



# Exploring the lived experiences of young carers in Cheshire East

Findings and Recommendations Report Presentation  
*January 2022*

**make  
better  
happen**

*Prepared for you by team* **ice**

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# *Background & objectives*

# Background and objectives

Cheshire East Council have identified that some young carers may be 'falling through the gap' and more needs to be done to ensure young carers are identified and supported. CEC partnered with ICE to conduct research designed to explore the lived experience of young carers aged 11 – 17 and to co-design what needs to happen to **support young carers in Cheshire.**

## **The research objectives were to:**

- Explore attitudes towards and experiences of being a young carer, including the current state and challenges (including Covid-19).
- Envisage what being a young carer is like at its best.
- Co-design what support/information young carers need and how solutions can be applied to support young carers to flourish.

Although our target audience was specifically *young carers*, we refer to them as *carers* in this report.

*What we did*

# What we did

## Research activities

In total, we engaged **16 carers and 16 professionals** working in education, health and voluntary organisations who interact with and support young carers.

This research was conducted virtually and included the following qualitative research activities:

- 2 x insight groups (90-mins) with 16 carers and 1 group (90-mins) with 16 professionals to explore experiences and support needs.
- 1 x co-design hackathon workshop (90-mins) with 8 young carers and 6 professionals together to test and co-design solutions.

# Hackathon workshop

**The hackathon was invaluable to achieving project objectives, allowing co-design and testing of ideas and solutions developed to support young carers by:**

- Enabling a critical review of a **touchpoint journey** of the carer experience and solutions that can help improve them, to establish what the touchpoints and a carer journey is ideally like, 'at best'.
- **Evaluation** of solutions/ideas, ensuring they are useful to carers themselves.
- Asking, what will enable that solution/idea to **work in practice**?

Informed by above, we can collate robust findings and make recommendations that will help improve young carer experiences in their day-to-day lives, but importantly that are made in collaboration with carers themselves.

# Sample Characteristics

## 16 young carers comprised of:

- Male (n=6) and females (n=10)
- Aged 11 – 17
- Black, African, Caribbean or Black British (n=6) and White or White British (n=10)
- Lived in a range of areas including:
  - Alsager
  - Middlewich
  - Bollington
  - Crewe
  - Macclesfield South/Tytherington
  - Sandbach Town/ Elworth
  - Congleton.

## 16 professionals working across education, health and voluntary organisations in the following roles:

- Family Liaison Officer (education)
- CEO (VCS)
- Leadership support manager (health)
- Teacher (education)
- General practice doctor (health)
- Community engagement officer (third sector)
- Learning support assistant (education)
- Service manager (VCS)
- General practice support staff (health)
- Pastoral support manager (education).

