Invisible in Plain Sight:

Young Carers and Cared-For Parents' Experiences in Health and Social Care Settings

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About the Project Partners

What is #SpeakUp?

#SpeakUp is Healthwatch Sheffield's micro grants programme, offering funding of £1500 to not-for-profit, voluntary, and community groups. The purpose is to run a project which will reach out to people across Sheffield, and hear what matters to them in relation to health and social care.

By working with groups which are already trusted partners in their communities, we can make sure we're hearing from even more people, including those whose voices aren't often heard by decision makers.

Who are Sheffield Young Carers?

Sheffield Young Carers (SYC) is a charity based in Sheffield that supports young people aged 8-25 who are young carers and/or impacted by familial substance misuse.

A young carer is a child or young person who provides substantial unpaid care for a relative who has disabilities, long-term physical illnesses, mental health difficulties and/or drug or alcohol issues.

There are over 1 million young carers in the UK and over 7,000 in Sheffield.

SYC supports young carers with one-to-one sessions with a specialist worker, group and holiday activities as we as supporting the family as a whole to reduce the impact of the caring role or substance misuse.

Who are SYC's Action Group?

SYC's Action Group is a group of young people who have been involved in the service and now help shape the work done by Sheffield Young Carers.

They speak up about what it's like to be a young carer and a young person impacted by substance misuse in the family. They share their views to help improve services, raise awareness, and influence decision-makers. They make sure young carers are listened to and taken seriously.

Who are Healthwatch Sheffield?

Healthwatch Sheffield Healthwatch Sheffield helps adults, children and young people influence and improve how NHS and Social Care services are designed and run. We're completely independent and not part of the NHS or Sheffield City Council. We want to understand your experiences, and help your views to influence decision-makers in the city.

Introduction

Why did we carry out this project?

At Sheffield Young Carers, we believe it is vital to listen to young people's experiences of the services they access, what works for them, what does not, and how those services can be improved.

In early 2025, our Action Group told us repeatedly that they felt they should have been identified much earlier by professionals in their lives. Many said they were only identified as young carers by schools or social workers after reaching crisis point, even though their families had regular contact with healthcare professionals for years.

They reflected that many young people do not recognise themselves as young carers simply because they have never heard the term. They suggested that clear information, such as posters in waiting rooms explaining what a young carer is, could help young people come forward earlier and ask for help.

As a service, we have also become increasingly concerned about the low number of referrals from healthcare professionals. In 2024–2025, only 3% (7 out of 188 referrals) to SYC came from healthcare services. Research consistently shows that early identification reduces the negative impact of caring on young people, and healthcare professionals are in a strong position to notice and support the young carer because they already work with the cared-for person.

What did we do?

In summer 2025, we held two day-long workshops and spoke to two groups of young people: those who are young carers for a relative with a disability or long-term illness, and those specifically impacted by a family member's use of alcohol or drugs.

- The first workshop explored their experiences of being identified, or not identified, as young carers and their interactions with health and social care services.
- The second workshop focused on creating resources that the young

people wanted to see in healthcare settings to improve early identification and support.

In early autumn 2025, we held a two-hour session with a group of cared-for parents supported by SYC's Family Project. We asked about their experiences of healthcare services and what support they felt was available for their children. We also shared the resources designed by the young people to ensure the language and tone felt appropriate and empowering from a parent's perspective.

Who did we speak to?

We spoke to 15 young people aged 14–25:

- Four male and 11 female participants.
- Four young people were affected by familial substance misuse.
- Seven young people cared for one or more family members for reasons related to physical health, mental health, or neurodiversity.

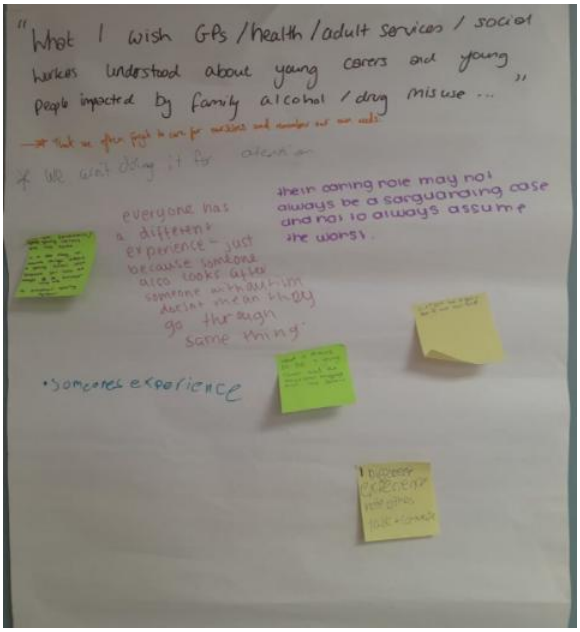
We also spoke to five cared-for parents, all female, each living with a combination of long-term physical health conditions, neurodiversity, and/or mental health difficulties. These parents were not related to the young people we spoke to.

