

CARERS TRUST

BREAKING THE SILENCE ON MENTAL HEALTH

A toolkit for young carer services on how to empower young carers and young adult carers with knowledge and confidence to have a voice and take action.



**MY
MENTAL
HEALTH**

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- The Carers Trust team, including Adem Ruggiero-Cakir, Lindsey Crawford, and the wider staff team.

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ABOUT CARERS TRUST

Carers Trust is a major charity for, with and about carers. We work to improve support, services and recognition for anyone living with the challenges of caring, unpaid, for a family member or friend who is ill, frail, disabled or has mental health or addiction problems.

We do this with a UK wide network of quality assured independent partners and through the provision of grants to help carers get the extra help they need to live their own lives. With these locally based Network Partners we are able to support carers in their homes through the provision of replacement care, and in the community with information, advice, emotional support, hands on practical help and access to much needed breaks. We offer specialist services for carers of people of all ages and conditions and a range of individually tailored support and group activities.

Our vision is that unpaid carers count and can access the help they need to live their lives.

1. OVERVIEW

ABOUT THIS TOOLKIT

This toolkit shares learning from Carers Trust's My Mental Health project and its intended audience is young carer and young adult carer services. It has information, guidance and best practice on amplifying the voices of young carers and young adult carers and providing more opportunities for their input into mental health support.

Although the terminology and legislation referred to applies to England the experiences, challenges and recommendations are applicable across the whole of the UK.

INTRODUCTION TO MY MENTAL HEALTH

My Mental Health is a Carers Trust project which ran from Autumn 2017 to March 2021. It provided young carers, young adult carers and the staff who support them with the knowledge, confidence and opportunities to understand their mental health needs and bring about positive change.

Children and young people who care for someone are known as young carers. They can be as young as three or as old as 25. They may be caring for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support. Older young carers are also known as young adult carers.

We worked with six Carers Trust Network Partners across England, with 281 young carers and young adult carers involved in local and national campaigning activity as part of the project. These activities have drawn attention to key issues impacting their mental health and wellbeing. This includes:

- Lack of available or suitable mental health support in their local area.
- Poor self-esteem and body image.
- Inconsistent availability or quality of support for young carers served by different schools, colleges and GP surgeries.
- Inappropriate responses from professionals to disclosure of issues relating to caring and/or mental health, resulting in distress.
- Lack of support in education. This was consistently highlighted by young carers as one of the largest determining factors for positive mental health and wellbeing.



What is participation?

Youth participation is about young people having a say and influencing change in decisions that affect their lives, organisations and communities. Some examples of youth participation work include, but are not limited to:

- Establishing a youth council or forum.
- Involvement in a consultation.
- Writing a letter or consultation response.
- Collaboratively creating media, such as videos, with young people.
- Organising and delivering events and workshops.
- Writing policy and strategy.
- Shaping a service – either your own or external.

Project activity

Carers Trust worked with six Carers Trust Network Partners throughout the course of the project that delivered action in their local areas. This section outlines some of the actions and successes. This is not a complete overview but is intended to provide a range of actions and examples for youth participation work.

Bath and North East Somerset (BANES) Carers Centre

- BANES Carers Centre co-produced and delivered a schools conference with young and young adult carers. Attendees reported an improved understanding of young carers and the centre developed relationships with new schools.
- The young carers voice group met with the local MP.
- The centre negotiated a temporary refresh of the local authority's Carers Strategy to ensure co-production of the strategy with young carers.
- Members of the centre's young carers voice group have taken part in various external events with decision makers. This includes meeting with their local MP, taking part in a radio interview during Carers Week to highlight the impact of being a young carer on their mental health, and joining a panel to contribute to the council's post Covid-19 lockdown renewal strategy.

Blackpool Carers Centre

- Blackpool Carers Centre delivered 'Living Room' sessions in schools and colleges, with young carers and the centre speaking directly to staff and pupils during breaktime about young carers' mental health and wellbeing and support in schools.
- They delivered a Young Carers Awareness Day event to 25 professionals and decision makers and participated in a consultation relating to the Children and Young People's Mental Health Local Transformation Plan.
- The centre wrote to and met with local MPs.
- Blackpool Carers Centre has been involved in shaping local mental health services, with Child and Adolescent Mental Health Services (CAMHS) (now known as Children and Young People's Mental Health Services – CYPMHS) now providing dedicated counselling support for young carers.

