



*“I felt like everyone was
working to make me better to help my parent more.
That’s not viable”*

Understanding the lived experiences of young people who care for others

May 2021

What's in this report?

An explanation of the method we used is on this page.

Page 2-3 has an analysis of the young people's accounts, what key messages can we take from these?

Pages 4-7 are the young people's stories.

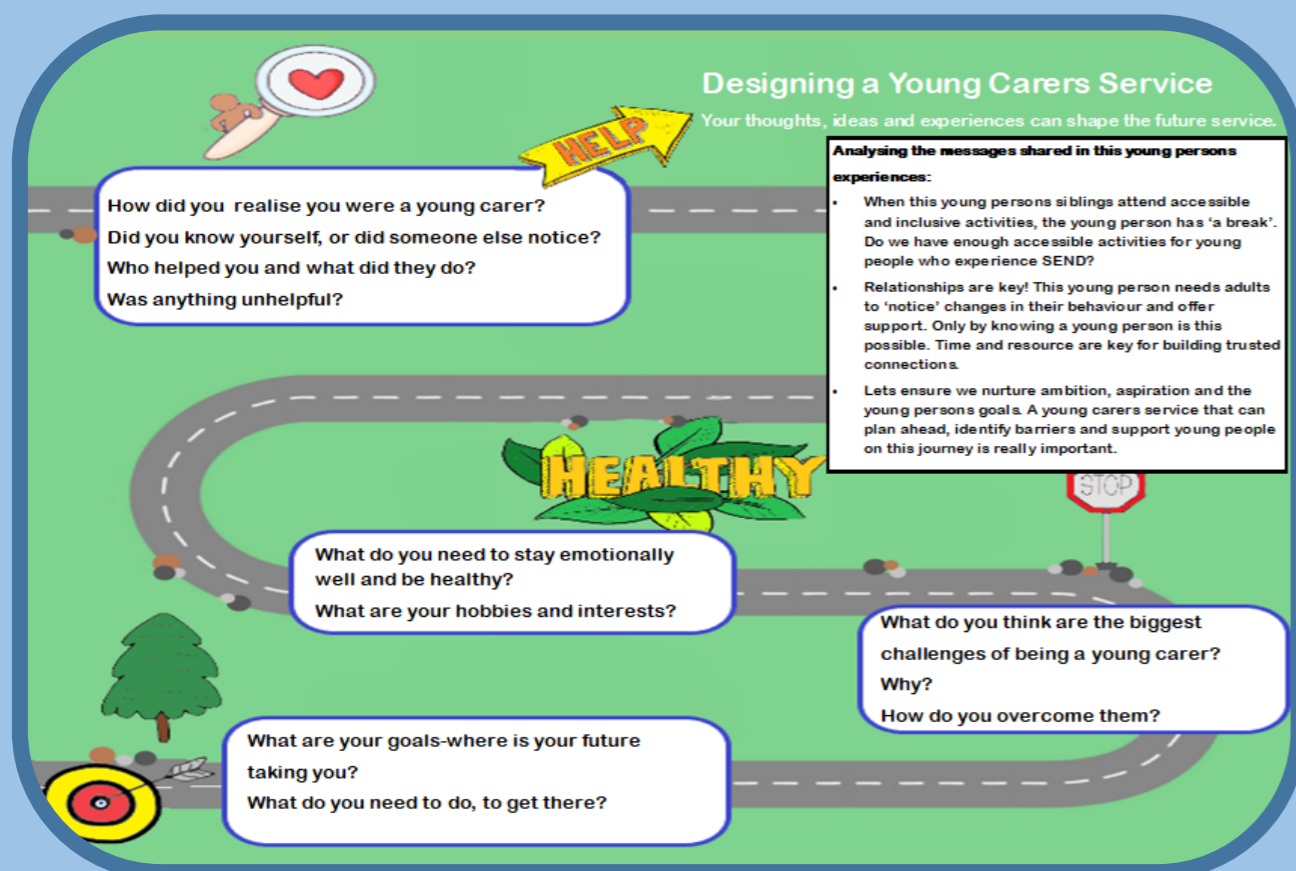
What did we do?

We held discussions with 4 young people, who have caring responsibilities, about their lived experiences. The young people care for their siblings and or parents. Their ages range from 10-19. We talked through their life journey: the experiences that had led them to be identified as a 'young carer', what had been helpful and any challenges or barriers. We finished the journey with aspirations for the future.

Why did we do this?

The Young Carers service is being commissioned. To make sure support meets need, listening to and understanding the experiences and suggestions of young people, with caring responsibilities is essential.

We acknowledge these are 4 young people's stories. They can not be said to represent the experiences of 'young carers as a whole'. However, they are rich, meaningful and provide us with some 'real' accounts of the joy, challenges and lived experiences of a young carer.