It should be noted that all of the young people and parents we spoke to have been supported by Sheffield Young Carers for at least one year. Therefore, these participants had already been formally identified as young carers or cared-for parents and were reflecting on their experiences both before and after identification.

Findings

Through the workshops with young carers, young people affected by familial substance misuse, and cared-for parents, several clear themes emerged. Across both groups, there was a shared message that health and social care professionals are often missing opportunities to identify and support young carers at an early stage. Participants described emotional, practical, and relational barriers that continue to prevent families from receiving timely help.

Lack of Identification by Professionals



Both young people and parents described a consistent absence of recognition from healthcare professionals. Despite having long-term contact with doctors, nurses, and other practitioners, none of the young people had ever been asked about caring responsibilities during appointments.

Young carers repeatedly described feeling overlooked in healthcare appointments for the person they care for. They said professionals often spoke only to the adult, even when the young person was actively supporting communication, transport, or medication collection.

One young person told us about their experiences supporting their younger sister, who is non-verbal and autistic. This young person regularly attends their sister's speech and language therapy sessions, as she is the only person her sister will speak to. However, the therapist has never spoken to her about her role or suggested that she might be a young carer. She explained that this made her feel ignored and invisible, and that her contribution to her sister's care was not recognised.

Another young person told us about their father, who had liver disease due to misuse of alcohol. Although healthcare professionals knew that the father lived with his children, it was never discussed how his illness or substance use might be affecting them. The young person reflected that, if more open conversations had taken place, their family might have received support much earlier.

"They knew my dad was really ill and that he had kids at home, but no one ever asked how things were for us. If someone had just started that

conversation, maybe we could have got help before everything got so bad."

Parents also shared that no one had ever discussed the care or support their child provided at home. For some, their child's role was only noticed once the family reached crisis point, often by schools, the police, or through self-referral to Sheffield Young Carers.

One mother told us how her child helps push her wheelchair to GP appointments, hands in repeat prescription slips, and waits with her during consultations. Yet staff at the surgery have never questioned why a child was taking on these tasks. She also described being in hospital for long periods due to a long-term condition and how her child would sit beside her every day, but no healthcare staff ever asked how this might be affecting them or whether they needed support.

All of the participants in the workshops felt that health professionals are in a strong position to notice caring roles but often miss clear indicators such as the presence of children at appointments, visible signs of caring, or long-term conditions within the household. They stressed that young carers support a range of family members, including parents, siblings, and other relatives, and that professionals should be alert to caring roles in all these situations. Parents suggested that healthcare professionals should be more curious, asking gentle, open questions and offering follow-up appointments to explore family circumstances in more depth.

Young people said that being acknowledged and included in appointments would make them feel "seen, listened to, and trusted." They also noted that small gestures, such as being asked how they were coping, could have a big impact on how supported they felt.

Fear and Distrust of Services

A strong theme across both groups was a fear of judgment and intervention from services. Young people said they worried that disclosing their home situation could lead to social services involvement or even family separation. They described feeling guilty for speaking up about their situation, worrying that it might upset their parent and families or lead to unwanted attention from services.

Additionally, one young person told us about a time when social services did get involved in their family and they were just dismissed as an 'angry child'.

"Maybe if they tried to get to know why I was angry, they would see that I was just too overwhelmed with everything I was trying to do – not just an 'angry child.'"

As a result, this young person felt very distrustful of social services and no longer believed they were there to support her.

Another young person explained that their parents were first-generation immigrants and that this made their family even more fearful of services. They said their parents worried that if professionals found out what was really happening at home, the family might face serious consequences, including the risk of being removed from the country. This fear meant that problems were kept hidden, and the young person carried a lot of responsibility on their own.

Parents expressed similar concerns, saying they feared being judged as "bad parents" or having their children taken away.