Carers Support Centre Bristol and South Gloucestershire

- Carers Support Centre Bristol and South Gloucestershire and members of its Young Carer Voice Forum worked with Bristol City Council to inform a new Young Carers Strategy. They also engaged with South Gloucestershire Council around the Building Stronger Communities Fund, which provides funding for local carer support.
- The centre co-delivered with young carers three workshops for local decision makers and professionals.
- Young carers gave a presentation to University Hospitals Bristol NHS Foundation Trust.
- The centre's young carers voice group members engaged with local MPs, sharing details of their campaign activities.

Northamptonshire Carers

- As part of Northamptonshire Carers Young Carers Mental Health Campaign, its Steering Group of Young Carer Champions helped to organise and deliver a My Mental Health Wellbeing Marketplace event at Northampton Town Football Club, on Young Carers Awareness Day 2020. Professionals who attended reported an improved understanding of young carers. Following the event, young carers reported better knowledge about support available to them.
- Northamptonshire Carers is continuing to work in partnership with the local youth counselling services (see Good Practice Case Study 1) to improve the support for young carers' mental health and wellbeing in the area, resulting in improved referral routes and pathways.
- The Network Partner secured the inclusion of young carers in its local Carers Strategy.
- It also created a My Mental Health short film series, which is available on YouTube (see Resources section).

Suffolk Family Carers

- Suffolk Family Carers worked with Healthwatch Suffolk to undertake and analyse a survey of young carers' and young adult carers' mental health and wellbeing (See Good practice case study 2).
- Based on this, they co-developed with young and young adult carers the "I Am..." campaign, which focused on young carers' self-esteem and body image.
- The centre delivered 'I Am Parent and Child' workshops to families, which were designed to improve parental support for young carers' mental health issues, as well as delivering this to Suffolk Family Carers staff members.
- They created and delivered personal, social, health and economic (PSHE) lessons on body image, with the resources now available on the Relationships, Sex and Health Education (RSHE) portal for schools in Suffolk to use with pupils.
- Suffolk Family Carers and young carers worked in collaboration with the Suffolk Youth Engagement Hub to create a video regarding the Mental Health Transformation model proposals as well as the planning for a self-harm support toolkit for young people.

Sutton Carers Centre

- Sutton Carers Centre established Young Carer Ambassadors to lead the project. They received an outstanding Volunteer Group Award from Sutton Community Awards.
- They wrote letters to ten schools and presented to three of them about how support in school can make a difference to young carers' mental health.
- Young carers presented to decision makers and professionals at Sutton Carers Centre's AGM, which also featured an exhibition of art and photography about young carers and their mental health.
- For Young Carers Awareness Day, there was GP-focused engagement, including surgery drop-ins, new posters, and a meeting with their MP and a local councillor.
- The local authority now requires schools to collect and include information about young carers in its Transitions Grid. This encourages schools to collect information about young carers in the school, and means information is shared when a young carer moves school, ensuring staff are aware of their circumstances.
- New schools have participated in the **Young Carers in Schools programme** – an initiative making it easy for schools to support young carers run jointly by Carers Trust and The Children's Society.



2. WORKING WITH YOUNG PEOPLE

SUCCESSSES OF THE MY MENTAL HEALTH PROJECT

Providing young and young adult carers with a platform to campaign for change to mental health and wellbeing support available in their local area has had a positive impact on them as well as organisations involved. This section outlines those impacts.

Young carer involvement in carer services

Young carers provided a lot more input into the My Mental Health project than anticipated, resulting in both growth and change in attitude of the organisations and young carers. Examples of this include a schools conference project, in which “as much power as possible” was given to young carers to make decisions about messaging and content. While the conference was a success, the biggest triumph was the extent of young carers’ involvement.

Allowing young carers to take the lead in the direction and delivery of local campaigns for change was a success. With support, young carers “were able to come up with the ideas and lead”. This responsibility has also contributed towards their investment in the project.

As a result of the project, young carers are far more involved in carer services than ever before – it was a catalyst for broader culture change. Beyond the project, there is more collaborative work at all levels, “doing with, not doing for or doing to”. This central role gives young carers the opportunity and confidence to shape the work and identify gaps in services. Examples include homework clubs, building peer support and co-delivering assemblies in schools.

