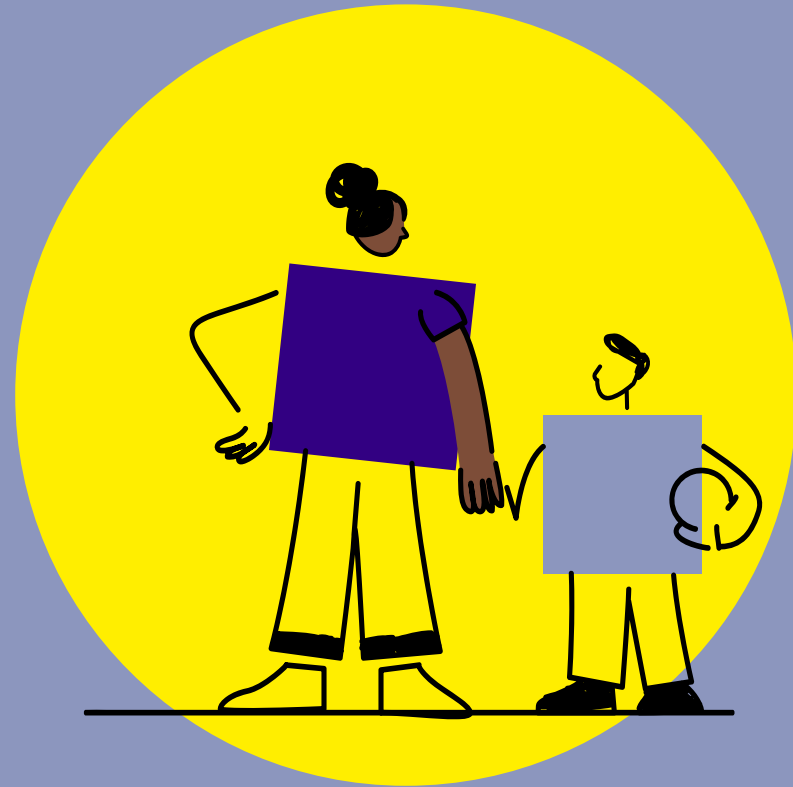


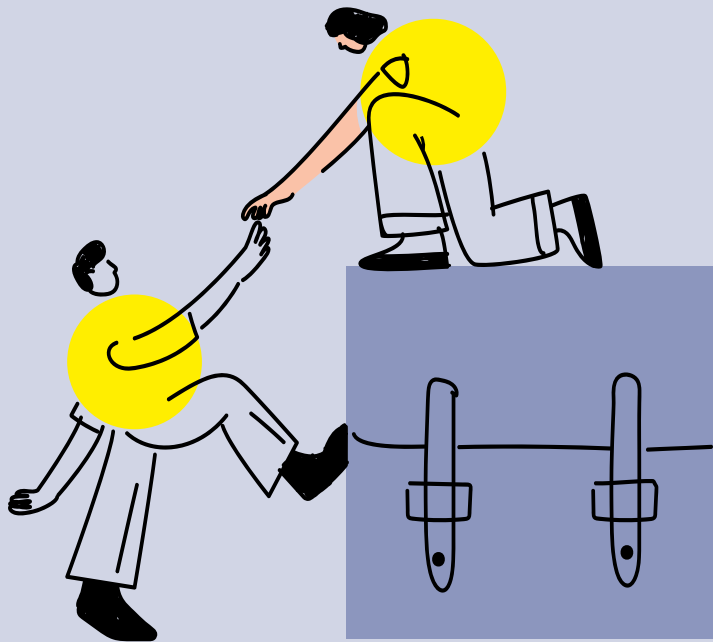
Safety in data:

Building data infrastructure that keeps Young Carers seen and safe



Social Finance

Social Finance is a not-for-profit organisation that works with our partners to design, fund and scale solutions to complex and enduring social issues in the UK and globally.



We launched the world's first Social Impact Bond in 2010 and since then our pioneering work has delivered lasting and widespread change that improves the lives of people and communities.

We are FCA-regulated and work to mobilise finance, strategy, design, data, and build partnerships, in a human-centred way.

We partner with local and national governments, commissioners, service providers, such as charities, as well as socially motivated investors, funders, international donors and philanthropic organisations.

This report and related projects sit within Social Finance's 'Early Inclusion Collective'. The Early Inclusion Collective is a partnership or community of practice that brings together organisations looking to create safer, more inclusive systems for children and young people through widespread systemic change.

We work to achieve this through programmatic work, policy and cultural change and cross-sector relational working.

More information about the Early Inclusion Collective can be found here: [The Early Inclusion Collective](#)

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Purpose

Young Carers face significantly poorer outcomes than their non-caring peers across many aspects of their life, including education, health, and safety.

Since 2023, Social Finance has been working to explore how we can create safer systems for Young Carers.

We define systems as the institutions that have a significant impact on Young Carers' lives, including local and central government, education and health, as well as societal attitudes.

Working in partnership with the sector we have identified five system priorities:

1. Enhancing data use in identification and research.
2. Recognising Young Carers and their complex identities.
3. Codifying best practice and what works.
4. Encouraging whole-family and whole system approaches to supporting Young Carers.
5. Tackling financial constraints and 'making the case'.

This report addresses system priority 1: Enhancing data use in identification and research

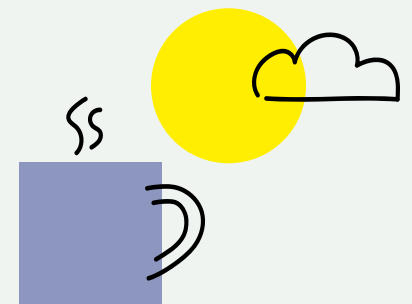
As a sector, we need to ensure that the data used to identify and support Young Carers is robust and representative. In addition, the systems and processes that make up the data infrastructure surrounding Young Carers must allow for accurate and effective data capture, usage and sharing.


Many young people are what we at Social Finance describe as 'intentionally invisible', i.e. deliberately do not identify their support needs to services. This should not be seen as a reflection on Young Carers – often staying under the radar is a means to keep themselves safe. We certainly should not blame Young Carers for being invisible or use this as an excuse for not supporting them. Instead, we should regard it as an urgent call to redefine our systems, so they are safe and inclusive for all children and young people, including Young Carers. During the research for this report, we were troubled to learn that many Young Carers do not want their caring responsibilities to be recognised, as they fear this might

have negative consequences for themselves or their family, for example being taken into care.