One parent described being told by a professional that she had "let her son down," which made her feel unsafe and hesitant to engage with services again.

"That comment made me feel judged, not supported. After that, I avoided any contact with them."

Others described professionals as "scary" or "intimidating," reinforcing a sense of mistrust.

This fear often led families to mask their struggles and avoid honest conversations. As a result, opportunities for early support were missed, and crises became the main trigger for identification and referral.

Communication and Relationship Building

Both groups emphasised that how professionals communicate can make the difference between a family opening up or shutting down. Young people said that professionals often use overly formal or clinical language, which can feel intimidating or alienating. They wanted professionals to be approachable, honest about their role, and to explain why they are asking questions.

Parents expressed a desire for professionals who are kind, patient, and non-judgmental, saying they feel most comfortable when staff take time to listen and show empathy.

One parent told us about an appointment where a healthcare professional hesitated to ask about her home situation. The parent explained that she could tell the professional sensed something was wrong but chose not to ask. Later, the professional admitted they "didn't want to open that can of worms." The parent reflected:

> *"That can of worms needed opening. If they'd just asked how things were at home, they would've realised how much my child was doing to look after me. It didn't need to be a big, scary conversation; just a gentle question like, 'Is everything okay?' might have made all the difference."*

Parents agreed that all staff in healthcare settings, including receptionists and medical staff, should feel confident to ask questions when something doesn't feel right. They stressed that professionals have a duty of care to both adults and children and should not avoid "awkward conversations." Even small, caring questions can open the door to meaningful support and trust.

Building trust and positive relationships was seen as key. Young people said that when they understood a professional's motivations, for example when someone explained that they went into the job to help people, it immediately made them feel safer and more willing to engage.

Need for a Whole-Family Approach

Both parents and young carers strongly supported a whole-family approach to health and social care. They felt that current systems are too focused on the individual patient, with little recognition of how illness, disability or substance misuse affects the wider household.

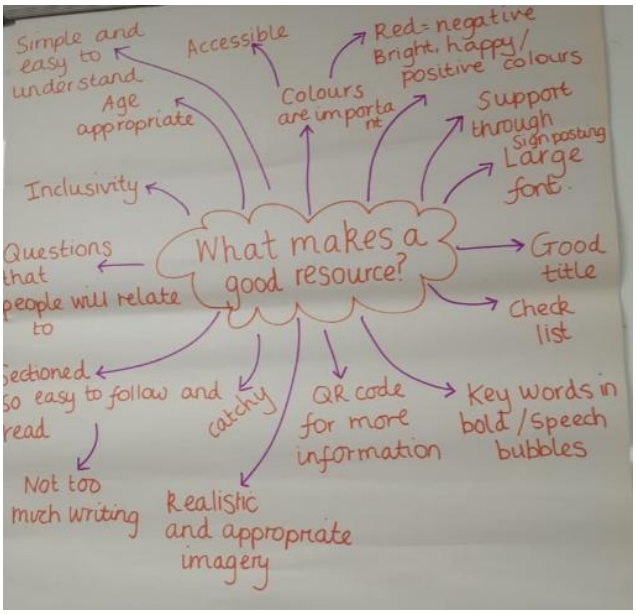
Parents wanted professionals to take time to understand the family dynamic and to signpost both the adult and the young carer to relevant support. Young people also stressed that professionals should not see the cared-for person in isolation, but instead consider how family members share responsibilities and emotional burdens.

Families who had received support through SYC's Family Project described it as transformative, helping them feel understood as a unit rather than separate individuals. They said they would like to see this approach mirrored across the wider health and care system.

Co-produced Resources

Following the first workshop, the young people worked together to design a set of practical resources for healthcare professionals and settings.

During this workshop the young people reviewed a range of posters that are already used by the NHS as well as young carer organisations across the country. They agreed that bright colours are useful to make the posters visually appealing and that clear language is required.



Their aim was to make it easier for professionals to identify and support young carers earlier. Additionally, they wanted resources that could be seen in waiting rooms that young people and families could read and potentially self-identify themselves as young carers.

The young people felt these were needed because a lot of people don't realise they are young carers because they have never heard the term, or think what they do is normal as they have never known any difference. The cared-for parents group then reviewed these materials to ensure the language felt respectful and sensitive to families' experiences. Together, they created a set of co-produced tools and recommendations for healthcare settings.

