

**ASK ME – I'M  
HERE TOO!**

**A Research and Evaluation  
Project into the Lived Experiences  
of Young Carers Providing Care  
for Siblings with a Long-Term  
Illness or Disability.**

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## Introduction

This short-term research and evaluation project (Oct 2020 – Mar 2021) was commissioned by Edinburgh Young Carers (EYC) and funded by The Listening Fund in Scotland to explore the lived experiences, specific support needs and outcomes of sibling young carers (SYCs). Recognising the growing number of referrals for young carers providing care for siblings and the limited research evidence on sibling young carers, EYC applied for and was granted funding for a two-year long pilot programme of support and research. This evaluation is intended to ensure the best support is available within EYC, whilst also informing other support agencies and contributing to the development of policy around sibling young carers.

In a recent overview of possible future directions for young carers research, Joseph, et al., 2019 recommended more participatory and action-led research to provide greater insights into the lived experiences of young people, their needs and how these can be met. From project inception through to evaluation, this research involved active participation from the young carers and young adult carers, including them as experts in the project, shaping its direction. The methods are discussed in Appendix One.

The evaluation project was undertaken during the second six-month period after COVID-19 emerged, which included a Scotland-wide lockdown. All respondents identified ways in which the pandemic affected them, which we consider in this report. Given the collective trauma presented by COVID-19 on top of existing significant issues faced by SYCs, one of the key recommendations of this project is the need to apply a trauma-informed lens to future service developments, as recovery for individuals, families and staff will continue to require care, responsiveness and kindness.

## Edinburgh Young Carers

Edinburgh Young Carers (EYC), established in 1994, is one of the largest voluntary young carer organisations in Scotland, providing support to children and young people aged 5 to 25 years old who care for someone else at home. The service aims to improve the lives and wellbeing of young carers by raising awareness, offering emotional and practical support and by giving each young person the opportunity to take a break from their caring role and have fun in a friendly, supportive environment. As well as delivering young-person centred support through group respite, residential, one-to-one work and therapeutic approaches, EYC also works closely with professionals across education, health and social care. The aim is to raise awareness of young carers and ensure appropriate supports are in place within these settings for children and young people with caring responsibilities.

Over one-third of young carers and young adult carers supported by EYC care for a sibling, a figure which has increased over the past five years. Despite this trend, the young people and families supported by EYC have repeatedly identified a lack of understanding of sibling young carers in other sectors supporting them. These experiences prompted the development of our sibling young carer focus groups in 2019, which led to a successful bid to The Listening Fund in Scotland to develop specific support and undertake this research. This funding allowed us to set up two sibling young carer groups in 2020, one for primary school age and one for secondary school age plus.

### Current Knowledge and Research: What we already know about sibling young carers.

We wrote an accessible summary of research evidence on SYCs to share with the young carers late 2020. This was partly based on a review of evidence on young siblings of children with developmental delays (Hastings, 2014). We then added to our review for this report, based on a special issue of the journal *Research in Developmental Disabilities* (Cebula & Kovshoff, 2020). Key messages from these publications were:

- There is already some research that tells us that being a SYC can have diverse effects. Every situation is different.
- Health and wellbeing: some sibling young carers report that they worry more or can feel a bit down, but this is not always the case.
- Siblings of a child with a disability tend to report a positive relationship with the sibling, but this can be different when there are behavioural or mental health problems.

It was also identified that while there is a gap in research relating to the specific impacts and lived experiences of children and young people providing care for a sibling, evidence so far shows distinct challenges for this group of children and young people and their families (Hastings, 2014). We needed to know more about how being a sibling young carer affects:

- Other relationships, including with parents, friends and at school
- What are the things that make it most challenging to cope at times?
- What helps and what is the right kind of support for a sibling young carer
- What difference does it make to young carers to have a disabled sibling when they are becoming adults?
- What changes need to be made in the wider community to improve inclusion of families with a child with developmental disabilities?

This research helps with some of these gaps, concluding with recommendations for practice.