Building new data infrastructure that ensures more Young Carers are identified and supported, will also enable a rich national picture of the experiences and outcomes of Young Carers to be created. However, it is vital that a foundational principle of this work is to centre the safety of Young Carers.


This report is designed to support organisations who hold data on Young Carers such as local authorities, health authorities, schools and charities. Our aim is to help them understand how they can take a safety-first approach to improving the quality, usability and shareability of their data in away that ensures more Young Carers are being seen and supported in safer systems.





Young Carers:

Experiences, outcomes
and barriers to improved
identification and support



Young Carers face worse outcomes than young people without caring responsibilities

These outcomes are being increasingly well-evidenced. In recent years we have seen new data on education, including on **attainment (from MYTIME Young Carers)** and attendance; an **all-party parliamentary group (APPG) report** collating evidence across a range of issues; and investment in longitudinal studies on life-long outcomes.

However, there are still gaps in the data and questions about whether the data is fully representative of the entire population of Young Carers.

Health

Young Carers consistently experience worse mental and physical health outcomes. Caring for yourself while caring for others can be difficult; and this is made significantly harder when you also experience ill-health. In the population of Young Carers:

56%

experience psychological distress¹

25%

have reported that they self-harm²

17%

of those who self-harm attempt to take their own life³

43%

have long term physical health conditions⁴

1.5x

more likely to have special educational needs or disabilities⁵





Education & work

Even before they enter primary school, Young Carers can experience a negative impact on their education. This can snowball, with poorer outcomes at primary school leading to poorer attainment at GCSE, A-Level and higher education level. Young Carers are:

2x

more likely to leave primary school below age related expectations⁶

65%

less likely to be predicted 7+ English and Maths attainment at GCSE⁷

5x

more likely to drop out of college⁸

37%

less likely to achieve A*AA or above at A-Level⁹

47%

less likely to have a university degree if they care for up to 4 hours per week¹⁰

86%

less likely to have a university degree if they care for 35 or more hours per week¹¹

32.9%

Not in Education, Employment, or Training (NEET)¹²



Safety

An under-researched area for Young Carers is the overlap of caring responsibilities with issues around safety – including exploitation and exclusion. While we know these overlaps exist, there is minimal evidence to demonstrate how and where they happen. What we do know is:

2.34x

Young Carers are 2.34x more likely to be suspended¹³

89

Young Carers (less than 1%) out of 15,866 pupils attending alternative provision schools were identified as being Young Carers in the 2023/24 school census¹⁴

**80–
100%**

We have heard from sector partners that staff at some Pupil Referral Units (PRUs) estimate 80–100% of their pupils to be Young Carers

Young Carers are believed to be more vulnerable to exploitation, e.g. online grooming due to loneliness or county lines activities to provide for their family

Locally, identification and whole-family support are the two key areas of focus for Young Carers

Identification

We know that there are huge underreporting issues around Young Carers with national figures from the **most recent school census (2023/24)** placing the number of Young Carers at 54,000 and the **most recent national census for England and Wales (2021)** identifying 127,175 Young Carers (aged 5–17) and 229,690 Young Adult Carers (aged 18–24).

This is in stark contrast to sector estimates which put **the number of Young Carers in the 11-16 group in England alone at 800,000**. Given that this does not include figures for Scotland, Wales and Northern Ireland or young people below 11 or over 16, the true number is likely to be significantly higher.

Support

It's crucial that Young Carers have access to whole-system and whole-family support that addresses the different areas caring responsibilities can negatively impact across experiences and outcomes.

This support could take a variety of different forms, including respite from their responsibilities; counselling; support during transition periods such as GCSE's and A-Levels; and support for the wider family to alleviate caring duties. There are also reasonable adjustments that can be made which allow Young Carers to fully participate in school and other activities. For example, we heard about 'late-cards' being given to Young Carers that exempt them from detentions, when caring responsibilities had made them late to school.

Unfortunately, a comprehensive system response from multiple organisations (including local and health authorities, education and

social care) is often lacking. This is despite the existence of legislation that aims to protect Young Carers and is often due to lack of data sharing, multi-agency collaboration and prioritisation of Young Carers and their needs.

Within this section we will examine key institutional, and social and cultural barriers that impact identification and support for Young Carers, and how they can be understood through the lens of data and data infrastructure.

There are also reasonable adjustments that can be made which allow Young Carers to fully participate in school and other activities.

Institutional barriers that impact identification and support of Young Carers

By institutional barriers we are referring to barriers existing within bodies relevant to the care and support of Young Carers, namely, local authorities, education and health.

Local authorities



Local authorities struggle to make the case for investing in Young Carers locally.

Local authorities are under significant financial pressures and frequently function in a 'reactive state', which results in Young Carers being seen as low priority unless they reach crisis point. Internal Young Carer 'champions' often struggle to access the resources to make significant changes.

While financial pressures are a significant factor, this is partially driven by limited statutory responsibility and guidance around how Young Carers' identification and support services should be run – meaning staff don't always have the necessary statutory leverage to secure additional funding.

The lack of data on Young Carers underpins this all. Without data that comprehensively makes the case for investment in Young Carers, there can only be limited success in creating a robust evidence base that drives funding at a local authority level; which in turn drives the expansion of statutory responsibility on a national level.

Additionally, the idea that Young Carers are a low priority reflects the lack of joined up data that points to overlapping vulnerabilities. Anecdotally, we know that there is significant overlap with higher priority areas, such as exploitation and exclusion.

Education



Schools feel the pressure from all sides. They also lack the capacity to inject resources into adjustments, training and support surrounding Young Carers.

In our interviews, we have heard that primary and secondary schools have taken on multiple new focus areas requiring additional resourcing, further stretching capacity to support Young Carers. These include children with free school meal status; children with a social worker; and summer-born children. In addition, post-Covid, many schools are playing an active and onerous role in supporting children to catch-up on missed education.

As is the case with local authorities, the lack of data on Young Carers means they are often seen as a low priority. It also means that schools do not have access to vital information about how Young Carers are navigating their lives and caring responsibilities. They are also not aware of the relatively small adjustments that might be required to increase a Young Carer's engagement with schooling.

Anecdotally we have heard that Young Carers were more likely than their peers without caring responsibilities to see their education significantly disrupted during the pandemic. Not only was access to education limited at this time, but their caring responsibilities multiplied. Furthermore, as we've seen a rise in home-schooling, many Young Carers have not returned to the classroom, creating further risk of exploitation.