"Do You Help Someone at Home?" Poster and Digital Slide

The young people felt a checklist style poster to display in waiting rooms, pharmacies and hospital wards would be helpful to self-identify as young carers. There has also been a landscape version created which the young people hope will be added to the slideshows that are often on the screens in waiting rooms. They all commented that often when they are waiting for appointments they will look at these posters or screens and having simple reflective questions might help them to think more deeply about what they do at home.

The poster asks questions such as:

"Do you live with someone with a mental or physical health illness, condition, or disability?"

"Do you help with any of these tasks?" (followed by clear examples like cooking, shopping, calming them down, or looking after siblings).

It also lists common feelings that young carers might experience, such as feeling “worried,” “responsible,” or “like you need a break”, helping young people recognise themselves in the descriptions.

The tone is intentionally non-clinical and reassuring, ending with the message:

> *“If so, speak to a healthcare professional, who can give you more information on how to get support (even if you just ticked one box!).”*

Parents fed back that they appreciated the poster’s gentle, empowering tone. They felt it would help remove shame or fear and instead encourage children to seek support confidently.

“Who Else Supports This Patient?” Flowchart

The flowchart was developed to help healthcare professionals identify and support young carers more confidently during appointments. It guides staff through a series of simple, reflective questions, such as:

“Does your patient have a long-term illness or disability?”

“Do they have any support from family at home?”

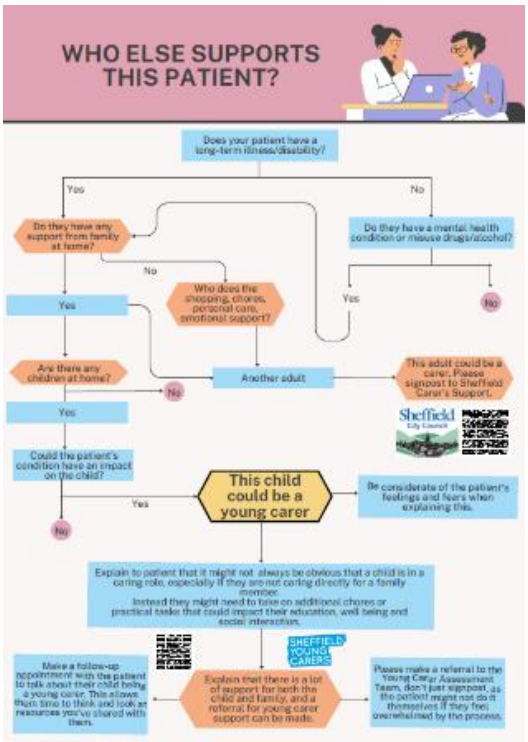
“Are there any children in the household?”

Depending on the responses, the flowchart prompts professionals to consider whether a child could be a young carer or whether an adult might also need carer support. It encourages staff to make a Young Carer Assessment Team referral rather than simply signposting, recognising that overwhelmed families may struggle to take that step themselves.

The final step reminds professionals to make a follow-up appointment and to “be considerate of the patient’s feelings and fears” when introducing the idea of young carer support.

Parents particularly liked this resource, saying it “takes away the guesswork” for professionals and gives them a clear, confident structure for having what can feel like a sensitive conversation. One parent said,

“That’s the kind of tool that would have made all the difference, it gives them a reason to ask the questions.”



Why These Resources Matter

Both the poster and the flowchart were created with one shared goal: to ensure no young carer goes unnoticed.

The poster empowers children and families to recognise caring roles and self-identify. The flowchart supports professionals to spot and respond to caring situations early, with compassion and confidence.

Together, they promote a whole-family approach to care, helping professionals see beyond the patient and consider the needs of everyone in the household.

With the support of Healthwatch Sheffield we hope to pilot these resources in a range of healthcare settings.

Sheffield Young Carers Next Steps

The voices and experiences shared through the workshops have directly shaped new tools that can help healthcare professionals recognise and support young carers earlier.

Sheffield Young Carers now intends to build on this work by taking the following next steps:

1. Piloting the Resources in Healthcare Settings

With the help of Healthwatch Sheffield, we will pilot the poster and flowchart in a range of healthcare settings across the city, including GP surgeries, hospital departments, and community health teams.

We will gather feedback from both professionals and families on how easy the resources are to use, how well they prompt conversations, and any changes needed to make them more effective.

This feedback will be used to refine the materials before they are rolled out across Sheffield as part of a wider awareness campaign.