## Methodology

Our methods were partly determined by restrictions of the pandemic. Adhering to regulations for the youth work sector allowed us to have face to face introductory meetings with the two SYC groups in October 2020. This was supported by creative activities within subsequent group meetings, culminating in a joint meeting with both groups, planned and delivered jointly with the older SYC group. During the second lockdown early in 2021, we hosted four digital focus groups with SYCs, guided by young carers as to their priorities for discussion. We also conducted telephone professional interviews, a parent survey online and telephone parent interviews. These were audio recorded. See Appendix one for details.

This report covers findings which emerged from thematically analysing data gathered from the above activities. The SYCS, their parents and professionals largely talked about the crucial role of important relationships in SYCs' lives, experiences of school and the pandemic, and the support provided by EYC. We include strengths and positive aspects of caring identified by SYCs as well as significant challenges. We conclude with recommendations for practice and policy, based on our findings. First, we consider our learning about distinctive impacts of being a sibling young carer.



## The Nature of the Sibling Young Carer Role: what is different for siblings?

We begin here by a brief description of the nature of the illness and/or disability of the cared for siblings involved in our research. Through discussion with the SYCs and staff, it was clear from the start that for the majority of SYCs in these groups, their cared for sibling has an autism spectrum disorder (ASD) (usually with at least one other condition such as mental health difficulty, physical health condition or additional learning needs). This was later confirmed by the parent survey. Our evaluation indicates high support needs and significant impacts on families and SYCs. This context is important in understanding our findings.

Recognition of the concept of a SYC is still at an early stage and this can be a barrier to ensuring that sometimes badly needed support is available, as explained by an EYC worker:

Recognition is a particular issue for SYCs. Most adults don't think about the possibility of children as carers. It might occur to them if they see an older child visiting a parent who has a serious illness for example. But where there is a sibling with a condition and a parent is visible, the chances of thinking about the other sibling as a carer are not that high. (Professional interview)

The language around caring and support for carers has traditionally focused on caring tasks. We found the extent to which SYCs are involved in specific caring tasks for their sibling varies. For some young carers, especially those with more complex or multiple caring roles, diverse demands included physical caring.

When my mum came out of hospital from her [brain] surgery I looked after her and [my brother J] since my parents were divorced and I only saw my dad from time to time...So, when I came back from school I had to change J, give him his snack and his tablet, help mum, clean the house, do my homework as well. (Siling young carer in focus group)

However, understanding the impact of being a SYC needs a broader focus, considering impacts on quality of life and particularly relationships. EYC staff noted that the support SYCs provide to their siblings, can be in addition to emotional care and support provided to their parents. In the initial large group session, a young adult carer told us that she had initially struggled with a sense of legitimacy as a young carer attending EYC when she compared herself to others with hands-on caring roles for a parent, for example. However, the emotional demands she was facing at the time were taking a toll on her health and wellbeing. We will consider other strengths and challenges identified by SYCs, and possible responses in this report.

We consider first family relationships, a key theme for our SYCs.

## SYCs and Time with Parents / Family

Sibling young carers almost universally struggled to get attention and space in their families. On being asked what her advice would be to other SYCs, one young carer described her own learning about keeping on top of her emotions and a sense of inevitability about her role:



I would just say “don't put pressure on your mum, don't get mad that they are the favourite because they need more help and time than you”. So have a way to take all that anger out and pressure and just help your parents to deal with your sibling because, yes, it is really hard at first, but you get used to it... they will need that help for the other child. (Sibling young carer in focus group)

This young carer describes here a learnt coping strategy, common amongst the older young carers who took part in this evaluation. These SYCs have become accustomed to the family dynamics and not coming first in terms of receiving attention, a situation that the younger young carers who took part in the research hadn't yet grown used to.

Where there are two parents at home, it was noted there can be opportunities for the parents to split childcare at times in an effort to more equally share quality time between siblings, although this could result in a sense that 'whole family time' was missing:



Some things my mum can handle between us like arguments about TV, but often our family will split up and one of use goes with one parent as a compromise to prevent arguments. We have very little whole family time. (Sibling young carer in focus group)

One of the education professionals emphasised the need to make sure family time happens:

Quality time between the sibling young carer and the parent(s) is so lacking. Finding ways of building this in is so important to avoid resentment building as they grow older. (Professional interview)

One SYC noted that it can be “quite intense and isolating within the house,” an experience shared by many others. This means that not only is quality family time difficult to find, but also that other people (friends or family) don't spend time in the house, reducing available in-house support mechanisms for the SYCs and adults at home.

