagement of all young carers generally, at both practice and strategic level, as well as local and national level. However, as well as these general approaches to strengthen identification and engagement, the literature also includes supplementary approaches for improving the identification and engagement of particularly 'hidden', 'seldom heard', or 'hard to reach' groups of young carers.

Kelleher et al. (2014) in their discussion of the participation of 'seldom heard' young people (who may be difficult to identify and engage) highlight that these young people are seldom heard not because of inherent characteristics, but because of the absence of appropriate support structures that enable their participation. They report that it is important to understand their heterogeneity and to identify the barriers to their participation and, citing Williamson and colleagues, to appreciate the complexity that exists within these groups. They argue that characteristics of these groups (demographic, cultural, behavioural, attitudinal and structural factors), citing Brackertz and other authors, must be understood, as well as their interplay, in order to tailor initiatives to meet their needs.

Citing the Health and Safety Executive, they report that by taking such an approach, good practice elements can be identified and applied across other 'subgroups'. They conclude (again citing Brackertz and other authors), that instead of simply listing 'seldom heard' groups, it is more useful to define their characteristics and link these to effective approaches to access and engagement. Kelleher et al. (2014) also conclude that evidence supports "the development of principles to guide participation practice rather than a uniform, prescriptive approach that is unlikely to meet the requirements of diverse individuals and groups" (p34).

In their discussion of definitions of young carers, Joseph et al. (2019b) highlight the 'complex web' of different needs of families (p11) and remind us that young carers taking on varying amounts of care will have distinctive needs, which when recognised, can lead to more nuanced and responsive policy targets. James (2019) states that "specific action and policies that address the particular needs of BAME young carers is needed" (p7), while the need for local services to be pro-active in engaging young carers from hard to reach communities is highlighted by Frank and Mclarnon (2008).

Understanding and awareness

As discussed previouslyliterature highlights the importance of increasing the recognition and awareness of all young carers in order to strengthen their identification - with the general public, with professionals, and with young carers and families themselves. Also, as introduced above, the literature further highlights how a deeper awareness, recognition and understanding of the

situations of young carers from 'hidden' and 'seldom heard' groups is key to their identification and engagement.

Countering stigma and its effects

One of the reasons that emerges from the literature as to why awareness and understanding needs to be raised at all levels, is in order to reduce stigma and discrimination, which in turn will help young carers and families seek support including children affected by HIV/AIDS (Becker and Evans, 2007). Countering stigma and myths at a societal level is important and can be done through specific awareness campaigns (Hughes, 2016). Hughes also proposes the need for further research into the effects of stigma on family carers and recommends organisations train staff working with carers in how to recognise those experiencing it.

Awareness, recognition and understanding by professionals

Becker and Evans (2007) highlight the need (from the local to global level) of greater recognition of children's caring responsibilities in families affected by HIV. The study by Kavanaugh et al. (2015) found awareness needed to be raised about those caring in families affected by Huntingdon's Disease and similarly, James (2019) reports the need for practitioners working with BAME families to have a better understanding of the issues impacting these communities. And despite some recognition of young carers in armed forces families, The Children's Society (2017) found that schools were not recognising or identifying these children.

Workforce development: professional awareness and training

In addition to training professionals generally about who young carers are, the impacts on them, and about their needs, supplementary elements related to 'hidden' and 'seldom heard' groups have been recommended within training programmes - for example (as above), training staff to recognise those carers who are experiencing stigma (Hughes, 2016) and training staff in equality and diversity issues (Bashford et al., 2002). Furthermore, specific and detailed information about particular groups can be included within young carer training; an example of this is highlighting that young carers from military families might not be caring for service personnel, but rather for another parent or for siblings (Phelps and Keenleyside, 2012).

Strategic level

Research and data to support understanding

Data is important to underpin understanding and to inform policy and practice development to support hidden young carers. Frank & Mclarnon (2008) for example proposed that services need to be developed according to local needs. James (2019) recommends an analysis of BAME communities within the health system by local authorities and clinical commissioning groups in order to gain insights for planning support for young carers within their "local transformation, area plans and NHSE arrangements" (p11). The need to understand a local population of young carers is also advocated by Carers Trust and Natcen (2019), who suggest using the Carers Strategy or a joint strategic needs assessment to do so and then mapping support available to those groups that are less likely to be identified or to engage. One local authority as reported in Ronicle (2011) aimed to undertake an assessment of the number of unidentified young carers with their area.