Health



Processes are not always in place to utilise the proximity health workers have to the cared-for individual and their families.

Health services, especially general practitioners (GPs) and community health services who frequently enter households, are in an ideal position to identify Young Carers. The Health and Care Act 2022 put further obligations onto NHS bodies to support local authorities in identifying, assessing and supporting Young Carers.

There are still significant missed opportunities where NHS bodies could take a more active role in identifying and supporting Young Carers.

However, implementation remains variable. Whilst there are pockets of good practice in health, particularly with respect to GPs, there are still significant missed opportunities where NHS bodies could take a more active role in identifying and supporting Young Carers.

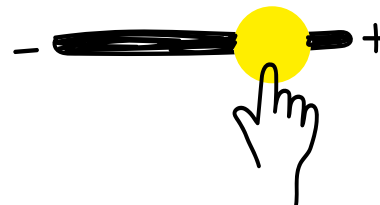
At a data level, the main obstacle will ultimately be how straightforward it is for GPs to note and share this data with their local authorities – and how the importance of collecting this data is being communicated within health authorities. However, in the next section we explore the ethical challenges that may contribute significantly to this issue.

Data sharing across organisations



Across three of the most crucial bodies necessary for effective support, (local and health authorities, and education), systems and processes in place at an organisation level to make referrals and share and report data are not always as effective as they could be.

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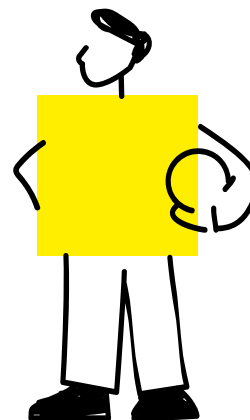
This means a Young Carer may have been identified by one organisation, but without the means to share and report this data effectively with others, the young person does not receive comprehensive support. It also means the Young Carer is not included in wider data sets, resulting in disjointed and siloed data that doesn't provide the full picture. There are multiple reasons behind this, three of which being: data processes and systems not being optimised to facilitate effective sharing, hesitation from Young Carers and their families to provide consent for information sharing, and ethical considerations that must be accounted for when considering whether to share personal data between organisations.

Social and cultural barriers that impact identification and support of Young Carers

By social and cultural barriers, we are referring to barriers related to a young person and their families social and cultural context and experiences, that can negatively impact identification and support.

Young Carers and families may be hesitant to identify themselves for fear of alerting social services and/or similar bodies to their circumstances

Being a young carer involves taking on roles and responsibilities that aren't typical for a young person. We have consistently heard from interviews that because of this, there's a fear that identification will result in interference from government, schools or other bodies, and that these bodies will enact safeguarding procedures that have negative consequences for the parent, or, in the worst-case scenario result in the removal of the Young Carer in question from their family.



Young Carers from global majority and low income families are also more likely to experience this fear and distrust of social care due to systemic discrimination, which is particularly concerning given Young Carers are more likely to be from these groups. This greatly impacts effective data collection about Young Carers and their families as it drives under-reporting. Similarly, this fear can hinder effective data sharing after a Young Carer has been identified; in most circumstances, consent must be gained from an individual to share information with other relevant bodies, but a fear of other services can prevent this, limiting a 'whole system' response.



Being a young carer involves taking on roles and responsibilities that aren't typical for a young person.



It's important to note that within this population there are pockets of Young Carers who are even more at risk and less likely to self-identify than others

We have heard that hesitancy to self-identify or consent for information sharing, from both the Young Carer and their family, can be exacerbated further when the Young Carer is caring for someone with mental ill-health or substance misuse issues, due to the stigma and shame attached to these conditions. Concerningly, we have also heard that these Young Carers often have the highest caring burden because the family as a whole are not receiving support that would alleviate some of the young person's caring responsibilities. This means that there is likely a group of highly in-need Young Carers underrepresented within existing datasets.



For some young people, caring for relatives is a key part of their culture and this can drive under-reporting.



There are cultural differences around keeping care in-family, and a simple label of 'Young Carer' may not be a holistic enough picture of a Young Carers situation

For some young people caring for relatives is a key part of their culture and this can drive under-reporting. Young Carers from these communities may feel like health and social care services wouldn't understand the nuances of their situation, or they may feel it's taboo to label themselves as a Young Carer given the role caring plays in their culture. This results in a subset of the Young Carer population being underrepresented in datasets. This in turn means less consideration is given to how resources can be directed towards these Young Carers and how that support can be tailored to suit their needs. A better understanding of Young Carer demographics and cultural experiences through improved data collection and analysis would alleviate these issues.

Fear of statutory service involvement can result in partial information disclosure

Some Young Carers known to statutory services may be careful about the type and extent of the information they share about their experiences and circumstances. Interview participants have told us that over time, through their interactions with statutory services, families can gain an understanding of exactly how much information is safe to disclose to receive support, without sharing too much and hazarding being flagged as a safeguarding risk. This means support does not always address the full extent of the issues Young Carers and their families face.

Transparency about how their data will be used and shared, and how this can be blended into relational, trust-based approaches, could help mitigate the understandable fears of Young Carers and their families.



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Why we need a
safety-first approach
to data infrastructure

Better data infrastructure can help to tackle these barriers, but we need safety to be the priority as we do so

Young Carers who have accessed social or protective services rely on the system to adequately safeguard them and ensure appropriate ethical considerations are made for their safety and wellbeing.

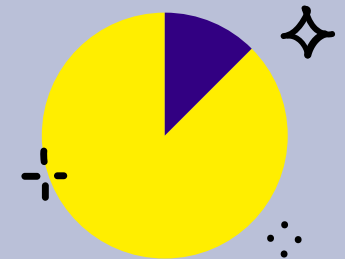
This relates just as much to how data is collected, used and shared as it does to practice-based support services. Unfortunately, conversations around ethics in relation to data usually revolve around the ability of staff to robustly follow safeguarding procedures and less so around how said collection, usage and sharing of data will impact the 'data subject' themselves (in this case, the Young Carer).

Prioritisation of ethics is hugely important when considering data and digital solutions to ensure that these solutions do not inadvertently expose Young Carers to additional harm. It also allows us to keep front and centre the purpose of the solutions – to improve outcomes for Young Carers – as opposed to solutions turning into a mechanism for impersonal or intrusive interventions. Additionally, the prioritisation of ethics limits the depersonalisation of Young Carers and their families into 'data subjects' as opposed to people that exist in a nuanced context with individual support needs.