The challenges of finding ways to spend quality time as a family were also highlighted by parents in the survey and in interviews. Fewer than 15% of parent survey respondents spend regular time alone with the SYC. The main reasons identified were the health and behavioural needs of the cared for child and lack of replacement care. These represent specific challenges to families of children with high support needs, and the impacts on family dynamics are different from those in families where children and young people provide care for adults.

Some SYCs also noted that opportunities for conversations and fun in the house are restricted, “I can be silent in the house as there isn't much to talk about”. The latter SYC also noted how difficult it can be to share how they were feeling with their parents due to being mindful of not adding to the stress already felt due to the cared-for sibling's needs:

I feel bad talking about myself, it feels like I just have to handle it, it feels like this all of the time, like everyone is on the edge of a nervous breakdown. (Sibling young carer in pre-application focus group)



Despite the challenges, there were some indications of family bonds being stronger as with the following young adult carer:

I think that it brought my family closer as we have gone through challenges and I think like it made us more resilient and understanding of each other's feelings and that whole thing of "looking out for each other" my family has gained, and made me mature for my age. (Sibling young carer in focus group)

## Getting Out as a Family

In addition to spending time together, getting out the house as a family was identified as problematic by most SYCs, although to varying extents. This was particularly challenging for some whose siblings had ASD and a learning disability, with one younger carer identifying that family trips tended to last 'about 30 minutes' and others noting similar restrictions:

All decisions about where to go and for how long would revolve round my sister. Then she would refuse to get out of the car when we had driven for a walk so would have to just drive straight home again. (Sibling young carer in focus group)

My older brother has autism, very strong autism, a learning disability, he has got ADHD... Maybe sometimes if something doesn't go his way, he can get mad.... I kind of start getting embarrassed I have to say. But I get over it. (Sibling young carer in large group session)

This was a strong area of concern in the parent survey. Over 50% of adults who responded to the parent survey found family outings "very difficult" or "difficult", with similar responses relating to taking walks or exercise as a family. The word difficult was used a lot by parents in relation to family time, through to 'practically impossible.' Some parents described the young carer being subjected to disruption to their activities and in a couple of cases physical assaults:

The first barrier is getting my sons cooperation to partake in activities. If we manage to get him out, we are at the mercy of his changeable mood/behaviour... We have to factor in that the destination is inclusive for my son and wheelchair accessible which is not often the case. Any activity is heavily based around my son leaving no opportunity for my daughter to make choices or take the lead. (Parent survey response)



The challenges of family activities were also highlighted by EYC staff, who noted that in addition to outings, families can be excluded from social gatherings and parties if the sibling had sensory issues, and the issue of 'meltdowns' was referenced by most respondents in the research. There was a wider sense that freedom was missing for the young carers:

What a lot of SYCs need is freedom! A lot of them are trapped in family routines built around their sibling. It's just the way the household works (Professional interview)

An older sibling carer described her own views of going out as a family changing over time and with age. She now feels comfortable explaining to people that her sister is autistic with "the confidence to explain what's happened and why". The same young carer observed differences in public attitudes towards autism during her 14 years as a young carer.

Now we go to things and there is a bit of understanding... Christmas we went to a light show thing and I had to go to one of the workers and ask if we could go first if that was ok? And he said no! But somebody in the queue at the front says 'it's fine you go first' and that would never have happened years ago, people know now about autism and a learning disability. (Sibling young carer in focus group)

The fact that SYCs have noticed changes in public attitudes towards disability and difference is positive and this step-change is one that EYC have been working towards in their mission and service delivery, alongside raising awareness of the roles, impact and support needs of children and young people who provide care.