At national level, The Children Society used the Longitudinal Survey of Young

People in England (LSYPE) to learn more about particular groups of young carers and used these findings in their report Hidden from View (The Children's Society, 2013). The Children's Society also report the lack of statistical evidence for the numbers of young carers within armed forces families and recommend a wide scale national consultation and data collection to ascertain the prevalence, as well as for Service Children in State Schools (SCISS schools) to correlate data of pupils who are young carers and service children. Others have recommended monitoring child poverty outcomes among young carers and using national household income surveys (Vizard et al., 2019).

Coordinated, multi-agency approach

As it is for young carers in general, a coordinated, multi-agency approach to supporting those who are especially at risk and/or from 'hidden' groups is endorsed in literature. Carers Trust and NatCen (2019) recommend the establishment of multi-agency networks and fostering a culture of partnership working, which will bring different skills and expertise (Joseph, et al., 2019b). The Children's Society (2017) draws our attention to the NHS Integrated Toolkit to support such multi-agency working to identify and assess young carers. The Children's Society (n.d) for example, reiterate the need for a multi-agency and 'no wrong door' approach, with all practitioners being in a position to support refugee and asylum seeking families. Similarly, James (2019) states that services working with BAME families and other vulnerabilities need to be more joined up.

Policy development

Policy development at both local and national levels can play a role in improving how organisations work with communities and groups, and it can play an indirect role when it is directed at addressing stigma. Bashford et al. (2002) calls for policies (and procedures) developed by agencies to be impact assessed for BAME groups, while Hughes (2016) promotes a push to understand the effects of stigma at policy level and for stigma to be addressed within organisational policies.

Engagement and communication with communities

Engagement with communities

The importance of proactively engaging with communities to improve the identification and engagement of young carers is apparent within literature. In fact, The Children's Society (n.d) asserts that "communities are the most important aspect of the jigsaw to engage young carers". James (2019), referring to BAME communities, reflects this by stating that links with communities are necessary in order to raise awareness of available services. James (2017) points out that services should be accessible and visible and work to overcome cultural and language barriers, a point also highlighted by Astrup (2019) who further asserts that websites and materials should be translated and recognise cultural issues. James (2017) encourages the provision of specialist support for BAME young carers in order that barriers are broken down, stigma is reduced, and fear of agency involvement lowered (Astrup, 2019).

Culturally appropriate and sensitive services

Approaches to support need to be culturally appropriate (Becker and Evans, 2007) and services need to be sensitive to and adapt to different cultures and needs (for example, Evans and Becker, 2009; The Children's Society, 2018). Sinclair (as cited in Kelleher et al., 2014) noted that "those tasked with

engaging young people are challenged to examine their practice to ensure their approaches are inclusive" (p. 28). Although not related to working with a 'community', but highlighting the need for services to be sensitive, the question is raised by Cree and Sidhva (2011) as to whether mainstream services have sufficient experience and knowledge to adequately support children and young people affected by HIV in universal services.

Engaging with different communities requires an understanding of the culture and cultural differences, which as well as understanding the language, is vital in gaining trust from children and families (James, 2019). In regard to working with service families, for example, Public Health England has recommended that health visitors and school nurses have an understanding of service life and culture (The Children's Society, 2017).

Avoiding cultural assumptions

However, the literature warns against making assumptions about a person's culture or background (The Children's Society, 2018). For example, it should not be assumed that a family does not want support because they are from a particular culture (The Children's Society, n.d.) and Astrup (2019) reminds us that issues may not be the same simply because families are from the same community and that approaches to engagement need to be tailor-made.