In this section we outline some of the key ethical considerations that must be considered when developing data infrastructure, in order to prevent additional harm to Young Carers and their families.



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Key considerations in developing 'safety-first' data infrastructure

Improvements in identification processes should occur in tandem with guarantees of support

During interviews we heard about cases where Young Carers informed their schools of their caring responsibilities but received no support. This led the Young Carer to shut off the possibility of receiving support from education. They then carried this belief into other educational institutions attended and ultimately closed off a vital support route.

A data driven approach can be extremely useful in improving identification, but we know from research and interviews that even if a Young Carer is identified, this does not always result in timely and effective support. To create meaningful change for Young Carers, we should examine how data can be used to improve identification and support in tandem. This will ensure updates to systems and processes aren't redundant when it comes to improving outcomes on an individual level. It is also vital that investment in data infrastructure is matched with investment in frontline services to match the increased support that will be required.

Structural racism, discrimination, and a lack of understanding of intersectional identities can impact the severity of a response to data

Young Carers are more likely to be from a global majority or low-income background, and there is the potential for overly intrusive statutory involvement or disproportionate interventions as a side effect of structural discrimination. It's crucial these potential negative consequences are considered during the data collection, usage and sharing process, and appropriate measures are put in place to mitigate them. In addition, not all stakeholders will understand the experiences of Young Carers and how being a Young Carer intersects with other vulnerabilities and characteristics. This can result in disjointed support without the necessary whole-family context being taken into consideration.

Young Carers should be seen as people and not just 'data points'

When examining a problem through the lens of improving data, it can be easy to lose sight of the fact that Young Carers, for example, are whole people and not just a set of data points to determine the allocation of resources and collect statistics. Data collection processes should allow for intersecting and nuanced identities to be recorded; information that is useful for social workers to provide bespoke support as well as build a picture of the population on a whole. Equally, it should be considered which elements of data being collected are necessary to build a comprehensive picture of Young Carers on a national scale, without being unnecessarily intrusive for the individual Young Carer and their family. For example, data on ethnicity is useful in understanding the demographics of Young Carers in the region, but the benefits of including detailed data on the mental health of Young Carers would have to be rigorously examined before being included in wider data analysis.

Updates to data processes and systems are not always the most appropriate response

In some cases, a relational approach is more suitable to create a more whole-system support package where individuals build improved relationships and communication across organisations to share relevant information. A relational approach can be more effective than investing in new systems and processes. It's crucial to examine exactly why updates to data infrastructures are required, with clear and tangible benefits to those involved being defined.

Young Carers and their families should be involved in co-designing updates to systems and processes

While there is a need for some standardisation of data to understand Young Carer experiences at a national level, there is also room to co-design nuanced, local data capture to reflect the needs of local Young Carers. Creating opportunities to co-design data capture with Young Carers and their families will contribute to greater trust and vital intel on how data capture will be perceived.

Young Carers may not want to be identified or receive support

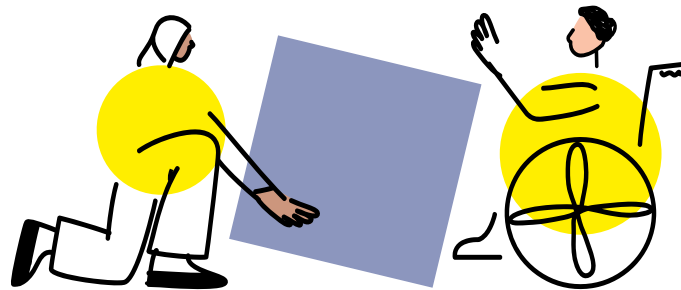
Some Young Carers remain intentionally invisible, and do not want to be identified or to access support services. Utilising data tools to 'find' these Young Carers can result in breaches of trust and runs contrary to consent given by Young Carers. Authorities should consider how and when it is appropriate to use datasets to identify and offer services to Young Carers who have not chosen to self-identify. They need to understand how to limit unintended consequences; particularly for groups who are more distrustful of systems and who face structural discrimination.

The needs and ethical implications for the whole family should be considered, not just those of the Young Carer

Statutory data experts have told us that creating a whole-family data picture creates extra risk. The ethical implications of data collection, usage and sharing for the family also needs to be taken into account and the processing of data from multiple people for the good of one needs to be justified.

Consider how data can be utilised to understand safety at a system level

We believe that data can sometimes lead to risk being attributed at a child level when it should be attributed at the system level. When collecting and analysing new data, it is vital to contextualise this data within the broader environment. This means thinking through how data can be used to change the systems around young people, rather than intervening with the child.



Surrounding context: Existing legislation and datasets

Existing legislation relating to Young Carers

Legislation on Young Carers tends to be inconsistently applied nationally.

Recommendations in this paper are ambitious and we recognise the constraints currently faced by many statutory agencies.

However, we believe improved data infrastructure will support agencies to carry out their legislative duties, whilst making the case for greater policy and investment focus.

Children and Families Act 2014

Young Carers needs assessments

A local authority in England must assess whether a young carer within their area has a need for support and, if so, what those needs are. This applies when:

- (a) it appears to the authority that the young carer may have a need for support, or
- (b) the authority receives a request from the Young Carer or a parent of the Young Carer to assess the Young Carer's needs for support.

A Young Carer's needs assessment must include an assessment of whether it is appropriate for the Young Carer to provide, or continue to provide, care for the person in question, in the light of the Young Carer's needs for support, other needs and wishes

See related: [The Young Carers \(Needs Assessments\) Regulations 2015 – regulations on how to carry out needs assessments](#)

Identification of Young Carers via local authorities

Local authorities in England must take reasonable steps to identify the extent to which there are Young Carers within their area who have needs for support

See the full legislation here: [Children and Families Act 2014](#)



Care Act 2014

Young Carers transition assessments

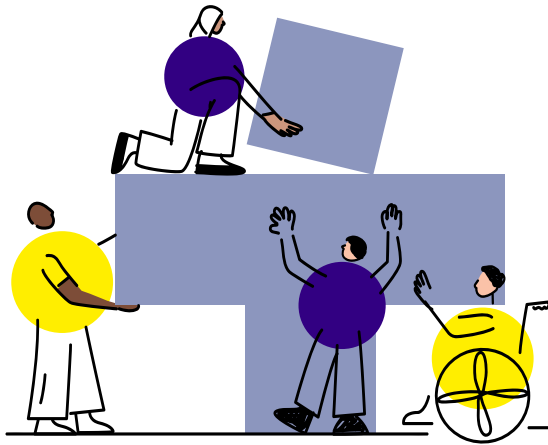
Where it appears to a local authority that a Young Carer is likely to have needs for support after becoming 18, they must, if satisfied that it would be of significant benefit in relation to the timing of the assessment, and if the consent condition is met, make the following assessments:

- (a) Does the Young Carer have need for support and, if so, what are those needs.
- (b) Is the Young Carers likely to have need for support after becoming 18 and, if so, what are those needs likely to be.