## Relationships Between the Sibling Young Carer and the Cared-For Sibling

There was consistency in the way that sibling young carers spoke about the sibling they cared for, with little difference as to whether the sibling was younger or older. There was an honesty around experiencing jealousy about the limited amount of attention received compared to the sibling. While this statement was always followed by a growing recognition that this was inevitable, there was a sense of resignation rather than relief:

I was 5 when I found out that my brother had autism and then, just like [other young carer], I was jealous because I was like...why does he get so much attention? I'd be to my parents "he's the favourite!"...but, as you get older you get used to it and he's not the favourite, he just needs more attention because of his needs... (Sibling young carer in focus group)

A member of EYC staff relayed their view of the difference of being a carer to a sibling, and the sometimes very mixed feelings involved:

With sibling young carers it is different. There is a loyalty there but there is also resentment. There is love, and in a way hate too. They understand why their needs may not be attended to, but there is hurt there too. (Professional interview)



For several young carers, feelings towards their sibling (and their family) included guilt, alongside the perceived need to put the sibling first. One SYC noted that “caring can dominate, even if I do get 5 minutes to myself I’m thinking of the list of things I have to do”. One young carer had to switch off her camera while her brother came into her room during a focus group. She expressed no negative feelings about that, but kept qualifying her view:

I was gonna say, like, I do help my brother but recently I haven’t helped as much because of school work... But I do feel a bit bad for it, because I used to help a lot more, but recently I don’t, but I do help still. But like, me and my mum’s lives have revolved around his... but then I feel bad when I put mine in front of his. (Sibling young carer in focus group)

This scenario was not uncommon and speaks to the intensity of providing care for siblings, particularly over the past year where lockdowns have not only increased caring hours and roles for many SYCs, but have also removed opportunities for respite and release.

SYCs also described situations of not being able to fully disclose or talk about their caring roles due to wanting to respect their sibling’s privacy, particularly around personal caring tasks. Some SYCs identified that their sibling felt more comfortable with personal care being provided by themselves rather than with their parents, particularly when the cared-for sibling was approaching puberty.

This was described as a “stress” and source of “anxiety” by one parent who told us this about her daughter’s relationship with her cared-for sibling:

It also leads her to have a lot of anxiety...She has had to be privy to medical knowledge that is beyond her years which places a heavy burden on her shoulders. She is not able to be carefree and do spontaneous activities like other children may have the luxury of doing. Her brother can be quite controlling and demanding of her time. (Parent survey response)

Despite challenges identified by these young carers, several identified a strong bond with the cared for sibling, with one identifying that the most fun thing about her brother was ‘everything. He makes me laugh a lot.’

Many of the parents who responded to the survey emphasised the strength of relationship between their offspring, despite the challenges. Almost all parents used the words ‘strong bond’ or ‘closeness’ when asked about the positives of the siblings doing things together. Siblings were most likely to watch TV together (56% of respondents), play together (50%) or go out together (69%). One parent described the relationship between the siblings:

They learn to understand each other, more love. X doesn’t like hugs, Y sometimes get one and she is so happy. The most happy in the world. She feels sad for him but also she feels bad to have a brother with autism and she feels embarrassed sometimes when he is having a meltdown. Y loves her siblings, she is very responsible. I think this benefits both because they can be better together. (Parent survey response)

## Friendship and Friends with “Interesting Stories”

There were mixed experiences regarding the topic of friendship. These ranged from young carers feeling that they had enough friends through to not having friends at all. For most sibling young carers, there were limitations on friendships due to their caring role and situation. Bringing friends home was a challenge for many of the children we spoke to:

Being a young carer is all I have known. It made me different as a kid, and being different as a kid is bad. I didn't want others judging me by coming to my house and I didn't want them judging my sister. So I didn't have friends to the house because I didn't want to get angry with them for judging us and then have to lose friends. (Sibling young carer in focus group)

Two of the younger ones said that they had told friends about their caring situation and, as one said, “yeah, they weren't mean about it.” However, overall, there was a sense of not usually confiding in friends about caring. In part, this was attributed to not understanding, and fear that friends would “think I'm just trying to get attention”. Several identified the importance of having a friend in a similar situation so that they could share experiences. A few identified that they didn't have this opportunity but wanted it.