Increased confidence for young carers

There has been a noticeable growth in the confidence of young carers involved in the My Mental Health project. They have been “instilled with a belief that they can make a difference”, and that going into adult life they don’t need to accept things as they are if they feel that it is unsatisfactory. Young carers have realised that they have valuable knowledge to share. For example, following a schools conference, one young carer stated “I taught the headmistress! I was teaching them!” In addition, bringing young carers together provided the opportunity for young carers to hear from others and feel less alone in their mental health struggles. This acted as an informal peer support group.

Gaining a better understanding of young carers’ needs

Participation in the My Mental Health project has supported carer services to gain a better understanding of young carers’ and young adult carers’ mental health and wellbeing needs. Following the project, they are more mindful of asking young people what they want rather than assuming. One service used the project to gather data on the needs of young carers, undertaking a survey of the mental health and wellbeing of young carers (see Good practice case study 2). This data not only supported local campaigning activity but also helped the service continue to adapt and shape its offer.

Positive impact of young carer involvement on external engagement

Involving young carers in organising and co-delivering My Mental Health activities has added significant value to the work. An example is a schools conference which would not have made such an impact without their input – attendees also appreciated the opportunity to hear from young carers first-hand. Throughout activities in the project, professionals who heard from young carers directly suggested that “lifting young people up” and providing them with their

own platform to share their own stories was markedly more effective than hearing the same message from the carer service.

In one of the project areas, young adult carers were involved in the consultation of CAMHS. The refresh of the Mental Health Transformation plan recognised their involvement, stating the refreshed plan had a “more robust narrative” around young carers and their mental health.

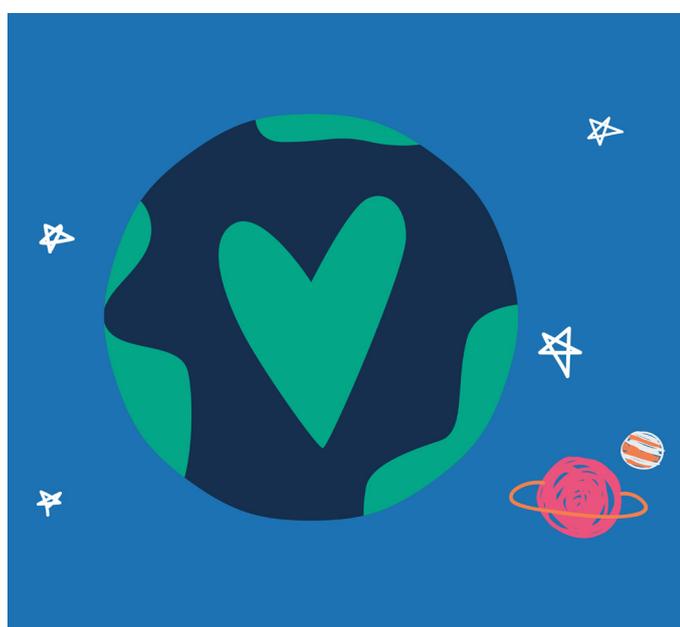
The youth led approach across the project also enhanced carer services’ awareness raising efforts. The first-hand conversation, dialogue and direct involvement of young carers creates a more memorable experience for decision makers and professionals. This places a higher expectation on their commitments to respond to stated needs. It also reinforces the value of the work of carer services, particularly in supporting the mental health and wellbeing of young adult carers.

A platform and opportunity to build and expand relationships

Involvement in the My Mental Health project has supported carer services to progress towards real change for young carers’ and young adult carers’ mental health and has provided a platform to get on the radar of the right people, including MPs and Commissioners. One example is a service that built new relationships and collaboration with local youth counselling services, which are now more aware of the specific needs of young carers and are committed to improving access to their services (see Good practice case study 1).

Due to involvement in the My Mental Health project, one of the carer services prioritised mental health as an issue and set about building new relationships with the local CAMHS (now known as Children and Young People’s Mental Health Services - CYPMHS) service. Where previously there was not an open dialogue, the local clinical commission group has now funded dedicated counselling support for young carers and works in close collaboration with the carer service.

Similarly, one of the carer services has reported positive growth in attitude and relationship with the local authority, who responded positively to a request by the service to push back the renewal of the local Carers Strategy to ensure the involvement of young carers. The service sees this commitment by the council as a reflection of its current positive relationships with the council. Another carer service was approached by a local authority to collaborate and deliver awareness raising around Young Carers Awareness Day, as well as consult on strategies and initiatives at the local authority.