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Thank you to the Colleagues who helped make it possible.

A HUGE THANK YOU to the young people who were willing to share their stories.



What do the young people's stories tell us?

1. First and foremost, the person we care for needs support

Holistic support for the parent/carer or their siblings would reduce responsibilities, pressures and challenges for 'young carers'.

"To be happy and healthy, I need to know my parent is happy and healthy. I've looked after them for a long time now and we've formed a strong bond. My parent isn't a burden. I just want them to feel better."

"I just want my Mum's health to be a bit better before I go, so I can be confident. I know I will still check in and see she's ok".

"I have time to myself when my sister is at her dance class, so that's when I can go out. I often find myself putting things off, having to say "I can't do that right now, or even today..."

2. Early intervention would improve outcomes

Some children and young people's parents have health difficulties prior to and upon the birth of their child. Although not all children in this situation will necessarily go on to become young carers, having gentle, open and honest conversations with adults about how their health may impact on their child's development and wellbeing is important. Are families, clinicians and professionals supporting parent/carers do this as early as possible? This may prevent parent/carers feeling resistant or fearful of making support plans and accessing services earlier. Children may then not have to assume the same level of caring responsibilities. For children who find themselves suddenly in the position where they become a young carer, do we have a process, pathway or plan?

Families may need support in exploring their adult networks around who else could help them. Tools like Family Group Conferencing may be of benefit as well signposting adults to reliable services. The older young carers who participated in this project both discussed the difficulties and confusion of 'reversed roles' whereby they had to 'tell their parents to do things'. Therapeutic support or mediation may also be beneficial in managing this challenge, preparing both parties for possible difficulties and assisting communication. For young people who care for siblings, having a more inclusive activity offer, where parents and carers feel able to take children with Special Educational Needs and or Disabilities (SEND) to clubs and groups, would again remove some of the pressures from the sibling who cares for them. Parents and carers need to feel confident that the clubs/groups or activities are inclusive, accessible and that the Professionals delivering them have the training, skills and knowledge to support children who experience SEND.

3. Language matters

Labels and definitions can help some young people, for others they may cause stigma and resistance. This may become a barrier to children and families accessing support. Each young person and family may feel differently and this should be explored rather than inferred.

4. The support offered to young people within education settings, particularly from Pastoral Staff, is beneficial valued

Ensuring educational provisions are aware of the amazing difference they can make and providing opportunities to share models of good practice should continue and bolster this great work. Training around the best ways to support young carers, their families and increasing school staff's knowledge of trusted services is important. This also raises the question, what about children and young people who are electively home educated or not in education, employment, or training?

What do the young people's stories tell us?

5. Planning and transitions are important

The young people we have spoken with are used to having to plan and often don't have the ability to be flexible or spontaneous. They say being unable to support their parent carer or sibling can add to their anxieties/difficulties. This means 'changes' generally can be hard to navigate. Developing clear plans of support and ideas on how to manage unexpected situations might reduce any negative impact from change.

Whereas young people who don't have caring responsibilities mainly consider decisions about themselves in their future plans, these young people are basing their next steps and career aspirations whilst considering the needs of others. Specialised careers support and transition work between provisions may be helpful.

The messages from these young people echo the experiences of children and young people from Social Care, that changes in support staff are hard. Discussing feelings, emotions and 'telling your story' is built on a relationship of trust. When people change, young carers feel they have to once again 'start from scratch'. Finding a way to record, communicate and handover a young person's story and care appears to be really important.

6. The complexities Young Carers face have strong parallels with the experiences of young people who are receiving Social Care interventions or SEND Support

Throughout these stories you can see other complexities which intertwine with these young people's caring roles.

Discussions around therapy or support including managing past trauma and self-harm are visible. These young people recognise low school attendance impacts on attainment outcomes. They speak of the social challenges in their friendships, as their peers may not have always understood their care commitments or responsibilities. Even the youngest participant could identify they have learnt additional skills and coping strategies, beyond their age to support their parent/carer.

Interestingly, one young person is able to recognise that if they had been in receipt of an EHCP or statutory intervention, they may have been able to navigate some of their challenges sooner and for them, this would have improved their situation. How much weight do we place on really understanding, funding and implementing interventions for young carers? Such complexities in a young person's life may need a multi-agency approach extending from them to their family.

7. These young people are full of maturity, strength, compassion and skill

The young people we spoke with are selfless, strong and proud of what they do. Considering all the above key messages should help young carers reach their full potential, be happy and healthy. It is worth considering the experiences of younger carers seem to be framed more positively than those of the older young people. Whether this is because awareness, process and support have improved or whether expectations and fatigue increase with age, is something which requires further exploration.