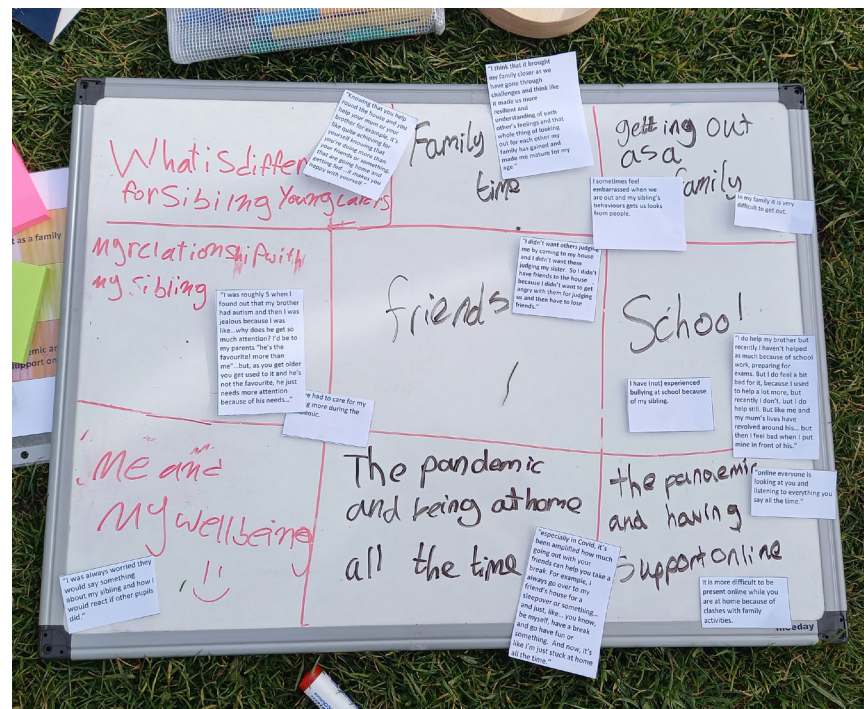
One of the parents commented that she had ‘always noticed’ that her daughter tended to befriend other children with ‘interesting stories’:

She has friends from another area but has not seen anyone since before Xmas...She has a very close pal at school who was adopted from another country. Her friends all have interesting stories. I've always noticed that about her. (Parent telephone interview)

Parents and SYCs themselves noted how the young people had different priorities and how this can set them apart from their peers in terms of maturity and often empathy. This was sometimes problematic (as discussed further in a theme below) but also demonstrated how personable and compassionate SYCs can be as a result of their daily lived experiences:

She has empathy and understanding to others and is non-judgemental. She is mature, friendly and doesn't stress about the small things.

(Parent survey response)



X seems to be able to zone onto anyone who has additional needs and is always willing to help, however I'm not sure that this is always a good thing as she will always put other people's needs before her own which I feel can be a lot for a young person. (Parent survey response)

## School Experiences for Sibling Young Carers

For some sibling young carers, school provides the main opportunity for a break from caring and this was identified as important by more than half the children we spoke to. The following young carer identified the benefits of this. She had previously explained that she was able to attend a nurture group in school which she really enjoyed.

Basically, people go to school and they are like "oh my god, I wish I didn't come to school." But me I'm like "I'm happy I'm at school..." even though I have to do work at school, I get like a little break where I also have nurture and stuff like that with my teachers and that, and it really helps, I really like it. Yeah, it's kind of my happy place, basically. (Sibling young carer in focus group)

When both children are in the same school however, this can present additional and significant challenges for the sibling young carer. The following member of EYC staff summarised the situation well:

A challenge for many sibling young carers is that they also have a secondary role within school compared to their sibling with a disability...They have some young carers who are called out of class to help manage a situation if their sibling is having a meltdown, as they are skilled in supporting the emotional regulation of their sibling. It blows my mind! That expectation that they have to fulfil that role. (Professional interview)





EYC has a Schools Awareness Raising project, set up in 2010 to work with pupils and staff to raise awareness and identify young carers, and encourage developing and adapting practice and policies to support young carer wellbeing within the school environment.