Where a Young Carer refuses a Young Carer's assessment and the consent condition is accordingly not met, the local authority must nonetheless carry out the assessment if the Young Carer is experiencing, or is at risk of, abuse or neglect.

See related: [requirements on how to carry out Young Carers transition assessments](#)

See the full legislation here: [Care Act 2014](#)



The Health and Care Act 2022

The Health and Care Act 2022 places:

- A duty on Integrated Care Boards (ICB) to consult carers (including Young Carers); both around service planning and commissioning.
- A duty on ICBs to consult carers (including Young Carers) about individual services relating to the patient for prevention, treatment and diagnosis.

- A duty on NHS England to consult carers (including Young Carers).
- New powers for the Care Quality Commission to assess the performance of local authorities which includes for their duties to carers and ensuring a whole family approach is taken.
- A duty on NHS hospital trusts to ensure that unpaid carers of all ages are involved as soon as feasible when plans for the patient's discharge are being made.
- Clarity that the term carer applies to carers of all ages and therefore includes Young Carers.

Statutory Guidance: Working in Partnership with People and Communities

The statutory guidance for the act indicates that carers (including Young Carers) should be involved in planning, codesign, decision making, delivery and evaluation at all levels. There is also a duty of transparency.

NHS Continuing Care

The "National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care" specifies that:

- NHS bodies have a responsibility to work in partnership with carers and Young Carers so that they can be better supported with their caring role. Healthcare professionals should be proactive in identifying carers and be sensitive to the level of support they need and desire.

- This approach should be reflected in any checklist and/or full assessment of eligibility for NHS Continuing Healthcare with carers and family members involved where appropriate.
- Carers and Young Carers must be told of their right to carers assessments and Young Carers needs assessments. Referrals for these should be made where appropriate.
- The ICB may need to provide additional support to care for the individual whilst the carer has a break from his or her caring responsibilities.

More information relating to Young Carers' rights and the NHS can be found here: [Young Carers' Legal Rights and the NHS](#)

Existing datasets we're aware of

Our initial objective in producing this report was to develop a comprehensive overview of the data that exists in relation to Young Carers. We learned quickly that:

- a) The data available in any one area may substantially differ to another.
- b) Ethical sharing protocols mean there are organisations within a single space with data about local Young Carers that, without consent, they cannot share with each other.

A key recommendation from this report is for comprehensive investment in an audit of existing data sets. On the right we indicate a small selection of datasets that we've identified and spoken about with partners. However, alongside that, focus must be on the duplication of registers, the inability to share this data, and the distrust that many young families have in terms of data being shared outside of the individual service that have registered with.

Annual Survey Data

School census

Young Carers were included for the first time in the School Census in 2023. However, it is well accepted in the sector that the School Census significantly under-estimates the number of Young Carers in the system. This is partially due to many schools simply not having awareness of the Young Carers in their school.

GP patient survey

The GP Patient Survey includes questions on both age and caring responsibilities. Despite this, the insights in relation to Young Carers (16+) tend to be muted with insights often being presented at a broad 'carer' level rather than a Young Carer level. There is an opportunity to utilise this survey more effectively to better understand the experiences of Young Carers within the health system.

Live data

School data

Information on Young Carers is often held within the case management systems of schools. However, the way in which this data is stored may vary significantly. For example, on some systems Young Carers may be easily identifiable via a flag on an individual young person's profile. Whereas in other systems, the information has to be manually inputted via text. These variances hold significant implications for Young Carers to be consistently identified and for validated data to be used within the School Census and then onward to national metrics.

Young Carer register

The Young Carers Register, designed to identify all Young Carers within a locality, is used in some localities and may be held by the local authority or a commissioned charity. Without appropriate data sharing agreements or consent, there are instances where a commissioned service would be unable to share a list of Young Carers with the local authority.

Frontline service data

Organisations such as MYTIME Young Carers have published data reports ([Overlooked and Overburdened: Educational challenges faced by Young Carers](#) and [Unseen Sacrifices: Understanding the educational disadvantages faced by Young Carers](#)) combining novel service data with school data. This has provided granular insights on the overlap of caring responsibilities with SEND, Pupil Premium, exclusions, absences and attainment. Much of this data exists on school records; however to see Young Carers within it still requires the involvement of specialist services because there isn't a comparable or reliable Young Carer dataset.

GP Carer register

GPs will also hold a Carers Register. As with Young Carers registers, consent issues mean that this data cannot necessarily be linked with other datasets without acquiring consent on an individual basis.

Creating safety in data:

Data collection and quality

Data collection and quality: Context

Data quality can be best understood as the 'fitness for purpose' of a dataset, i.e. whether the data is of high enough quality to effectively and accurately serve its purpose.

Better quality data can drive efficiency as it means services can trust data (avoiding unnecessary validation) and create a more comprehensive picture of the population and identities of Young Carers. Data quality is comprised of three key dimensions:

Representation

The extent to which a dataset accurately reflects the characteristics and diversity of the population of Young Carers.

Representative data ensures all relevant subgroups are accounted for and are in proportion to the actual size of those subgroups.

Data that is not representative can lead to poor decision making and insights that cannot be applied generally to the broader population. This increases the chance of inequity and discrimination for underrepresented groups who may be ignored or unfairly treated.

Currently, data does not represent Young Carers accurately and this underrepresentation is driven by a number of factors. For example, stigma attached to conditions like mental ill-health and substance misuse can further increase hesitancy in self-identifying as a Young Carer, particularly within underrepresented populations. Another group we have heard to be underrepresented are Young Carers in Pupil Referral Units (PRUs), a type of alternative provision (AP) school. Our sector partners have told us that in some PRUs surveyed, between 80–100% of pupils were believed to be Young Carers. Despite this, the 2023/24 school census identified only 89 Young Carers from a total of 15,866 pupils attending alternative provision (AP) schools nationally. Given that PRUs make up 56% of the pupil population in AP schools, it's likely the number of Young Carers officially identified within PRU's is even lower.