2. Developing a New Resource for Professionals

In early 2026, we will work with cared-for parents to co-produce a new resource for health and social care professionals focused on how to have sensitive, supportive conversations with parents about their child's caring role.

This resource will build on the success of our previous publication, Breaking Down Barriers: Between school, college and families of young carers, adapting that approach for the health and social care context.

It will include practical examples of language to use, common barriers parents experience, and tips for creating safe, trusting environments for families.

3. Adapting Resources for Education Settings

We will also adapt the poster for use in schools and colleges.

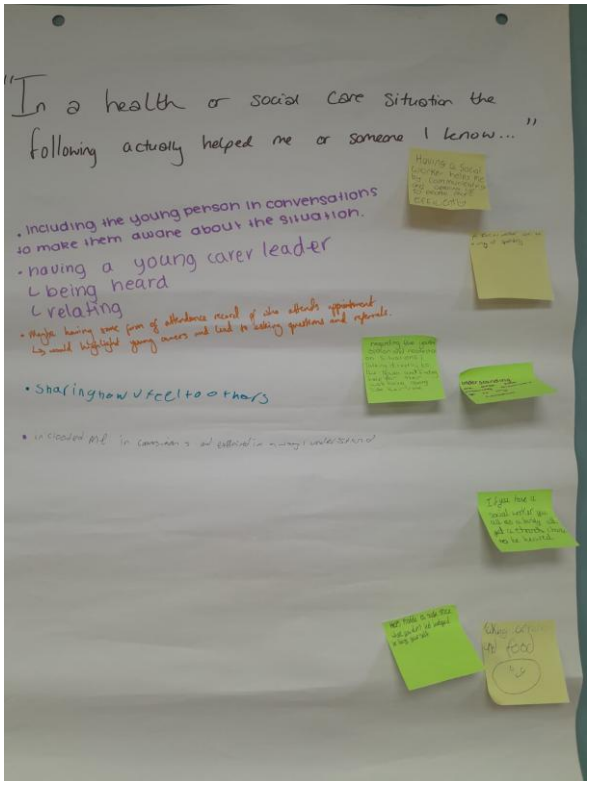
The education versions will use familiar language and scenarios relevant to students, helping to strengthen early identification within education settings.

These will be shared across Sheffield Young Carers' School Network, which now includes more than 100 schools across the city.

4. Continuing to Amplify Young Carers' Voices

As part of our ongoing commitment to youth participation, Sheffield Young Carers will continue to involve young people in co-creation of all new resources.

Their insight will remain central to ensuring that identification and support for young carers are led by lived experience and reflect what young people truly need from professionals.



Recommendations

Young carers and cared-for parents were clear that healthcare professionals have a vital role to play in identifying and supporting young carers at an early stage. They recognised that small, simple actions, taken consistently and with empathy, can make a huge difference. Together, they outlined a series of steps that all healthcare settings can take to improve awareness, communication, and support.

1. Be Curious and Ask Questions

Every member of staff, from receptionists to GPs, has an opportunity to notice when something does not feel right. A simple question such as “Is everything okay at home?” can open up important conversations and help uncover caring responsibilities that might otherwise go unseen.

Young carers and parents agreed that curiosity is not intrusive when it comes from a place of compassion. Professionals should feel confident to ask gentle questions and follow up when they sense a child or family may need support.

Young people and parents suggested examples of language that helps start these conversations in a caring and natural way:

For children and young people:

- “What do you do for Mum/Dad/Brother/Sister?”
- “What support can we get for you?”
- “I know of an organisation where they support other children like you who have similar situations at home. You can go and meet them, make friends, and have fun. You can go away and think about it. Here’s some information about them. I’d like to check in with you in a week to see what you think and if you’d like me to make a referral. It’s a safe space for you.”
- “There are probably two or three children in your class who have similar experiences.”

For parents:

- “I want to check in with your child to see how they’re feeling about your illness or condition and what support they might want. I’m letting you know so you feel included and understand what’s happening.”
- “I understand you get support with your condition, but I also want to check what support your child has with this.”

These questions show care and curiosity without judgment. Families said that this kind of language helps build trust and reassures them that professionals genuinely want to help, not criticise.

2. Recognise the Whole Family

Professionals are encouraged to think beyond the individual patient and consider who else may be affected by their condition or treatment.

If children are regularly present at appointments, or if an adult patient mentions having dependents at home, this could indicate a young carer role. Asking about how illness or disability affects family life should become routine practice.