My Story: An early teen aged young person who cares for their siblings

“I didn't actually know I was young carer. I grew up supporting my Mum and three siblings. It was just 'normal' to me.

My friends didn't have brothers or sisters, so we couldn't compare or see that we had differences. I had always just looked after my Mum, brother and sisters.

I'm proud of myself really for being kind and doing that my whole life...

My Mum was the one who said we should contact the Young Carers Service. My Mum had noticed all the things I do and could see some of the pressures. I said ok. I'd say my Mum is the person who helps me the most and the one person I usually speak with when I need help. Finding time for us to talk together can be a challenge as I usually have to wait until everyone else has gone to bed; so it's calm and quiet.

As well as my Mum, I've a Head of Year at school who really helps. He organises meetings and checks in with me. Both my Mum and Teacher help the most by noticing when I'm not myself and asking "Are you ok?" they know me and offer to help. I can struggle to ask for people to help because although I know they aren't, I always feel like they are too busy and that I could be wasting their time.

One of the things that makes me unique is that I can't 'just do things' like my mates. I have time to myself when my sister is at her dance class, so that's when I can go out. It's not always easy finding activities that can include or understand my siblings. I often find myself putting things off, having to say "I can't do that right now, or even today..."

My mates don't always understand. If I'm online gaming and it gets noisy at home or I need to help look after my brother and sisters, they will say things like "just tell them to be quiet". I usually say "Do you understand autism? Do you want me to explain how they can't just do that, that's not how things work". My friends who aren't young carers are great for playing card games, console games and tennis with. It's nice to be able to go out for an hour with them at the weekend. It gives me a break. I think that sharing what I've learnt by caring for my family has helped me with my goal for the future. I want to become a person who works with children who have Special Educational Needs. I've lots of skills, understanding and knowledge to bring to one of those jobs. I think I need to do Health and Social Care and maybe study some sciences so that I can understand all the research around autism.

I haven't had the opportunity to meet with other young people who care for their family, because of corona and lockdown. I'm looking forward to being able to do this as I think that it will be useful. Moving forward I think a Young Carers service that offers both online and face to face opportunities would be good. Some things are easier to talk about when you aren't sat face to face. The second lockdown has been better than the first, because my siblings could go to school. Their education would have suffered if not. This meant the house was quiet and I could concentrate on my learning. When it isn't so quiet I just put on my headphones.

If I'm stressed I sometimes want to talk, other times I want to have some quiet time to myself. I would feel ok to search for 'help' online, but I'm not always sure that what I find is 'right'.



My Story: A young adult carer who supports their parent

Do I count myself as a young carer? Yes. I am. I came into young carers services when I started High School. The whole situation was really bad.

The family situation which led me to be a young carer kicked off when I went to High School. I was miserable, I was bullied relentlessly and school didn't do anything about it. This led to me self harming in year 8 and 9. At that point, School thought they better help and told me to go to the GP. The GP sent me back to the School SENDCO, who then sent me to the wellbeing centre. I think that's how I was eventually referred to the old service at Northorpe Hall. It really felt like only when I was suffering so much, they actually looked for the problem. When I was referred I waited months and months,

ChEWS took ages...It was well over a year. There wasn't anything to help while I waited, something to help while I waited would have been useful. I'm unsure what, but mainly help for my parent as life was pretty terrible while things were kicking off. School were really as unhelpful as they could be. I had 62% attendance in year 7. My parent was frequently ill, some days they were just sad and said "*have the day off and stay with me*". I was young and thought great! They gave me an attendance person who blabbered on about the need to be in school, but didn't actually help. I felt like everyone was working to make me better to help my parent more. That's not viable. It's my parent that needs the help really, not me.

To be happy and healthy, I need to know my parent is happy and healthy. I've looked after them for a long time now and we've formed a strong bond. My parent isn't a burden. I just want them to feel better.

I find it really hard to do things if my parent is unwell. I need to step back and my parent needs to step up. That's the really hard bit because it feels like I'm watching them struggle.

I also hope my siblings might help, but I'm not so sure they will. Maybe it will be easier for my parent when I do move out? Trying to grow up is really hard, because I don't think my parent is ready to let go. I also struggle with the balance of letting them do things for themselves. The recent diagnosis have helped, because a Doctor is now saying "*you need to do this or that*", not me. It's hard swinging from being the child to the carer. Parents don't want to be told what to do by their children. This can cause arguments, as a kid this was really confusing.

The challenge for me is being able to have the time to do the things that keep me well, like working out or go on a walk. What would help is if there was someone else to support my parent. The difficulty is my parent won't accept a strange person being in the house or someone from 'services'. My parent doesn't like me being labelled a young carer; they see themselves as a burden because of this.