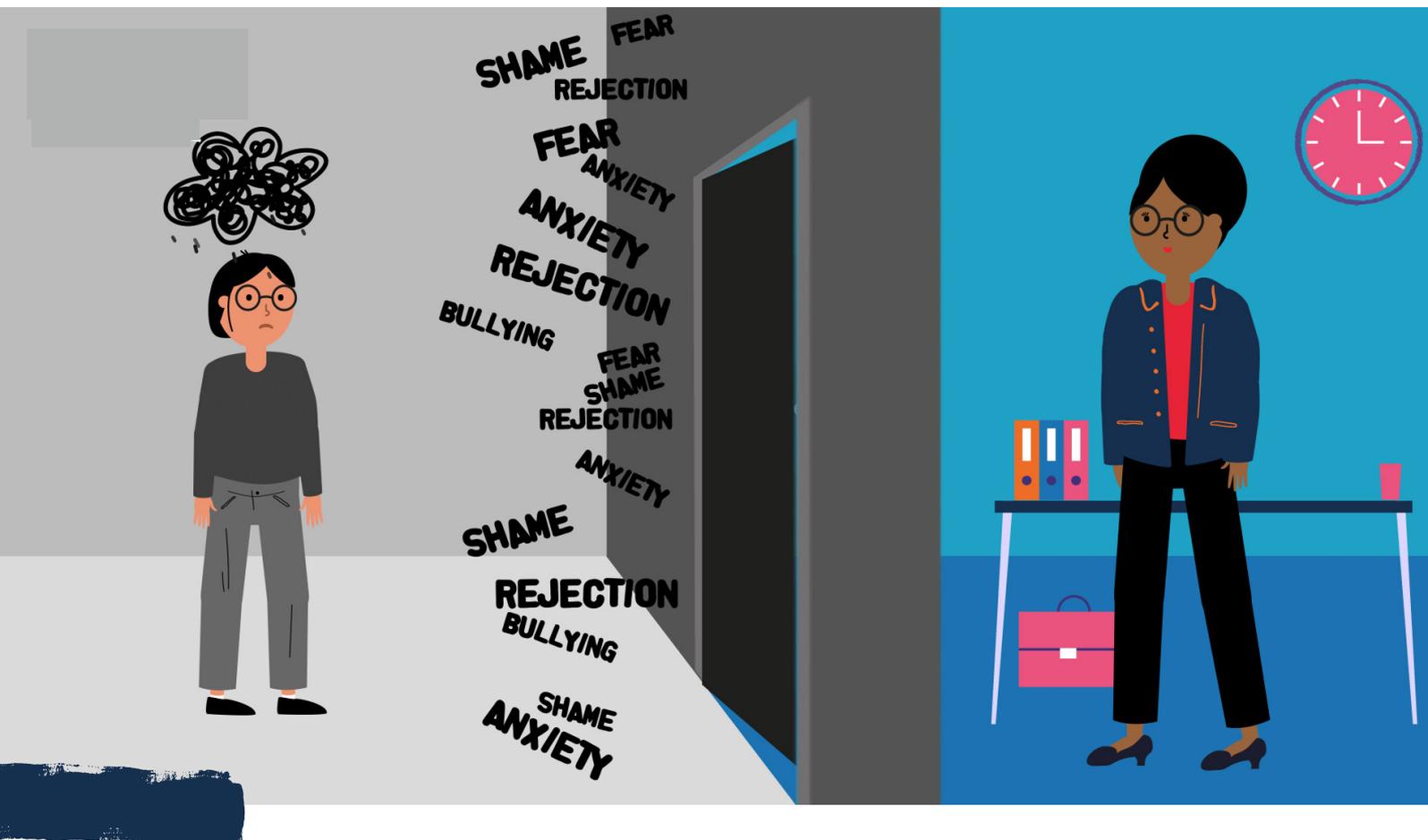
One carer service noted that as the profile of the My Mental Health project grew, local decision makers and professionals became aware of the project and its campaign on mental health. As a result, the service “haven’t had to seek out opportunities” because local decision makers approached them. For example, young carers were approached to consult on the transformation of local mental health services and support the local Youth Engagement Hub to develop a self-harm support toolkit.