Professionals should remember that young carers may support parents, siblings, or other relatives, and caring responsibilities can look very different from family to family. A young person might not use the term carer to describe themselves, so recognising these situations requires curiosity and sensitivity.

3. Use and Display Awareness Materials

The poster and flowchart co-produced through this project are practical tools designed to make identification easier.

- Display the poster in waiting areas, children's corners, and consultation rooms so that young people and families can self-identify.
- Use the flowchart during appointments or staff training sessions to guide conversations and referral decisions.

Both resources have been created with language that is warm, accessible, and family-friendly, helping to reduce stigma and build trust.

4. Undertake Training and Build Confidence

Training gives professionals the skills and reassurance they need to recognise and support young carers effectively.

- Staff should be encouraged to complete Sheffield Young Carers' e-learning or attend SYC's multi-agency training.

- Teams can also use the flowchart as part of internal discussions about improving identification pathways.

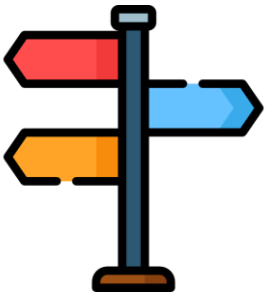
Building confidence across all roles, from clinical to administrative, ensures that every staff member feels part of the safeguarding and support process.

5. Create Safe and Supportive Spaces

Young carers and parents highlighted the importance of feeling safe and understood when talking to professionals.

Health settings should create an environment where families feel comfortable sharing personal information without fear of judgment or negative consequences. This includes being sensitive to cultural differences, language barriers, and fears related to immigration status.

6. Follow Up and Stay Involved



When a potential young carer is identified, it is vital that professionals do not simply signpost and move on.

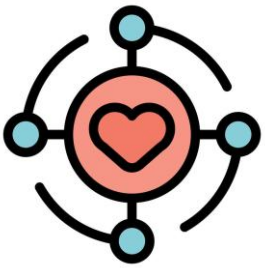
Making a formal referral to the Young Carer Assessment Team and arranging a follow-up appointment shows commitment and continuity of care. Families said that knowing a professional would check back in with them made them feel supported and less alone.

7. Equip all health providers to identify Young Carers

Commissioners should use Service Improvement Plans (SDIPs) to embed young carer identification into every patient-facing service. This ensures that identification becomes a natural part of the clinical conversation rather than a separate administrative task.

8. Prioritise "Whole-Family" principles in new service designs

Ensure that all future commissioning activity and service redesigns include a mandatory check to identify if a patient has children at home. This shifts the focus toward supporting the whole family from the point of diagnosis.



The Difference These Steps Can Make

Implementing these steps helps create a culture of awareness, empathy, and early support across healthcare settings. When professionals are curious, compassionate, and confident, young carers are more likely to be identified early, families feel safer to share their experiences, and crises can be prevented before they arise.

Beyond immediate identification, these changes ensure that:

Young people feel seen and listened to: By involving young carers in appointments, we validate their vital contribution and reduce the feelings of being ignored and invisible that many currently experience.

Barriers of fear are dismantled: Shifting to a gentle, non-judgmental approach helps remove the fear of judgment that prevents many families, particularly those from minoritised communities, from asking for help.

The Whole-Family is supported: Moving away from a focus solely on the individual patient allows the system to recognise the emotional and practical burdens shared by the entire household.

Trust is rebuilt: Clear communication and a genuine interest in a family's circumstances transform clinical interactions into supportive relationships, making families more willing to engage with services long-term.

Ultimately, these small, consistent actions move us toward a city where young carers are no longer "invisible in plain sight" but are instead valued and supported to thrive

Acknowledgments

Sheffield Young Carers would like to extend heartfelt thanks to everyone who contributed to this project.

First and foremost, we want to thank the young carers and young people affected by familial substance misuse who shared their experiences, insights, and creativity so openly. Your honesty, courage, and compassion shaped every part of this work, from the discussions to the design and creation of the resources.

We also want to thank the cared-for parents who took part in the consultation sessions. Your reflections, ideas, and feedback ensured that the language and tone of the resources are sensitive, inclusive, and supportive for families.