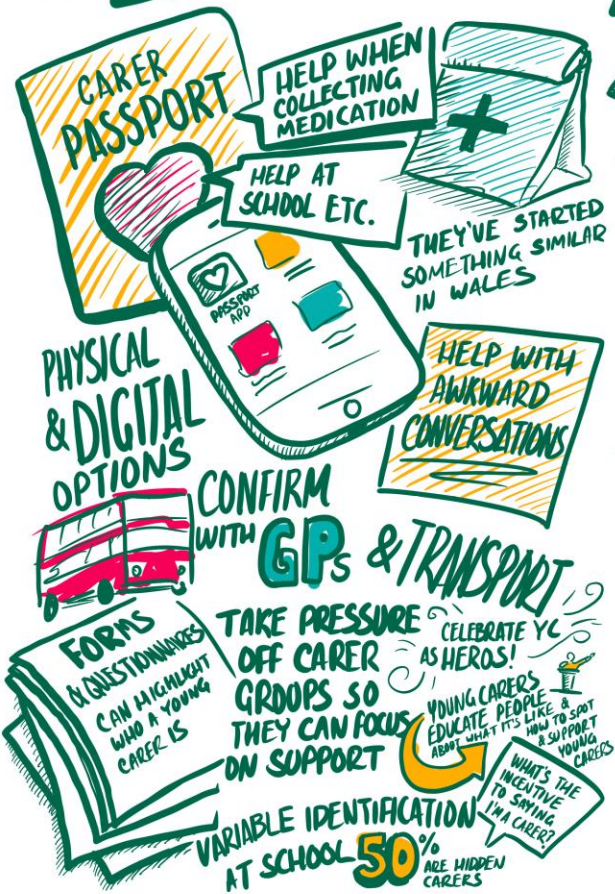


# *Key findings*



# EXPLORING EXPERIENCES OF YOUNG CARERS

## IDENTIFYING



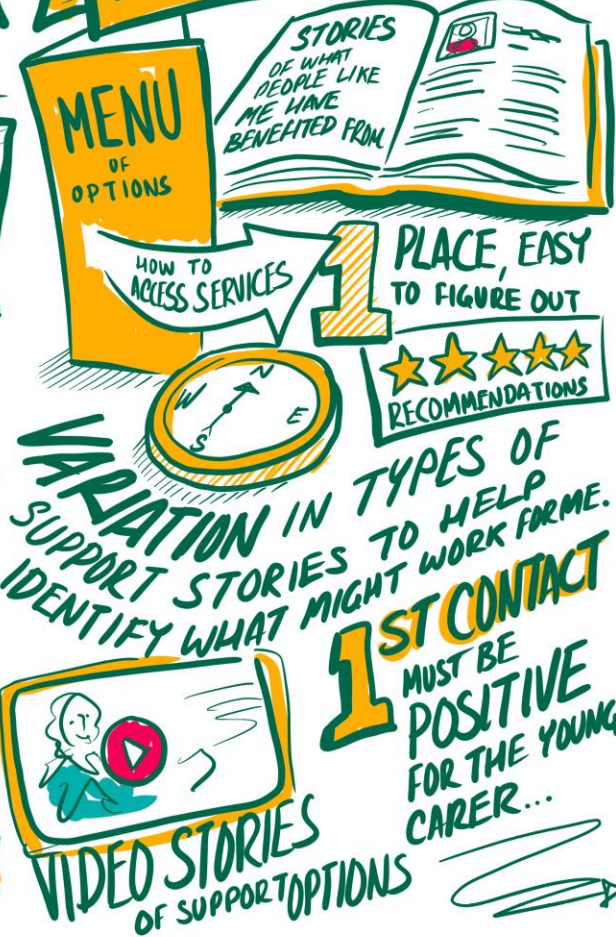
## AWARENESS & UNDERSTANDING



## RESPITE



## ACCESS & NAVIGATION





### What is it like being a carer currently?

Summary based on carer feedback

- Carers discussed being **overwhelmed** - they didn't have enough time to do everything they needed to and struggled to balance their priorities which could be emotionally challenging.
- They put the needs of the person they care for before their own, which leaves them feeling tired and pressured, with very **little time for friends, personal time/ respite**.
- Some worry about the person they care for when they are not with them (emphasised by Covid-19 concerns), so they can **never fully relax**.
- Conversely, there were **positive aspects** fed back about being a carer.
- Multiple carers said their responsibility meant they were **more mature** for their age.
- There is **pride** in the important things they do for others, they are noted as “heroes” by themselves and those around them.
- Despite pressures, some have **managed to make time** for the things they enjoyed and that were important to them.

### What are the barriers to identifying and supporting carers?

Based on young carer and professional participant feedback the following were found as key barriers...

- Trust
- Not wanting to be judged
- Limited of understanding from others
- Inconsistency

*“Understanding them [trusted adult] as a person and whether you think they’ll support you, there is no point in telling them if they will just judge you.” Carer, 16*

*“I don’t tell people because I don’t want others to feel sorry for me.” Carer, 12*

*“It took me going into school crying one day to be offered support.” Carer, 13*

*“I don’t but I know some other carers my age who get help. I’m not sure it’s for me” Carer, 11*

### Trust

Findings suggest trust is a key theme underpins carer experiences.

- Uncertainty around trust was fed back from many carers towards peers and trusted adults, making carers hesitant to share their experiences or challenges with others.
- Multiple carers said they only spoke about being a carer with people they trusted highly.
- Carers didn't feel enough trust to talk to others about being a carer or even say that that they were a carer at all. In addition, some carers didn't want to "burden" others by speaking about being a carer.

#### **This suggests**

Carers have different notions of trust and trusting others enough to share their experience as a carer. Mixed perceptions of carers' trust in people and environments around them meant they were less likely to speak about their experiences and responsibilities. Discussion with carers and professionals highlighted that carers who are less open are harder to identify and offer support to. They may not be aware of support that could help them.

### Not wanting to be judged

Not wanting to be judged was another salient theme fed back by many carers.

- Carers worried about others judging and stereotyping them negatively.
- They didn't want to tell peers they were a carer because they were embarrassed - they worried that peers may treat them differently once they knew they were a carer.
- Some thought their family members may be unfairly judged based on their support needs or health conditions.