TOP TIPS FOR YOUTH PARTICIPATION

- Provide **flexible opportunities** to get involved, with different levels of involvement. This can be opportunities to present or lead workshops or be on camera for young carers who enjoy meeting new people, as well as opportunities behind the scenes during steering group meetings, behind a camera or organising. A mixture of online and in-person meetings also makes involvement more accessible.
- When creating a steering group/voice forum, a mixture of young people who have experience in campaigning and voice work, and young people who are new to this, is beneficial. In steering groups and voice workshops, more experienced young carers understood at an early stage how to take the project forward, while new faces introduced new perspectives and ensured ideas remained fresh. A **diversity of voices** also ensures young carers can learn from each other.
- Provide **skill development opportunities** to secure buy-in from young carers. These opportunities are also core in ensuring young carers take project activities forward with confidence.
- Having a strategic member of staff involved in project delivery is beneficial as they hold the relevant relationships with decision makers and professionals, making it easier to convey the young people's voices. Utilise these **strategic relationships** as they will be vital in accessing opportunities to influence change.
- Do not be afraid to **move out of comfort zones** to enrich engagement with young carers. Try new things, learn from failures, and accept things will never be perfect. Do not be afraid to give young carers control with the project – but also be conscious of not overwhelming young people.
- **Manage the expectations** of the young people involved. There is a balance between trying to enthuse young carers and secure their investment in campaigning, and managing their expectations regarding outcomes. The project will begin with considerable optimism, but it is understandable that there will be difficulties, for example arranging meetings with stakeholders may be difficult, even with longstanding supporters.
- A sustained focus with **consistency and clarity in messaging** helps get the message across and buy-in from external decision makers and professionals. It is also important to identify the correct decision makers and professionals. This will help reach the correct people with messages and local campaigning.
- Take a sustained and in-depth approach to participation work, providing the **time and space** to young carers so that they feel valued.
- Balance the commitment of young carers with their **vulnerabilities**. Some of the young carers who are most passionate around campaigning on mental health have lived experience of mental health issues. Be conscious and aware of the time and energy invested by young people and the emotional impact sharing their story may have.
- Be prepared for **follow up** with individual young carers as discussions focussing on mental health and wellbeing can cause distress. Similarly, be aware of the emotional wellbeing of staff tasked with supporting young carers involved.
- **Demonstrate the outcomes of young carers' input** – young carers are more likely to remain engaged if they see a return on the investment of their time.
- Use a **range of platforms to advertise the campaign** and target areas where young carers are present such as schools.

RESOURCES

- Young carers from the **Carers Support Centre Bristol and South Gloucestershire's Young Carer Voice Forum** created a video as part of their involvement in My Mental Health. This video focuses on the distress caused by professionals' incorrect responses to situations that affect young carers. They highlighted the turnover of key decision makers within statutory bodies as a particular challenge, and the role of resources such as this in ensuring lasting recognition for young carers. [View the video](#)
- **Northamptonshire Carers** has worked with Screen Northants and its My Mental Health steering group to produce a series of videos. These have provided something "tangible and real" for the young people to work towards, were vehicles for keeping momentum going and are a vessel into which they can channel the young people's ideas, views and excitement regardless of whether external opportunities to influence are available. [View the video](#)
- **Suffolk Family Carers** created a video to support its 'I Am...' campaign, focusing on worries about body image and low self-esteem. [View the video](#)
- **Suffolk Family Carers** has worked with Healthwatch Suffolk on a survey of the mental health and wellbeing of young carers in Suffolk. Further information on this is outlined in the case study below. [View the report](#)
- **Northamptonshire Carers** and three youth counselling services in the Northamptonshire area – The Lowdown, Service Six and Youth Works – worked on a video. In it they discuss young carers' mental health and wellbeing, and how they intend to work together to meet the needs that exist in Northamptonshire. [View the video](#)



EXPERIENCES OF YOUNG CARERS AND YOUNG ADULT CARERS

We spoke with young carers and young adult carers who were involved in the project to hear from them first-hand what the project and involvement meant to them. This section provides feedback on their experience.

With their feedback, we produced an animation to show the importance of providing a voice to young and young adult carers and what involvement in the project meant to them. View the animation at: carers.org/my-mental-health

What made you want to get involved in My Mental Health?