Our schools project is unique. We support YCs in school, colleges, trying to support institutions to be young carer friendly. This mainly involves encouraging flexibility in how YCs are treated, around homework deadlines, returning forms and late arrivals in school. (Professional interview)

The outcomes of the schools project include supporting school staff to understand what being a sibling young carer means. SYCs in this evaluation identified wider challenges of being recognised as carers amongst health and social care professionals supporting the family. One SYC said one of the most difficult things about caring was “professionals not taking you seriously as a carer – listening to your parents more than you”.

One of two teacher interviewees advised that a possible advantage of both children being in the same school was that the sibling was more likely to be identified as a young carer. Both teachers identified identification as an advantage because additional support was available in their schools. One teacher noted that it would help if there was less paperwork attached to identifying carers, as each young carer statement can take an hour.



There are still barriers for services to recognise sibling young carers, who are easily missed by professionals and often remain “hidden” due to the assumptions that it is parents who do the caring at home for siblings with an illness or disability. Yet, being a SYC can affect experiences in everyday life, such as attainment and motivation within school, their ability to find and sustain hobbies, interests and friends, as well as life decisions around future choices and opportunities. What this project shows is that the impacts of being a SYC are distinct, can be significant and change over time, and that identification is important to maximise the wellbeing and quality of life for these children, and for their families.

It was concerning to hear the extent to which bullying at school was a problem for the sibling young carers. A few young carers identified a fear of it becoming known that they had a sibling with a disability, in case they were bullied. There were also concerns for the siblings with disabilities themselves being bullied. The empathy of the young carers was very evident in these discussions:



There is one thing ...the boys at my school normally tease boys that are different because they are in wheelchairs. There's a lot of kids in my school that are in wheelchairs and that... Some people just make fun of that, but others like me that have grown up with a sibling that has disabilities and that...we understand what they are going through... (Sibling young carer in focus group)

SYCs could also be susceptible to bullying because they were seen as being 'different', as identified by one of the teachers:

A key thing is that young carers have a maturity and an empathy that sets them apart. They are more susceptible to bullying because they are more open. They all have bits of adult roles (Professional interview)

Being a SYC, as with other young carers, sits outside of expected societal norms around adult care-givers and child care-receivers. This (as described below) becomes part of a SYCs identity and can be difficult to set aside when entering settings such as the school, where more age-appropriate expectations are placed upon young carer. Being seen as "different" or more mature, can lead SYCs to being more susceptible to bullying behaviours from peers.

## Impacts on Sibling Young Carers' Identity and Wellbeing

We have considered diverse feedback about SYCs having limited freedom and choices. In the large group session, a ten-year-old carer identified that decision-making in the family revolved entirely around the sibling with the disability, with several others agreeing:



SYC: Being a sibling, it can be hard when you have a brother or sister with disabilities because it's either their way or it is nothing (others agree).

R: So you have to compromise?

SYC: No it's not compromise – it's either what they want or it's nothing! (others agree)  
(Sibling young carer in large group session)

Not having a voice in family decision-making was also a common theme in focus groups, and for some this was connected to a sense of identity and in the following case self-worth:

Growing up I didn't have a say in anything and I have really struggled with a sense of self or self-worth. I found it hard to grow up and figure out who I was and what I liked and that's because I wasn't given opportunities to make choices. Take for example theme parks. I couldn't say I didn't like them as my parents would be upset and I didn't want to cause them any further issues.

I only recently told my dad that I don't like theme parks. (Sibling young carer in focus group)

One of the EYC staff noted that this confusion with identity and associated emotions can really start to surface with puberty. More generally there was a need to build confidence:

It's a hard life being a SYC. Needing to feel valued is crucial and it is about building self-esteem and reducing anxiety. They need to believe in their own thoughts.

(Professional interview)

Our evaluation suggests that SYCs can struggle to separate their own identity from that of caregiver. Hearing the voices of SYCs of different ages suggests that the longer this continues without support, the more likely that young carers will experience mental health difficulties as they reach adulthood. One SYC told us that in order to regain her identity as a person in her own right, and not just a young carer, it took a move to another continent to put this in motion.