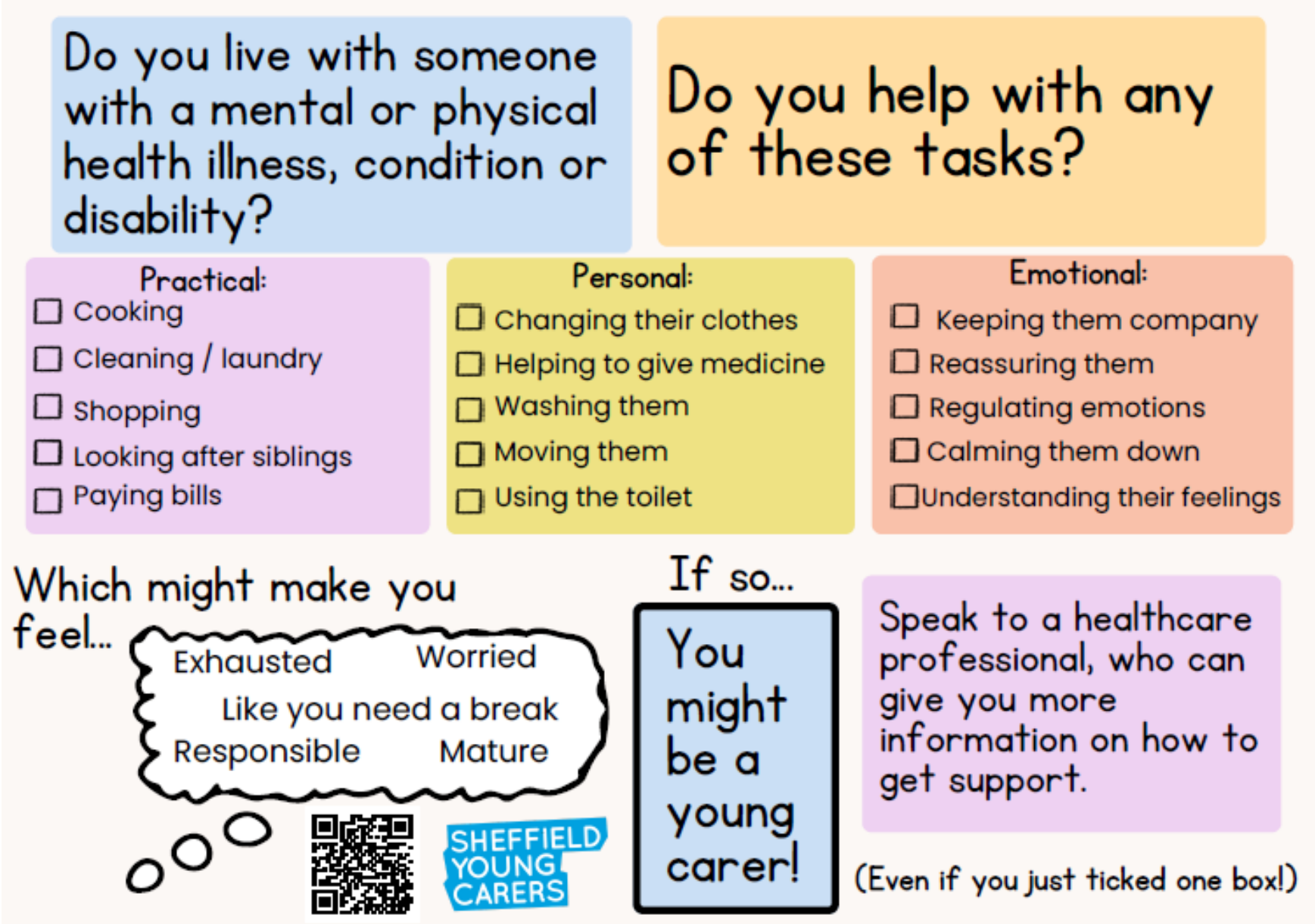
A special thank you to Healthwatch Sheffield for their partnership, funding, and ongoing support through the #SpeakUp grant. Your belief in the importance of hearing lived experience has made this project possible.

Finally, we are grateful to all the professionals across Sheffield's health and social care settings who are working to recognise and support young carers. Your commitment to learning, listening, and improving practice helps make Sheffield a city where young carers are seen, valued, and supported to thrive.

Printable Co-Produced Resources

Appendix 1: Poster for young carers and families to be pinned up in waiting rooms, hospital wards and pharmacies etc.

Appendix 2: Landscape poster to be added to slideshows that are on the screens in waiting rooms.



Appendix 3: Flowchart for healthcare professionals to use when talking to patients.