"I spoke to one of the workers – the worker said I should be an ambassador here because I suffer with my mental health. I will take my bad experience and help other people before they have a bad experience."

"I've suffered with mental illness before and it was a struggle to reach out to services. And when I did they kind of failed me, and I don't want people my age and other young carers to have to go through that because it was a struggle."



"It's made me want to stand up for what's right and what should be said, and not for just hiding away anymore. There's no point in hiding."

What does it mean to you to be involved in the My Mental Health project?

"It means the world to me – it keeps me going."



"It has helped me to realise my mental health is a lot more important – because before that, I didn't really notice my mental health very much ... didn't notice when I was struggling."

"It has helped me to get the knowledge when others need support, how I can advise them to go and get support, I can show them the routes into different support groups, I can say 'okay, I think you should go and speak to one of the workers so they can give the advice that they could give.'"



"It means I have a family."

"You can be yourself, you can be normal, you can open up and have a laugh. It's just a whole family friendship. The most I got out of it was the confidence, knowing, no matter what I look like or how I speak, I deal with stuff, personal stuff, it's okay to be human ..."



"We're giving a voice to the people that never had a voice – we are saving the hassle for other young carers, they don't have to go through what we've been through."

"It's time that we speak up and show the world we've been hiding in secret. We didn't want to but there was no help, and now there is."



"I've had to deal with it first-hand, and so many of them in the group have had to deal with it as well, we appreciate being able to change other people's lives and make sure they don't have to go through the things that we had to and it just makes things easier."

What opportunities have you had because of your involvement in My Mental

"I've had loads of opportunities to help others, chatting to others, just helping, volunteering at Mind."



"For me, it was a day of overcoming fears, overcoming anxiety, being around new people, new adults that I didn't really know."

"To overcome the fear of talking in front of hundreds of people, for so many people to say thank you for hearing us."



"I've had a chance to voice my opinion, I've learned that it's okay to feel the way I do and it's okay to speak up and not be ashamed of what I do, and I'm not alone. I kind of broke the silence for young people, and we're breaking the silence on mental health."

"The big event recently opened me up to all the services – I knew we had them before but I didn't realise there were so many. And the service that failed me, we had a talk to resolve it and they opened me up to more opportunities that would be better off for me than the service provided before."





“We all have different experiences, and they all come together to make this big meaningful thing. It’s good that we got to put our voice out there, and hear all the feedback that we got about how much it affected people and the awareness that we brought.”

What have you gained from having the opportunity to use your voice and share your experiences?

“I learned how to feel more confident talking to teachers about how I want support, how I want my school life to be like.”



“I feel more confident in speaking out more. Instead of just agreeing with something, I can actually agree to an extent or talk about why I agree.”

“I think I’ve grown more confident in being able to talk about my mental health. I’ve now grown more confident to be able to talk about how I’m genuinely feeling, knowing that people are there to support me.”



“I think it has helped me to share how I feel with my friends a lot more.”

What are your favourite things about being involved in participation work?

“Communication because I feel like the whole project was based on communication. No matter what any of us have done ... we’ve done such different things, but the whole main idea is to communicate what we feel to other people. So I just think that’s really important.”



“It gave me a sense of leadership, it gave me opportunities, and in a way, I feel like I became someone who can lead, like the teachers and adults and to do new opportunities for young carers.”

How does it make you feel to speak up for yourself and other young carers?

“Looking back, we’ve all done so much ... I look back at all the footage and I think, I am actually really proud that I was a part of that and that we managed to accomplish something with our own ideas and creating our own version of awareness.”





“By doing this, we’re making it easier for other young carers.”

“I put courageous because while we were doing the project, I felt a surge of courage, to be able to voice my opinion. And in turn, make sure that people get the support that they need and are not left in the dark.”



“Before I didn’t speak to any other young carers, I felt a bit closed in and I didn’t feel as confident as I am now.”

What would you say to other young carers who are scared or shy about having their voices heard?

“Take the leap ... because it makes a big difference to future young carers but it also makes a difference to yourself. Because it gives you an opportunity that you would never have before unless you took that huge step forward. And it might be tough at times to voice your opinion, but you grow ... this thing helps you grow into a completely different person.”



VOICE



3. CASE STUDIES

CASE STUDY - EXPERIENCE OF PARTICIPATING IN THE MY MENTAL HEALTH PROJECT

We spoke with a young adult carer who was involved in the project to understand their experience of the My Mental Health project.