#### **This suggests**

Judgement is an obstacle limiting carer experiences, preventing their journey from being 'at best'. Carers can be apprehensive about telling others about their responsibilities for fear of judgement or stigma by peers and trusted adults/professionals, making this a key barrier in identifying carers and them getting the support they may need.

*“People assume the worst case scenario when I say I’m a carer, as if both parents are in wheelchairs, then I get asked loads of questions that can be awkward.” Carer, 13*

### *Limited understanding/awareness from others*

Carers reported limited understanding and awareness of those around them.

- Some carers said trusted adults, such as teaching staff and healthcare professionals, weren't supportive or sensitive to their situation.
- This made them less likely to speak about being a carer and getting support that could help them.
- People around them needed to be educated about what a carer is and what being a carer involves. Participants said they would appreciate it being brought up and outlined in their school assemblies.

#### **This suggests**

A need to educate and raise awareness around carers sensitively – carers want awareness raised without feeding into stigmas, feelings of judgment or embarrassment. If others had more understanding, carers would be more comfortable to explain their specific circumstances and challenges. Carers can be intimidated having to explain being a carer in detail, when they may want to speak about only some aspects of their challenges or caring responsibilities.

### *Inconsistency in carer support*

Support that carers received varied. Some are receiving good levels of support from school, peers and from voluntary organisations (Cheshire Young Carers, Crossroads, Cheshire Hub).

- Most participants did not receive this level of support if any at all.
- Trusted adults and peers could make their experiences harder by holding carers to the same standards and expectations of others without their level of personal responsibility.
- Lack of support impacted carers in their personal wellbeing, such as feeling more stressed or pressured at school and in their personal lives.
- Their ability to care was limited by people who didn't support their responsibilities. For instance, teachers not allowing them to leave a lesson to call the person they care for, pharmacists not letting them pick up medication for the person they care for.

#### **This suggests**

There is support available for carers in Cheshire East that is helping carers currently. Although, others receive less or no support. In addition to this, there are carers whose challenges go unrecognised or are exacerbated by those who have the capability to improve or enable carer support.



# *What needs to happen to support young carers to be their best?*

Several questions were asked to explore what needed to happen to overcome the challenges identified and what the carers journey would be like at it best in the future. Four key themes were elicited:

1. Carers are identified
2. Awareness, understanding and good communication around carers
3. Carers have respite opportunities and can do things they enjoy
4. Accessing services and navigating what's right for carers.

These 4 themes will be outlined and as **touchpoints** that can help to illustrate and understand a positive carer journey.

# What needs to happen to support young carers to be their best?

### Touchpoint 1. Carers are identified

A carer is identified by trusted adults or professionals and/or feels comfortable enough to tell others about their caring responsibilities.

### Touchpoint 2. There is awareness, understanding and good communication around carers

Carers experience awareness and communication that feels judgement free, enabling a trusting environment. They feel they can communicate with others if they want to and are treated fairly.

*“I don’t like having to explain I’m a carer, especially when some people don’t understand what that means – the responsibilities I might have.”*  
Carer, 14

# What needs to happen to support young carers to be their best?

### **Touchpoint 3. Carers have respite opportunities and can do things they enjoy**

Once identified, and good communication and awareness has been established, carers are able to have the type of respite they want, when they want it. They do not have challenges which limit them doing things they enjoy.

### **Touchpoint 4. Accessing services and navigating what's right for carers.**

If a carer wants to access services, they can in a trusting environment. They can see all available options so they can choose support that suits them.

*“Sometimes you want to talk to someone if you’re stressed, but sometimes I just want to have some time to myself.” Carer, 17*

# *Insight-led recommendations*

# Recommendations

Informed by the insights, **3 key recommendations** are made:

- **1.** Make it easier for carers to be identified in multiple settings
- **2.** Ensure appropriate awareness and communication is in place for carers in their daily settings/contexts
- **3.** Give carers a central point of access and easy way to navigate support and respite.

This has resulted in **4 solutions**, developed to achieve the above recommendations. Each solution will be discussed in the remaining sections of this report. These solutions have been developed to improve a carer's journey and/or help them to overcome challenges and stigmas they experience, making room for them to be happy and proud of their achievements and personally flourish.

*1. Recommendation to make it easier for carers to be identified in multiple settings*

# Solution: Young carer card/passport

## Obstacles in the identification of young carers

Barriers around **trust, awareness and/or perceived stigma** they may experience means carers can be hesitant to tell others that they are a carer. They can find it hard to tell people who know they are a carer that they may feel overwhelmed and need some time to themselves. Some experienced problems in being identified and other people treating them appropriately when trying to fulfil their responsibilities as a carer, e.g., trying to pick up prescriptions for the person they care for and being questioned or even turned away by pharmacists, or not being allowed to take a moment to themselves in schools.