Currently, data does not represent Young Carers accurately, as shown by significant under-reporting

Relevancy

The extent to which individual-level data fully captures essential characteristics, behaviours, and experiences of Young Carers.

This includes types of caring responsibilities, gender, ethnicity, and socioeconomic status. Insufficiently relevant data can lead to inaccurate insights, poor decision-making that overlooks the actual issues Young Carers face, and misleading conclusions that may reinforce biases or stereotypes.

Nationally, Young Carer data lacks relevance. For example, the Multidimensional Assessment of Caring Activities (MACA) and Positive and Negative Outcomes of Caring (PANOC) assessments are commonly (though not consistently) used to assess Young Carers' caring activities and mental health impacts, but omit data on physical health or vulnerabilities like risk of exploitation.

Relevant data should be collected in conjunction to caring activities as is outlined in Young Carers (Needs Assessments) Regulations – assessments should determine “whether the care which the young carer provides (or intends to provide) impacts on the Young Carers well-being, education and development”. However, current practice means that the specifics of these assessments are determined by local agencies, and neither the methodologies nor the outputs are shared on a national level. This prevents the creation of a comprehensive national picture.

“**Current practice means that the specifics of these assessments are determined by local agencies, and neither the methodologies nor the outputs are shared on a national level.**”

Accuracy

The extent to which data collected is accurate and/or complete, according to the data that is supposed to be being collected.

Inaccurate data can result in policies or interventions that fail because they are based on faulty assumptions. In turn, resources are wasted by addressing issues that are misrepresented and generating inaccurate insights due to them not reflecting the true traits of Young Carers.

One factor leading to inaccurate data is partial information disclosure whereby Young Carers/families don't share the full extent of their circumstances for fear of statutory services. When this occurs, data collected is not fully reflective of true experiences. Without transparency and trust-building on how data will be used and shared, families will continue to offer partial information – leading to inaccurate datasets.

“**Inaccurate data can result in policies or interventions that fail because they are based on faulty assumptions.**”

Data collection and quality: Recommendations

Improving data quality would allow for a more accurate picture of Young Carers to be built, both in terms of their demographics and experiences.

This will lead to a greater understanding of where to direct resources, tailor support packages, and evidence the need for increased resources and funding.

Create transparent systems where it is clear how personal data will be used and who it will be shared with

Action: A lack of transparency on how data will be used and with whom it will be shared, adds to hesitancy from Young Carers and their families to share personal information. Those collecting data from Young Carers and their families should outline explicitly the purpose of the data collection, where the data will be stored, who will have access to it, how it will be used to inform support and make decisions and who it will be shared with – and when. This approach should also make it clear when a Young Carer can change their mind or pause a process.

This should happen in conjunction with the previously outlined ethical consideration of a guarantee that accessing services results in support. By sharing more personal information with statutory bodies on who they are and what they experience, Young Carers are opening up about their vulnerabilities and placing trust in the receiving body to appreciate the importance of that information and action it to provide support.

Outcome: This transparency will help Young Carers and their families to be less fearful that their data will be used against them. They will therefore be more likely to share a full picture of information. More broadly, this means that the data being collected will more accurately describe Young Carer experiences.

Explore with frontline staff how to improve the accuracy and comprehensiveness of their day-to-day data collection

Action: Frontline capacity is often stretched, which can result in data collection being deprioritised. This is due to a) a natural focus on immediate need, b) the value of data and how it can be used to support services is not recognised and c) challenging systems that don't support efficient data collection.

A key step in improving data collection and quality is designing the approach and process of collecting data with frontline workers, to make this incremental and manageable, and help frontline workers to see the value of doing so. As part of this process, it should also be examined how new data procedures can be used to understand safety for Young Carers at a system level so updated processes mitigate the issues we see in attributing risk to the child as opposed to the broader environment they exist in.

Outcome: This contributes to improved data quality and buy-in from frontline staff in terms of how the data will be used. As a result of more comprehensive and up-to-date data sets, data can be utilised to drive timely responses to families' current circumstances and ensure resource allocation is being done effectively.

Conduct local audits to understand existing size, quality and overlap of existing data sets

Action: We know data collection can be disjointed across organisations with relevant bodies not having oversight of what data exists about Young Carers within a locality. Without understanding what data currently exists it's difficult to build an accurate picture of the current data landscape and therefore work cohesively to improve data infrastructure. To remedy this, localities should conduct an audit of what data exists locally, utilising our framework of existing data sets. As a next step, this should also include an analysis of the quality of the data, the ethical safeguards put in place, and the story the data tells about Young Carer experiences.

During analysis, it should be considered from an ethical perspective what data is strictly necessary to include to understand the quality of the data and the 'story' it's telling. The inclusion of highly personal data, e.g. experiences of mental-ill health, should be thoroughly examined to weigh the benefits it will provide in wider data analysis, against the importance of respecting boundaries of Young Carers' information.

Outcome: Firstly, this will drive an improved understanding of what data exists locally and where Young Carers are being identified in one place and not in another. It will also create a convening tool for relevant authorities and service providers who are interested in delivering a whole-family approach to supporting Young Carers, in line with recommendations in "[No Wrong Doors for Young Carers](#)", a memorandum of understanding designed to improve joint working between adult and children's social care services, integrated care boards and other key organisations in respect of identification and support for Young Carers and their families.

Creating safety in data:

Data usage

Data usage: Context

Data usage in this context relates to how effectively data is utilised after its collection to identify and support Young Carers, and this is in relation both to data directly from Young Carers and utilisation of parallel datasets and tools.

Data should be used for the following purposes:

To deliver whole-family responses and provide support at an individual level

Data should be utilised in such a way that it creates a whole-family picture of a Young Carer, to allow interventions for that young person to be tailored to the context of their specific family, circumstances and environment. When data on a family is limited, the focus is usually on the Young Carer themselves – which can limit the effectiveness of measures or interventions put in place.

To understand trends, allocate resource and tailor local offers

At a population level, data should be utilised to create interactive dashboards to understand and identify trends and needs. Having this birds-eye view of a population and being able to drill down into demographics or sub-groups can give highly impactful evidence and direction. Importantly, data at this local systems level helps to make the case for resource and to allocate that resource.