Overcoming language barriers

James (2019) asserts that services need to overcome any language and cultural barriers. They highlight that as a consequence of language barriers, the need for translators is a particularly pertinent issue for parents who rely on children to care. They recommend that NHS staff are trained in cultural competence and on the demographics of the communities where they are working, so that they are mindful of such issues. Moreover, they recommend that "the Department of Health and NHS England should seek to review the current guidance on the use of interpreters and translators within the NHS and look to ensure that it is being more widely implemented" (p4).

Working in partnership with specialist agencies and dedicated staff

Two chief ways of facilitating engagement with communities are discussed in the literature. The first is the formation of partnerships between young carer services and universal services, or with specialist services with close links into a community which can garner necessary skills and experience. For example, partnerships can be developed in order to promote awareness or undertake joint family visits (Carers Trust and NatCen, 2019). Cultural barriers can be overcome by working for example in partnership with military organisations (Phelps and Keenleyside, 2012).

The second approach is for services to employ dedicated staff from within communities who come with their own specialisms, experience and knowledge of their communities (James, 2019; Carers Trust and NatCen, 2019).

Increasing the awareness and understanding within communities

The importance of increasing the awareness and understanding of communities is focussed on three main areas within the literature: (1) increasing the awareness and understanding of the term 'young carer' and the impacts on young carers and their rights; (2) raising awareness in order to reduce stigma; and (3) raising awareness of support services.

Awareness and understanding of who are young carers

Firstly, James (2019) for example, highlights the need for BAME communities to have a better understanding of the term 'young carer' and the negative impacts of being a young carer, and The Children's Society (2017) reports the need for accessible materials to promote the needs and rights of young carers in armed forces families. The HIVE information centres are specifically highlighted as a way to offer training and information.

Reducing stigma in communities

Secondly, awareness and understanding within communities has been proposed as a perquisite to engaging families. For example, James (2019) recommends that to ensure that families access support, NHS England and community outreach groups "do more within BAME communities to reduce the stigma of mental illness, special needs and disability" (p4). Similarly, Becker and Evans (2007) assert that a greater awareness and knowledge of HIV/AIDS within families is required in order to enable children and families to seek support.

Awareness of support and targeted promotional work

Thirdly, the importance of appropriately promoting services to ensure that young carers and families are aware that there is support available is commonly advocated for. Carers Trust and NatCen (2019) report that regular communication with community groups raises the profile of support services, while James (2019) recommends that targeted promotional work with BAME communities is undertaken. It is also important that all young carers are aware that they are acknowledged and that support is available for them and not only for those who they look after (Kavanaugh et al., 2015).

Improving self-identification

A key barrier to identification of young carers has been found to be children, young people, and families not self-identifying which can be, as discussed, a result of several factors. It follows therefore that addressing the reasons why young carers and families may not self-identify should improve identification generally. Carduff et al. (2014) report that their study to identify carers in primary care suggests improving carer identification requires a two-pronged approach, i.e. proactively identifying carers in primary care, but also empowering carers to self-identify. Carduff et al. also suggest that professionals can encourage carers to seek advice and support when their situation changes and that "the carer's perception of their role and where they are on the caring trajectory may influence their willingness to identify" (p7) and Banks (as cited in Hill, 2012) concludes that non-intrusive support is needed because of the reluctance of young carers to self-identify.

Hill (2012) discusses the agency of young people and their ability to make active choices to share information about their lives. They report that trust is a significant factor for young people sharing information about their lives and state that "the centrality of relationships suggests that this is an area that should be considered in policy and practice for children and young people affected by parental alcohol use" (p213).

Voice and participation

Bell et al. and McEvoy (as cited in Kelleher et al., 2014) assert that seldom heard young people are more likely to become involved in mainstream participation

structures if their involvement is directly targeted. Phelps (2017) highlights the need for the voice of hidden young carers to be heard and amplified, and while they discuss the challenges of this, they highlight how some areas have taken a proactive and targeted approach in order to capture their voices. This is in line with what Phelps (2012) suggests, that "in order to hear what these young people are saying about their needs and current services, commissioners will need to take both a proactive and creative approach and seek to gather views from young people through other routes such as schools, youth services, health and social care settings" (p15).