“I am a university student and am 27 years old. I was a young carer, young adult carer and am the primary carer for my mum. She has been ill for a very long time now and can need a lot of support day to day. Outside of my caring role, I enjoy going to the cinema, volunteering as the Disabled Students’ Officer at my university and being part of the Autism Advisory Panel in my area.”

How do you define your mental health and why is it important to you?

“I would define my mental health as my emotional and psychological wellbeing. It is important to me, because it impacts everything within my day-to-day life. I can’t care for myself, let alone anybody else, when I am struggling with low mood or anxiety. It has a huge knock on effect. When you have bad days with your mental health it makes everything so much more difficult. It’s really important to keep on top of things and ensure that you’re keeping yourself well.



Also, I have recently completed my BSc in Psychology and am currently doing my MSc in Child and Adolescent Mental Health. Therefore, I spend almost my whole week researching or thinking about mental health in one way or another. The whole reason I opted to do those degrees was because I strongly believe that more needs to be done for young people and their mental wellbeing. It’s much more of a complex field than people realise, but it can also be improved with some really simple changes.”

What did you do during the project and how has it impacted your mental health?



“During this campaign I worked alongside other young carers as part of a Steering Group. We attended the Carers Trust Network Partner AGM and got to network with a lot of professionals from throughout the county.

I also did a talk at my university and shared my story. This has led to some changes on campus and greater levels of staff awareness. I also took part in some filming with a local screening company, where we were able to show some of the discussion we had at the AGM and I was able to share parts of my story again.”



The best part for me however, was attending the awareness day event we put on at a local sports stadium. I found it hugely validating and really humbling. There were so many professionals there to support and listen to us. It was great that they wanted to hear what we had to say and our views on how they could better support young carers within their services. This was consolidated through them making pledges on our pledge wall. That helped me to feel that they really meant what they were saying and action would be taken.

It did help my mental health, as it allowed me to see that we (young carers) really do matter and helped me to feel less alone. I found the events very inspiring and they definitely made me feel less alone."

Did your participation in the project provide you with any new skills or confidence to help during the pandemic?

"It most certainly helped with my self-esteem. I hadn't really shared my story before, let alone been filmed doing so. I also found the confidence to talk in front of a room full of people, twice. I think it improved my social skills and assertiveness as well, all of which I have needed to get my needs met during the pandemic."



How has the project made you more aware of local information, advice and support for your mental health and wellbeing?



"To be honest, due to being a current service user and the amount of fairs we have at university, I was quite aware already. However, I did learn about services that could potentially help others. For example, the charities that work with LGBTQ+ young people. I had never come across them before."

Is there anything you would change about the My Mental Health project now that you have completed it?

"It might have been useful to have more media coverage both locally and nationally to raise awareness about what we were doing."



Do you think other young carers or young adult carers would benefit from taking part in My Mental Health and do you have any final thoughts?



"Definitely!"

"Just that I am so glad I was able to take part and think it was a brilliant opportunity."

GOOD PRACTICE CASE STUDY 1

NORTHAMPTONSHIRE CARERS AND YOUTH COUNSELLING SERVICES



Northamptonshire Carers, a Carers Trust Network Partner, participated in the My Mental Health Project. As part of local project work, Northamptonshire Carers, and the young carers and young adult carers that it supports, raised awareness of the mental health and wellbeing needs that exist within their group and have captured the attention and imagination of The Lowdown, Service Six and Youth Works – three services providing youth counselling in the Northamptonshire area.

Carers Trust brought Northamptonshire Carers and these three counselling organisations together to discuss young carers' mental health and wellbeing and how they intend to work together to meet the needs that exist in Northamptonshire. We covered questions on:

- Why did Northamptonshire Carers and the young people it supports feel the need to raise awareness about young carers' mental health and wellbeing?
- How did the messages that they were articulating, and the awareness raising that they've been doing, come to the attention of counselling services?
- What have the counselling services learned about the mental health and wellbeing needs of young carers?
- How do the services feel that mental health services for young people might need to adapt to meet the needs of young carers and young adult carers?
- Why do the services think it is important to work together to make this a reality and improve the support available for young carers around their mental health?
- What are the next steps for all the services in making sure that young carers can access the mental health and support that works for them?