Part of the challenge for Young Carers is that while there will be data on their increased likelihood of exclusions or absenteeism, this data is not being used as an indicator of caring responsibilities. Instead, their primary identity is seen as a young person at risk (of exploitation, or academic failing, for example), but their role as a Young Carer is not recognised or considered, meaning their root needs around caring responsibilities are not addressed.

The linkages between data and resources at a local level remain true at a national level also. The correct and consistent identification of Young Carers is a critical part of ensuring national policy reflects local reality, alongside meaningful investment that allows local authorities to put in place tailored support, that harnesses the local assets in communities.

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Part of the challenge for Young Carers is that while there will be data on their increased likelihood of exclusions or absenteeism, this data is not being used as an indicator of caring responsibilities.

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Data usage: Recommendations

Improving data usage would allow for existing Young Carer data to be harnessed to its full capability in terms transforming data into actionable, effective support.

Contribute results of data analysis towards the national picture of Young Carers

Action: The information that does exist on Young Carers within localities is rarely shared to create a national picture of Young Carer experiences and demographics. To create this national picture, organisations could share information regarding Young Carer demographics and experiences, anonymised and with consent from young people and their families, with other organisations or publicly to build a national picture of Young Carer experiences.

One means to do this could involve establishing a central hub where local authorities can submit data and the hub will work to build out the national picture. Social Finance have previously worked with London Councils and London Innovation and Improvement Alliance (LIIA) on the **Child Level Data Project** to bring together data collected by the 32 London local authorities on children in contact with children's services. The purpose of this project was to deliver analysis that gives a deeper understanding of the problems Directors of Children's Services look to address, identify areas for greater collaboration, and highlight good practice that can be adopted regionally and locally.

From an ethical perspective it should be considered, if possible with input from Young Carers and families, what data is necessary to create a comprehensive national picture of the Young Carer population without contributing overly sensitive information that is useful for analysis but is unnecessarily intrusive.

Outcome: This contributes to improved data quality and buy-in from frontline staff in terms of how the data will be used. As a result of more comprehensive and up-to-date data sets, data can be utilised to drive timely responses to families' current circumstances, and ensure resource allocation is being done effectively. The creation of a national database, that has centred the needs of Young Carers and their families, can be used to inform Government policy, investment and the strategies of other sectors such as charitable foundations and academia.

Explore how existing data within Case Management Systems (CMSs) can be used to create a richer understanding of the experiences of Young Carers

Action: Existing data relating to Young Carers and their families within systems is not always best used to provide whole-family context or identify potential Young Carers. To take full advantage of existing data, organisations can investigate methods of developing systems to incorporate information that improves identification and support.

For example:

- Within CMSs related to the Young Carer, attach a profile of the individual the Young Carer is caring for to provide more context of the Young Carers circumstances for the individual accessing the record, which they can then use to tailor support and communication. Examine within this what level of information would be genuinely useful to the individual accessing the record, versus unnecessarily detailed and intrusive for the person being cared for.
- Within primary healthcare settings, understand where an adult with chronic conditions will likely be supported by a child and ensure the GP provides follow-up identification and support services.
- Incorporating a marker on the adult social care (ASC) CMS record of adults with long-term health conditions/substance misuse issues who have children, confirming whether there has been enquiry into the child's Young Carer status.

Solutions that involve accessing data of individuals relating to the Young Carer should always have additional ethical assessments of the potential impact on the related individuals, not singularly assessments on the benefits and ethical implications solutions would have for the Young Carer.

Outcome: Data that facilitates frontline social workers' abilities to track whether there are potential Young Carers who are 'slipping through the cracks', and alert them to the need to enquire about caring responsibilities within the household, improving identification rates and implementation of support.

Case Management System:

A digital tool that holds relevant information and case notes about individuals accessing a service.

Case study Family Context

Social Finance, in partnership with Stockport Metropolitan Borough Council and Leeds City Council, developed 'Family Context'. This is a digital tool that allows social workers to easily access information on what other agencies across the local authority are involved with a child. Importantly, the dashboard within the tool does not include specific details on the involvement of services but includes contact

information so that social workers can communicate with relevant colleagues about the child's care. Its purpose is to facilitate conversations with lead practitioners from other services so that social workers can better support families and safeguard children.

More information on this piece of work can be found here: [Helping Social Workers Better Support Families](#)

Creating safety in data:

Data sharing

Data sharing: Context

Existing data on Young Carers is not always shared efficiently between organisations to optimise identification and support.

Some of these challenges result from consent and data sharing restrictions. However, this can limit the ability of services to take a whole-family approach to supporting Young Carers. From our work with children's services, we know that data sharing is a complex process and with it comes barriers at multiple levels, which can impact the ability to identify and support Young Carers. Barriers can include:

Gaining consent to share information

There can be difficulties in gaining consent from Young Carers and their families to share personal information. There are many drivers behind this, some of which include: fear of social services and agency involvement; a lack of understanding of how data will 'travel' i.e. how it will be used, who will see it and how long it will stay on an individual's records, and concerns specific to other organisations such as a fear of bullying if schools learn of a young person's Young Carer status.

In some circumstances, multiple vulnerabilities stemming from caring responsibilities occur where it would be useful to refer to other organisations to provide holistic support. However, sometimes organisations are limited in the action they can take because the severity of the vulnerability on an individual basis does not meet the safeguarding threshold requirement to override consent for data sharing. So, organisations are hindered in providing holistic support if the Young Carer refuses, despite the potential benefits.

Data sharing agreements (DSAs) and information governance (IG)

Data specific to young people is sensitive and therefore only held by a few organisations within the system. These stakeholders often cannot share data without consent or legal necessity (above safeguarding threshold).

For organisations to share data to better inform practice, data sharing agreements are required which can be time consuming and resource intensive to put in place.

Local authorities often find that they require expert IG support to share data effectively. We have heard through interviews that establishing DSAs between health authorities and other statutory agencies can be especially difficult due to differing levels of confidentiality requirements regarding 'data subjects'. This can be further compounded by very valid concerns from health authorities that sharing data will stop individuals engaging with their services.

Establishing DSAs to include Young Carers is difficult because the specificity of the data being shared and how the data will be used is not necessarily clear. As a result of uncertainty on the type of data points collected and how they relate to the experiences of Young Carers, it is hard to justify the purpose, necessity and proportionality for including these data points within data sharing agreements.

Data sharing: Recommendations

Improving data sharing would allow for a 'whole-system' response where the wider context of Young Carers and their families is accounted for in support offers.