Other considerations

Early identification and intervention

While early identification and intervention are key principles in the identification of any young carer, for some young carers from particular groups these may be particularly germane. For example, Hutchinson, Roberts, and Kurrle, 2014 (in relation to young people caring for someone with dementia) assert that programs and support need to be put in place as soon as a diagnosis of dementia is made in order to reduce the intensity of any caring role and that this is important since "issues have often existed for a long time prior to a diagnosis" (p21). Similarly, Hagström and Forinder (2019) (regarding children growing up with alcohol-dependent parents) assert the importance of early identification of these 'invisible', trauma exposed children" (p2).

Mechanisms for triggering assessments

Specific mechanisms can be developed to improve the identification of children from particular groups. For example, utilising the Veterans Passport to record information about caring roles and to trigger a statutory assessment for young carers in armed forces families (The Children's Society, 2017).

Assessment of needs

Again, although the assessment of the needs of all young carers and families is crucial, as Frank and Mclarnon (2008) state "it is important that special consideration is given to specific groups to ensure inclusive working practice, especially when undertaking an assessment of needs" (p5). The Children's Society Refugee Toolkit highlights the importance of cultural competence and appropriateness and advocates as good practice offering a choice of health workers and interpreters trained in health and the needs of asylum seeking families.

Bespoke tools for particular groups

Carers Trust and The Children's Society (2016) discuss the development in Surrey of age-appropriate assessment materials to facilitate the assessment process and support the statutory assessment. One tool is for primary-aged children ('About Me') and the other ('iCare') is aimed at secondary-aged young carers.

Definition and eligibility of young carers

Leeson and Morgan (2019) state that "there is a high degree of social acceptance and value placed on a child who cares for a parent or sibling with a disability, thanks to the hard work of those who have raised our awareness of their existence" (p12). As a consequence, they assert that these children have fewer barriers to services and they contend therefore that extending the young

carer eligibility criteria to include children with a parent in prison, will allow those children to access effective support and have their needs met "in a non-judgmental, non-stigmatised environment" (p12).

Consistent support when young carers move location

The Children's Society (2017) highlight the need for there to be consistent support for young carers from service families when they move location. Phelps, 2017a, highlights the benefit that the county-wide collaborative service within Hampshire can bring to referrals of young carers from different parts of the county.

Conclusion, Part E: Improving the identification of young carers from groups that are particularly hidden, 'seldom heard' or 'hard to reach'

The third question that the review set out to answer was 'how can we increase recognition and identification of young carers from the 'hidden', 'hard to reach', 'seldom heard', or 'specifically disadvantaged' groups?' The literature reveals that there are many general approaches that are key to the identification and engagement of all young carers, but in addition, there are supplementary approaches needed for these particular groups. Approaches must be at both practice and policy levels, as well as at local and national levels.

Firstly, a proactive approach must be taken that is underpinned by an improved awareness of the situations, needs and barriers faced by all young carers, but also of those from 'hidden' and 'seldom heard' groups. Awareness raising should also aim to reduce stigma. Awareness needs to be raised with everyone – including young carers and families and with professionals through workforce development that includes specific training on particular groups. Improved data about specific groups of young carers at both a national and local level appears vital to underpin understanding and inform policy and practice.

Targeted engagement with communities through culturally appropriate and sensitive services and overcoming language barriers is important. This can increase awareness of young carers and the support available to them, as well as reducing stigma within those communities. Supporting and empowering young carers and families to self-identify and proactively identifying young carers in primary care and adult social care are also needed, as is engaging young carers from different groups to participate and share their views.

A coordinated, whole family, multi-agency approach which focuses on early intervention and incorporates mechanisms for triggering assessments appears even more important for those from hidden groups. These good practice approaches that are well understood and are underpinned by legislation, can be enhanced further with additional mechanisms and tools and with special attention given to particular groups.

Discussion

The overarching research question from the DHSC project brief was:

> Whether and how increased identification of young carers from cohorts perceived to be 'hidden', 'hard to reach', 'seldom heard', or 'specifically disadvantaged' can be achieved?