Watch the video

GOOD PRACTICE CASE STUDY 2

SUFFOLK FAMILY CARERS AND HEALTHWATCH SUFFOLK



Suffolk Family Carers, a Carers Trust Network Partner, participated in the My Mental Health project. As part of its local project work, Suffolk Family Carers collaborated with Healthwatch Suffolk, which engages with service users in Suffolk to find out about their needs, experiences of health services and what needs to be improved.

The organisations worked together on a **survey of the mental health and wellbeing of young carers in Suffolk**. Carers Trust brought them together to find out more about that project, and the difference it has made to their practice and the mental health and wellbeing of young carers in Suffolk. The following is a summary of the discussion.

Working together and benefits of collaborating

Suffolk Family Carers and Healthwatch Suffolk previously had a strong working relationship, but this was the first time Suffolk Family Carers and Healthwatch Suffolk collaborated on a piece of work which would focus specifically on young people with a caring role.

What was the survey and what did it aim to measure?

Healthwatch Suffolk run an annual survey to understand the mental health and wellbeing of young people in Suffolk, and had surveyed 12,000 people in 2019. For this joint work, the survey was replicated with a few additional questions about the experience of being a young carer.

Promoting the survey and responses to the survey

The survey was shared across social media platforms, with schools and colleges as well as external organisations such as Suffolk County Council. This allowed more people to be captured in an anonymous survey and not just those registered with Suffolk Family Carers. There was a representative sample across Suffolk:

- 192 young carers aged between 11 and 18 completed the survey.
- 61% of respondents identified as female, 39% male.
- Respondents came from 46 different schools and colleges.

Benefits of modelling this survey on the yearly annual version

This survey was based on a survey undertaken annually by Healthwatch with young people in Suffolk – My Health, Our Future. It was the first time the core survey questions deviated and was a pilot to see how it can be adapted for different groups. It has set a precedent to show it is possible to tailor it to other groups' needs. Using the same questions allows for comparisons between young carers in Suffolk and their peer groups to see how their needs differ.

Findings of the survey

The findings demonstrated that young carers have a good awareness of their mental health and wellbeing, and they know where support is available and what to do. The survey measured the wellbeing and self-esteem of young carers in Suffolk against the Warwick-Edinburgh Emotional Wellbeing Scale (WEMWBS) and the Rosenberg Self-Esteem Scale. Although young carers in Suffolk had lower scores than the national average on both scales, they had higher scores, therefore indicating better wellbeing and self-esteem than other young people in Suffolk.



The survey found that males were open and honest about the worries they have with their body image. Suffolk Family Carers young carers campaign group used this to base their 'I Am...' campaign theme on body image.

One of the findings was that young carers do want to talk to their parents about their mental health and wellbeing, but that they did not feel they could and explained why it was not happening. Suffolk Family Carers is looking at how this can be addressed within their service. As the survey was anonymous, it was felt this encouraged more honest responses, for example with feedback on support accessed in the past and what support should look like.

Impact on Suffolk Family Carers

By capturing the voice of young carers across Suffolk, the survey has helped Suffolk Family Carers continue to adapt and shape its offer so that it is needs led rather than target driven. This has shown young carers that their opinion is important and demonstrates there is value in voicing their opinions as it can make a difference. For example, on finding that face-to-face support is most valued, the service has responded by providing more.

Suffolk Family Carers shared the results with its young carers campaign group, allowing the group to decide the theme and direction of the My Mental Health campaign, based on the survey data. This process meant young carers were at the centre of the campaign, "we are a service with them, not a service for them." This inclusive approach has meant the resulting project was co-produced.

The survey results have provided Suffolk Family Carers with a stronger message and ask when going to decision makers, schools, colleges and other organisations. It was particularly relevant with the Mental Health Transformation plans in Suffolk. It gave Suffolk Family Carers a platform with decision-makers, particularly as young people were involved, with decision-makers approaching the service and asking for young people to feedback into the Mental Health Transformation model.

Findings support the work of Healthwatch Suffolk

Healthwatch Suffolk promotes the voice of people who use services, particularly those that need additional support. The responses from the survey allow Healthwatch Suffolk to promote the needs and voices of young carers, influencing decisions and strategic planning on the groups and boards they sit on. The survey was also an opportunity, beyond collecting data, to be used as an educational tool for participants. It contained videos about mental health and where to go for support.



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