Maximise processes within your organisation that enable effective data sharing between key bodies such as adult social care and health

Action: One crucial step to improve data sharing is identifying or establishing an individual person who is responsible for information governance within your organisation to initiate appropriate procedures to share data.

Action: Different organisations have different levels of data maturity and processes in place that work to enable data sharing. To improve processes, organisations must first evaluate their current data maturity, including an assessment of existing data infrastructure, to understand the limitations, feasibility and practicalities involved in sharing and receiving data from other organisations.

It should also be assessed whether enacting new data sharing processes is strictly necessary to improve services. Data sharing generates multiple ethical risks and should therefore not happen for 'data sharing's sake'. New projects should only occur if there are clear and tangible benefits to those involved; simply 'sharing data' does not solve a problem. As an alternative, some cases may benefit from a relational approach to improvements.

Outcome: Knowledge of crucial developments related to the cared-for individual would allow for support that's relevant to the Young Carer at that time and timely interventions should the Young Carers circumstances change for the worse.

Outcome: More open data sharing early on with adult social care or the relevant body providing support for the cared-for person would maximise a whole-family approach, where the needs of both the cared-for and the carer are considered. The additional information would allow for more tailored support packages relevant to the context of the Young Carer and create opportunities for support directed towards both the Young Carer and the cared-for individual. This in turn would improve targeted interventions that can reduce the Young Carers burden.

Outcome: Holistic, whole-system support wherein the different bodies involved in supporting the Young Carer, including local and health authorities, and education, receive timely updates that allow for an ongoing comprehensive support package addressing the various needs of the Young Carer.

Case study

Joined up decision-making about children

Social Finance is currently working in London and Liverpool to enable ongoing data sharing between local authority children's services teams, ICBs and NHS Trusts, which leads to better and more joined up decision-making about children.

This has involved surfacing use cases and developing the technical infrastructure and information governance documentation that enables the information sharing required. We are then able to develop dashboards that allow for aggregated and individual level analysis of cases.

Call-to-action

Call-to-action and next steps

This report has been written as a starting point for organisations who hold data on Young Carers to understand the first steps they might take in developing data infrastructure that centres as a priority the safety of Young Carers, seen and unseen, within their systems and data.

In doing so, we've identified the key ethical considerations that should be considered and laid out a series of recommendations across the spheres of data collection and quality, data usage, and data sharing. Most of these recommendations sit at a local level. At a national level, we believe the broader ambition should be to:



Build on local audits to create a national picture of the quality, scope and interoperability of existing datasets on Young Carers.

We know that the availability of data varies across localities. These local audits should be combined with audits of national data sets held by central government. As more local audits are delivered, a national analysis that combines these local audits will be an ideal first step in developing a national data strategy for Young Carers.



Utilise data to develop a more ambitious and nuanced understanding of Young Carer identities.

While we believe embedding an improved data infrastructure is vital, this must be paired with a more ambitious and nuanced understanding of Young Carers and the multiple disadvantages they may experience. For example, if they have special educational needs (SEN), have been in the care system or are at risk of exclusion or exploitation. It's also important to understand the different ways Young Carers show up and do not show up in the systems they live in.



Create a new, public conversation on what "safety in data" means – and how to balance risk-management and efficiency with a focus on making young people feel safe to be seen.

As we've highlighted, we believe in an ethical 'safety first' approach to data. We therefore encourage new, public conversation on what 'safety' in data might mean and how it can

be implemented in practice. The aim being that Young Carers are more willing to self-identify, to share information and to feel comfortable engaging with statutory and charitable services. This in turn would reduce the need for crisis-point interventions.

At Social Finance, we are keen to work with local authorities, health authorities, central government, charities, education and all those who align with our vision for Young Carers, to help develop data infrastructure to create safety in data for Young Carers.

If you are interested in working with us, please contact: info@socialfinance.org.uk

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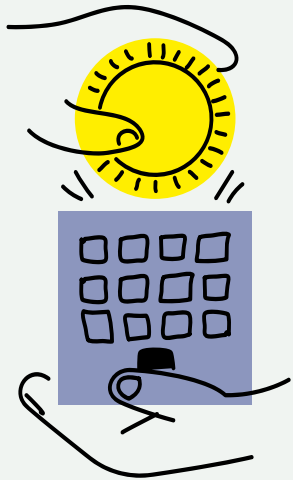


Appendices

Methodology

We conducted desk research to:

1. Gain a deeper understanding into Young Carers' experiences
2. Map the data landscape
3. Determine gaps in the data infrastructure



We conducted interviews with frontline workers and data experts to understand how the data infrastructure around Young Carers can improve

The purpose of the interviews was to hear directly from a broad set of experts to understand how data infrastructure can be improved to create permanent improvements in identification and support of Young Carers.

Given our findings from desk research that there is little national information available on how data is collected, used and stored on a day-to-day basis for Young Carers, we also used interviews to fill research gaps in what data exists.

The findings from primary research interviews have been woven into all sections of this report and informed the recommendations laid out.

Key interview questions

- What are the barriers preventing more joint working to support Young Carers, and what would you need to overcome these?
- Do you think there are any bodies in particular that are best placed to have an impact on improving identification and support of Young Carers?
- Do you have thoughts on how to ground an updated data infrastructure in a whole-family approach?
- What ethical considerations are most pertinent when thinking about using data to identify and support Young Carers?
- In an ideal world what data processes should be in place to identify and support Young Carers?

End notes



1. <https://cosmostudy.uk/publications/mental-and-physical-health>
2. <https://cosmostudy.uk/publications/mental-and-physical-health>
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6. MYTIME oral submission, <https://carers.org/downloads/appg-for-young-carers-and-young-adults-carers-reportlr.pdf>
7. **Overlooked and Overburdened – Educational Challenges Faced by Young Carers**
8. <https://learningandwork.org.uk/resources/research-and-reports/driving-change-supporting-young-adult-carers-in-higher-education/>
9. <https://carers.org/downloads/young-carers-in-education---summaryfinal.pdf>
10. <https://www.sciencedirect.com/science/article/pii/S1040260823000242>
11. <https://www.sciencedirect.com/science/article/pii/S1040260823000242>
12. <https://www.youthemployment.org.uk/being-a-young-carer-you-have-to-choose-between-your-future-and-the-future-of-the-person-you-care-for/>
13. **Overlooked and Overburdened – Educational Challenges Faced by Young Carers**
14. 2023/24 school census raw data, downloadable at: <https://explore-education-statistics.service.gov.uk/find-statistics/school-pupils-and-their-characteristics>