**Research suggests** that a quick, easy and discrete tool like a card or 'passport' to signify that they are a carer would be beneficial. This can help overcome hesitancy from carers in discussing being a carer publicly or with certain people, which many carers felt was too personal. In addition, the settings in which young carers felt comfortable varied based on individual preferences, so making the pass useful in multiple settings was well received and even more attractive for many participants.

# Young carer card/passport

## Solution in practice

- Participants predominantly mentioned identification obstacles in **education settings, however obstacles occurred in a range of social settings**. Schools/classrooms, primary care and transport were given as salient examples by professionals and carers as to where a carer pass or card could be useful. To be as effective as possible for carers, a pass should be supported by people working in these different settings.
- For example, a 'timeout' feature was mentioned and could be implemented in school settings, so carers can show the card if they need permission to leave a classroom. For buses, it would be method for carers to obtain transport discount.
- The **process of implementing a pass** in some of these settings would also work towards raising awareness about carers and how they can be better supported.

*“We’re currently using a blue timeout card with some similarities to this pass in our school, so we could quite easily help implement this for carers. It would help raising staff awareness too!”*

*School teacher*



# Young carer card/passport

## Solution in practice

- A version of a carer pass/ card is already in use in Wales on a national level, best practice and useful learnings should be evaluated from this and applied to CEC carer pass where possible/ relevant<sup>1</sup>.
- Physical and digital formats of a pass or card should be considered as both formats have benefits. As well as being convenient for many, a digital pass could link or be integrated with wider 'back-end' systems in health/primary care, education and more.
- Although a digital phone pass would be useful, it could exclude carers with limited digital access or without smartphones, so a physical pass should always be considered as a digital alternative if a pass was made in digital formats.

*“It’s a really handy idea. I know that young carers find it difficult in General Practice. So I definitely would be an advocate for working with primary care and young carers themselves for it to be okay to flash a card out.” General practice staff*

<sup>1</sup><https://socialcare.wales/service-improvement/care-worker-card-faqs>

*2. Recommendations to ensure appropriate awareness and communication is in place for carers in their daily settings/contexts*

# Solution: Young Carer Ambassador

## Obstacles to awareness, understanding and communication around young carers

Carers aren't always **aware** of who can help them. Knowing 'who to go to' can be unclear and/or awkward for young carers, particularly in school settings. They aren't aware of other carers, or people they feel they can trust to understand their experience. Carers want to know there is someone available who can **advise them appropriately** (whether it's advice, support, or respite needed). **Supporting carers after identification** was noted as a key challenge by professionals. Findings also suggest that it is important that when a carer does reach out for advice or support, that their first experience is a positive one to facilitate them continuing to reach out for support in the future.

**Research suggests** that an ambassador who can act as a point of contact for carers to speak would be appealing and practically beneficial. Importantly they would have an understanding of carer backgrounds and responsibilities, so ambassadors can better signpost carers and provide resources based on specific needs and in ways that don't feel judgemental. Ambassadors can also ensure carers first experience in reaching out for support is a good one and well joined up/signposted to other useful resources or services.

# Young Carer Ambassador

## Solution in practice

- A carer ambassador should be equipped with **up-to-date information** and easy to share resources. They need to be able to **identify with or understand carers experiences**. It was suggested that ambassadors could be a similar school age to carers.
- They need **a point of contact** for support from adults, if ambassadors need it. We suggest this is a voluntary organisation, or someone with experience who will understand carer situations and practical solutions available, such as:
  - School mentor
  - Cheshire Young Carers
  - Pastoral services.
- Once ambassador set up is underway, a **buddy system** can be introduced to help induct and support new ambassadors.
- **Facilitate annual meetings** for ambassadors to exchange information, within school or a time/place agreed by carers – protecting respite and their own time wherever possible.

*“I think a peer would be better as an ambassador for some young carers, an adult can seem like someone who may be looking down on them and can feel more daunting.” Carer, 15*

# **Solution:** Publicly speaking about and raising awareness for young carers

## **Obstacles to awareness, understanding and communication around young carers**

Carers worry about being **misunderstood and stereotyped** by others which makes them less open to communicating openly and honestly. They worry about being judged burdening others by speaking about their experiences/challenges. Carers don't always feel that others communicate with them appropriately or sensitively, even in settings that are significant to them, like classrooms and activity groups. Carers believed more should be done to raise awareness about being a carer and agreed school assemblies would be a good place to do this.