College gave me an Inclusion Mentor, that's been extremely helpful. The inclusion mentor has been really helpful because he has been on my side and has helped me see things from a different perspective if I didn't understand. Instead of just siding with my parents because they were the grown ups. We built routines and came up with some coping strategies that really did work just being able to talk to someone. Also a laptop, when I think back I struggled to write. Once I was provided an laptop in school, my grades improved massively. I didn't have assessments or an EHCP. It took ages to secure something as basic as a laptop.



My Story: A young adult carer who supports their parent

I never counted myself as a young carer. I care for my Mum and I don't mind doing it, she brought me into the world, so I just do it.

I was at High School when I was introduced to the young carers service by my Mum. When I was at high school, my Mum was constantly in and out of the hospital because of her health at the time. I was constantly calling home to check in on her. My Pastoral Manager noticed and I remember being called up to the wellbeing centre around the end of year 8/beginning of year 9. They introduced me to the idea of the service, then asked me to tick some forms. My Mum then got a call and I was confused because she said "Have you told the teachers you look after me? It's ok to do that but I wouldn't want you 'labelled' as anything". We then spoke with the Pastoral and Wellbeing staff and the situation made sense. Looking back on this now, I really would've wanted to be asked for help, rather than it be forced on me. It was overwhelming. Once school did know they were really good. They didn't 'expose me', my teachers knew about my situation and when I needed extra time with course work or anything like that, they let it happen.

School Pastoral Workers were really helpful. I did get really attached to them, when they changed, I found it hard and although I liked the new person, I would go back to the older one. They knew me well and understood my 'story'. It was a comfort thing. I loved the pastoral support. If I needed to speak with someone, I could just ask a teacher and go...

I'm at college at the moment re-sitting English and Maths. I want to go to University and do applied science. I just want my Mum's health to be a bit better before I go, so I can be confident. I know I will still check in and see she's ok.

When I reflect back now, I can see I had some complexities in my life which hit me a bit later when I was at High School. This also impacted on my mental health. I had a referral to mental health services but this took so long. The counselling was really good, but the sessions were only a set amount of time. My counsellor said "we have to end now, we can't really carry on. We should try a mentor". The mentor support took a year and then we were both always busy. Then they left. I waited for another mentor, but it was a new person and we had to start again from scratch. The young carers service has been great because I've known my support worker a long time. It takes me a long time to open up. I've told my story so many times and it makes me feel bad every time I bring it up.

I had to move college this time as my grades didn't work out on the last course. The support team at the old college were really good, I had a great tutor. Now I've had to start over again. I don't really know anyone yet to talk to. I know I've the skills and can do it. It's just hard starting again. I just need to pass my maths and then I can move onto the next step.



My Story: A primary aged young person who cares for their parent

I do count myself as a young carer. I help my family and people in school. I'm good at giving advice. I'm proud of myself and people are proud of me. I came into the young carers service when my parent suggested I should get some support. We looked online together to find the Young Carers Service.

What's been helpful about the support, is that I saw other children too who help at home. I get help from my Nanna and Grandad. They help me to look after my parent. The Pastoral Teachers at school are also a really big help. They come and check in on me, ask me how I'm doing. My parent knows if they need anything they can ask school for help. I've had the same 3 pastoral teachers all through primary school, they know me. They don't just help me learn things to help me care for my parent. They've also helped me understand growing up, staying clean and staying healthy.

What makes me happy? Looking after my Parent. We bake together, we pamper each other with massages. Although I love to care for them, it is really helpful when other adults can help. The Doctor can do things I can't. I'm glad when other people help.

If I feel sad, I bake. I've done classes on Zoom. I also like to do Yoga with my parent. It's nice to do things together.

If I'm stressed or worried, the first person I would speak with this the Pastoral Team. I am a bit worried about what will happen when I go to High School this September. Our Head of Year has been to my school to introduce themselves.

My friends all have similar experiences. They all have play therapy and support because of some of their issues in their lives and with their families. So I think they get me and my life, it's useful.

The challenge came for me when I was about 10 and my parent needed a lot of support with their mental health. Things weren't good then at all. I had lots of things to do and needed to learn lots. This is when I started to get more support. My Nanna came to help and school and the Young Carers service also helped me. I want to say, without the help of the Young Carers service I don't know what I would have done. They have worked with me and my parent together. They helped us understand each other, I've learned things. It's been really helpful.

I dream to be a cupcake baker when I grow up. I think I know how to get there, just keep baking!



Our Voice is Kirklees Children and Young People's Participation programme

You can contact us on ourvoice@kirklees.gov.uk

Or view our webpage at [Young People's Voice - KSCP \(kirkleessafeguardingchildren.co.uk\)](http://kirkleessafeguardingchildren.co.uk)