From this question, three sub-questions were developed agreed upon by the steering group:

- What are the 'hidden', 'hard to reach', 'seldom heard', or 'specifically disadvantaged' groups?
- What are the barriers to identification and engagement for 'hidden', 'hard to reach', 'seldom-heard', or 'specifically disadvantaged' groups?
- How can we increase recognition and identification of young carers from the 'hidden', 'hard to reach', 'seldom-heard', or 'specifically disadvantaged' groups?

The review found that despite some improvement in recognition and awareness of young carers since the 2015 of duties on local authorities to identify young carers, young carers generally remain a hidden population and more needs to be done to achieve consistent, effective, early identification of young carers across all sectors and in particular through health services and adult social care.

The review also found that although sharing commonalities, young carers are a heterogeneous group with different needs, who can face multiple and common barriers to identification and support which are both interconnected and interdependent and which can be viewed as falling under three categories: lack of self-identification; lack of professional awareness and recognition; and systems that are lacking.

A number of groups and communities of young carers were found to be especially likely to be 'hidden'; those from groups whose caring is related to stigmatised conditions/disabilities, those from communities where there are cultural barriers to identification and support and young carers with particular hidden caring roles. Other groups were also identified but who were not discussed to a great extent in the literature. Furthermore, a number of other factors were identified that can be barriers to identification for all young carers but especially pertinent to some groups.

The review identified a wide range of approaches to improving identification of all young carers in a coordinated and strategic way, at both policy and practice level. The approach to identification for all young carers should be that which is underpinned by legislation, i.e. a proactive (early intervention, whole-family, multi-agency approach). Moreover, the need for supplementary and targeted approaches for particularly hidden groups has been highlighted.

Intersectionality

Although all young carers are potentially hidden from services, some will experience a more complex mix of factors that may further inhibit their identification and subsequent support. This intersectionality will be unique to each individual (as all circumstances will be different and factors will overlap in different ways), although there may be common combinations of factors

associated with particular groups that may especially inhibit identification (for example, a young carer from a BAME community having a caring role for a family member with a mental health condition or a young carer from a middle-class family where there is harmful parental drinking). With increased understanding and awareness of these combinations of factors, the identification of young carers can be improved through being more alert to certain individual's caring roles and by more nuanced practice that addresses specific barriers to identification.

Identification - not in a vacuum

It is clear from the literature that identification of young carers in general, as well as identification of particular groups of young carers, does not happen in a vacuum and is linked to and underpinned by, for example: the awareness of society, professionals, young people, and families; referral and assessment processes; the participation of young carers in the development of policy and practice; the promotion and awareness of support; and how services engage with communities and families. Therefore a broad, holistic approach to identification and support must be taken. Although identification of young carers can be viewed as the first step to supporting them directly, the support itself (if it is accessible, known about, understood and trusted by young carers and families) will be a factor in improving subsequent identification within an area. The converse is true and will be a barrier to identification.

One unexpected finding perhaps is just how broad the issue of identification of hidden young carers is, and how interconnected and interdependent it is with and on other areas of practice. This has implications for the development of local services. Although the identification of young carers can be viewed as the first step to supporting them directly, the support itself (if it is accessible, known about, understood, and trusted by young carers and families) will be a factor in improving subsequent identification within an area which would suggest that where services are already well established that identification would be facilitated, whereas the converse would be true where there is no support services or support is in its infancy. Furthermore, a broad, holistic approach to identification and support would seem to be a necessary approach.

There are of course numerous other groups and communities that were not picked up as potentially hidden within this review. This is most likely a consequence of the research community or voluntary sector not as yet being attentive to these other groups perhaps since they are smaller or perhaps less championed. It is likely however that, many other young carers will be from other groups or communities where there is perceived stigma and associated barriers to identification

As a consequence of the selection procedure, literature with a significant focus on young adult carers was not selected in this review and the author is aware that the issues of young adult carers is more thoroughly addressed in literature. Although this is a perhaps a limitation of the review, young adult carers as a potentially hidden group were still highlighted.

Although not explicitly mentioned in the findings, not all young carers are identified through the statutory young carers needs assessment and in fact many are not receiving these. Going forward it might be helpful to consider delineating identification before a young carers needs assessment takes place and the identification of a young carer through a young carers needs assessment.