**This suggests** that carers, peers and professionals will benefit from speaking publicly/ raising awareness. This should be done sensitively, with feedback from school age carers themselves if they are comfortable with informing this. If they do not want to take part in assemblies/public speaking, they can be drawn upon to say what needs to be communicated about being a school age carer. This helps normalise the topic among carers and dispel perceived stereotypes. Hearing the topic of carers spoken about publicly in places significant to them would make them feel less alone and more open to honest communication about their challenges.

# Publicly speaking about and raising awareness for young carers

## Solution in practice

- Again, cross-sector application would be useful here. Efficiency and best practice should be shared by creating a comprehensive, easily shared and **easily understood 'presentation'**. This can be adapted and changed to suit a variety of settings where carers attend.
- In the presentation make it **clear to carers who they can speak to** and how they can find or reach them.
- **This route should be informed by carers themselves** to define how they would like the process to take place, as carers in some schools or activity groups may not want this at all, or want public speaking to be done on a smaller scale, e.g. in small classes or groups.

*“It’s chance for us to say, ‘don’t treat us any differently, but this is what we may be going through, why we might be sitting taking a minute to ourselves over school break.’” Carer*

*3. Recommendation to give carers a central point of access and easy way navigate support and respite.*

# A menu and central point of access for young carer respite and support services

## Obstacles to carers getting respite

There are **practical obstacles** to carers having respite. They discussed not being able to get transport, to get buses or 'lifts', to activities they enjoy. Having the resources, such as having the equipment/ kit needed or prepared to take part in activities is a challenge. Many carers also don't feel like they have adequate time to have respite.

Findings also highlight **emotional obstacles** to carers respite. Carers can worry about the person(s) they care for while taking respite, which can limit them taking it in the future. We also know carers can feel too stressed or overwhelmed – juggling responsibilities.

**This suggests** carers need to be given options that suit their needs (e.g. respite that matches transport capability, or that includes transport) in a way that is easy to access and understand. Carers would appreciate having a central point of access for activities and respite options, in a menu format that could be physical and digital. This gives carers better access to quickly and easily read up on all of the options available to them. It also gives them the control to make decisions on what they want to do.



# A menu and central point of access for young carer respite and support services

## Obstacles to carers accessing support

Carers **don't always realise** support is in place to help them, in what ways they can receive it and if it will benefit them. Carers **don't know enough about the service to access it confidently** (e.g. will the people there understand my situation/pressures I face). In addition, not one size fits all - type of service carers want can vary e.g. (121 or group support) and how they access it (phone, in-person, online). Carers can be unsure if a service or respite option is right for them.

**This suggests** carers want to see feedback and stories from people they can relate to, speaking about the services or respite options they are considering. This review format helps to make carers feel more comfortable accessing support as they can clearly see the benefits. It also helps them find an activity or support option that feels right to them, based on feedback from people in similar positions to themselves. *The challenges around carers receiving support and respite overlap significantly, so a menu of services and respite in a central location can be implemented to help carers in both support and respite access.*

*“Its about access, connections and building relationships in services.” Voluntary sector professional*

# A menu and central point of access for young carer respite and support services

## Solution in practice

- Carers should be given a clear and easy to access matrix in a menu format, that will help to provide advice on respite/support and show follow-up options, should they want to query any options further.
- A menu of choices should show available services and how to access them (e.g. transport options available, resources required) with relevant signposting information. Carers who are trying to access respite/support when they are at a point of immediate need will find this useful, as navigating service options under high levels of stress can be difficult.
- A menu can be distributed in a range of digital, social media and traditional formats. It should be shared in community and in professional settings. A menu and central point of access can also tie into being a resource for carer ambassadors, giving them a tool to inform their peers and adults.
- Seeing options for support and respite in this way shows the diversity in support available to suit the varied preferences and lifestyles among carers.

# Insight-led recommendations summary

**Based on findings from this insight report, 3 recommendations are made:**

1. Make it easier for carers to be identified in multiple settings.
2. Ensure appropriate awareness and communication is in place for carers in their daily settings/contexts.
3. Give carers a central point of access and easy way to navigate support and respite.

**These recommendations can be achieved by implementing 4 solutions:**

- Young carer pass/ card.
- Young carer ambassador.
- Publicly speaking about and raising awareness for young carers.
- A menu and central point of access for young carer respite and support services.

Informed by insight, the above recommendations and solutions will help improve carer experiences in their daily lives, enable social resilience and help them to personally flourish.

*together we...*

**#MakeBetterHappen**

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