This review has brought together and categorised a number of different groups of young carers identified in the literature as being particularly hidden. It has highlighted the breadth of the issue of identifying young carers and how it links to other areas of practice and has helped to bring about clarity as to how the issue of 'hidden' young carers can be addressed. It has also reinforced the understanding that all young carers are potentially a hidden population, but also that a significant number of groups and communities of young carers may be especially hidden. It would be reasonable to conclude that there are also further groups not identified in this review (for example, faith groups) that are also potentially more likely not to be identified and receiving support.

In order to bring about consistent identification and engagement with all groups and in all areas, it will be important to continue to improve our understanding of the combination of factors that inhibit identification for all young carers as well as particular groups and communities. This understanding will be needed by all professionals working with young people and families, which has implications on workforce development and the resources assigned to the task. Next, based on this understanding, policy and practice must be developed to improve the identification and engagement for all young carers generally as well as supplementing this with targeted approaches for specific groups and communities.

Further research would be helpful which specifically focuses on the 'hiddenness' of those groups of young carers found in this review to be only briefly discussed within the literature, as well as with other groups not found to have a mention. These other groups should not be overlooked when developing policy and practice.
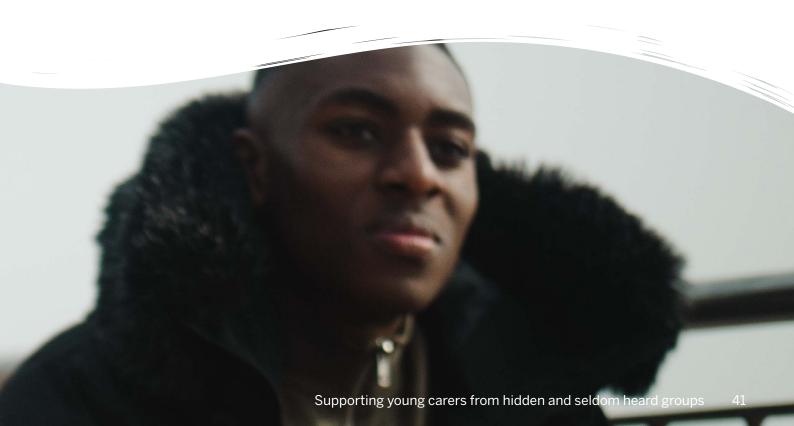
Conclusion

The overarching question that this literature review set out to explore was 'whether and how increased identification of young carers from cohorts perceived to be 'hidden', 'hard to reach', 'seldom heard', or 'specifically disadvantaged' can be achieved?' Drawing the different strands together it would be reasonable to conclude that an increase in identification can indeed be achieved. Firstly, a deep understanding of the issues and the barriers experienced by all young carers as well as by particular groups and communities of young carers is needed as well as an understanding of the impacts from the interplay of different characteristics of these groups.

A broad, strategic, and proactive approach at different levels (policy, systems and practice) is needed that addresses the different barriers for all young carers and should aim to improve self-identification, recognition, and identification by professionals and systems. Approaches could include: (a) campaigns to counter stigma and increase awareness about who young carers are, the impacts of caring and the support available to them; (b) improving workforce development for all relevant sectors to include training on identifying young carers; (c) developing and improving mechanisms for triggering early identification in schools, primary care and social care in particular; and (d) developing and showcasing case studies of good practice in identification of young carers.

To supplement these general approaches to improving the identification of all young carers, professional awareness of and engagement with specific groups and communities should also be developed and targeted interventions employed to respond to local needs that are understood through improved local data collection and analysis. A repository of good practice for targeting specific groups could be developed to support practice in other areas. Finally, consideration and focus should be given to what are likely to be the 'big hits' when it comes to improving identification nationally and what approaches will be sustainable so that identification is improved in the long-term.

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Footnotes:

1. This review was carried out in 2020. There was a delay in publication due to the Covid-19 pandemic.

2. Daniel Phelps is a Visiting Knowledge Exchange Fellow at the University of Winchester.

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