### **A few of the children viewed their caring role positively, at least in some respects:**

Knowing that you help round the house and you help your mum or your brother for example, it's like quite achieving for yourself knowing that you're doing more than your friends or something, that are going home and getting fed ...it makes you happy with yourself. (Sibling young carer in focus group)

However, this could extend to identity and caring being perhaps too closely connected:

I feel the need to help, like if there's nothing to help with, I ask mum if she needs help or anything. Like what do I do if I am not helping someone, you know what I mean? [laughs]. (Sibling young carer in focus group)





One of the teachers noted that sibling young carers could struggle to not take control because of their caring role:

There's almost an attachment issue with sibling young carers. They don't know how not to be in charge and will take control of the group, because that's what they are used to. (Professional interview)

When asked about strategies for getting some time out or downtime from the caring situation, several young carers identified multiple factors which support this:

Residentials, getting a break, seeing friends, having bunk beds, getting away from stress. (Sibling young carer in large group session)

I would put my headphones and listen to some music and I would just draw because when I was little, I used to write stories and stuff. I would just draw and write about my feelings, listen to music and play games. Things like that. (Sibling young carer in large group session)

In addition, a few children identified that they found talking helped, with one emphasising the importance of 'not bottling things up' and another adding that he had learned "to be more open than in a tight little bubble, as like all your thoughts in your head and telling other people what's wrong it really helps you".

## Edinburgh Young Carers and Respite Support

Edinburgh Young Carers offer diverse services to young carers and young adult carers, such as school liaison, regular respite and residential trips. Their scope has extended in recent years to cover ages 5 to 25. There are multiple referral routes into Edinburgh Young Carers, including the option for families and young carers to self-refer. Two parents described how their families originally got involved, one through a health visitor who recommended a parent to refer herself and a school who asked permission to contact EYC for a family.

EYC staff emphasise that their role with siblings is to focus first and foremost on the SYCs:

It's important for the kids we support to know that we are there for the SYCs, not for the sibling. We might be the only part of their life that works like that for them (Professional interview)

The need to replace missed family days out for SYCs was emphasised by staff, particularly where the sibling has autism, and 'meltdowns' keep the family at home. EYC staff described a range of aims and intended outcomes from the service, including creating memories, reducing anxiety and isolation, increasing fun, providing nurture and peer support:

It's about supporting their growth, connection with peers and their wellbeing. I see our job as creating opportunities to just be a kid, to have fun and be less isolated. In a group setting we want to see the kids relaxing and we tend to let the conversation flow. (Professional interview)

The young carers described benefits which aligned with the descriptions given by staff:

And it's like your own self to be responsible for and don't have to worry about anyone else and its really nice and I really enjoyed it...and that's the thing of having the memories. (Sibling young carer in large group session)

Residentials are fun and a good way to get away from home – you are not allowed phones so you can switch off and not worry as much; my Netflix subscription helps too. (Sibling young carer in focus group)

Parents were overall very positive about the role of EYC in the survey, highlighting the benefits of respite, fun and confidence building for their children. Also highlighted were benefits to family life and connections to other services:

EYC is a network I am not sure I can live without, they have been amazing for my son and my family through emotional support, financial support I cannot thank them enough. (Parent survey response)

Areas for improvement in the survey included nearly half requesting more one to one support and a third requesting more counselling for their children. In interviews, two parents informed that their teenage SYC children had struggled with confidence and, while there were benefits from EYC, their children had not formed friendships there. They also thought that there could be more opportunities for their SYC children to be supported more directly with concerns about their caring roles, as well as opportunities for fun activities.

EYC do a lot of activities...I thought as well that it would be good because they could exchange tips with other kids in similar situations. I thought they would talk about caring. (Parent telephone interview)

SYC's emphasised the importance of peer acceptance at EYC groups and respite activities:

Well I think young carers is a good place as you have other people that you can talk with and you can talk with other young carers and you can meet other people in the same situation and it can make you feel a wee bit happy to know that there is other people it is happening to. (Sibling young carer in focus group)





An additional benefit was identified by a parent in interview not covered in the survey:

It really makes a difference that everything at EYC is free. It's always a struggle for us financially and the fact that residential breaks and taxis are free and she has been picked up from the door – what a difference that has made. (Parent telephone interview)

## EYC and Family Work

EYC staff also spoke about their connection with families and the need to be respectful and mindful of the pressures faced by parents in creating early connections, as emphasised by the following teacher who was also a sessional worker with EYC:

It is so important that parents don't feel judged...We emphasise that as well as their child having a fun break the parents get a break too with one child taken care of briefly. We also point out how many other kids are in the same situation – it normalises it. (Professional interview)

The same member of staff spoke about family days out as a valuable opportunity, but one which could be limited in terms of joining in for parents of disabled children:



Regards family work we do try to create opportunities to work with SYCs and parents. We usually have a family day out in summer and Xmas, sometimes other trips too. Most often they bring the cared for person too which means that the parents mainly look after the cared for sibling and the EYC staff engage the SYCs. It is interesting to see the dynamics in the families though and how often SYCs take over caring roles. (Professional interview)

This aligns with parent responses to the survey, whereby the second most popular desired improvement identified was more family activities (with more respite coming first). The increased delivery of family activities, possibly through onward referrals or partnerships, with the correct professional support in place for the cared-for sibling, could substantially improve whole-family outcomes in terms of building intra-family supports and communication.

Our findings identify that families of (mainly) children with developmental disabilities are prone to being socially isolated and face challenges with getting out as a family. This impacts on outcomes for all family members. EYC provides an essential service in filling what can be significant gaps in family life by creating memories, improving confidence and providing space for the SYCs to just be children/young people. The parent survey feedback shows how much the service is valued by families, with many identifying that EYC fills gaps left by intense caring situations at home.

## EYC and Emotional Support

EYC staff frequently identified that the focus for SYCs is more about providing emotional support and developing self-care and improved wellbeing than with young carers more generally, especially if the cared-for sibling has high level support needs.

We have a Happy Heids' group for emotional wellbeing. We had to delay running it due to the earlier lockdown and it's on hold for now. (Professional interview)

We had an older primary school pupil recently who was acting out. We tried to find out what was going on, and there was no one-to-one with either parent. The parents were separated and both children were always with one or other parent. The child spoke to his mother and things changed. The parents just hadn't realised the impact, they had so much going on. (Professional interview)

Despite the support available in EYC, some SYCs are carrying a lot of worries in their heads:

I want to talk about my brother and his seizures and that, but I don't want to upset my mum... I worry about it a lot. I have talked to my mum a few times but.....I worry about his seizures and getting bullied..... I saw it happening all the time. I talked to the headteacher but he wouldn't listen. (Sibling young carer in large group session)

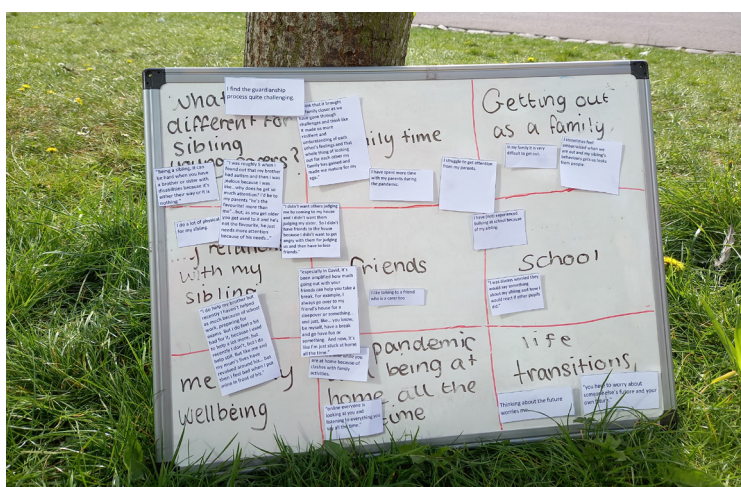
One of the support workers in EYC identified the need for trauma informed approaches to supporting young carers:

Trauma informed approaches to practice were becoming more widespread prior to the pandemic but are more to the forefront now. (Professional interview)

All young carers at EYC have a personalised Footprints assessment and support plan, developed with the young carer and the family unit. This tool, alongside the Young Carer Statement, which all young carers have a legal right to, helps to build appropriate supports to meet the needs of the SYCs and can include one to one support and access to counselling.

## EYC and Transition Support

Transitions for SYCs were discussed by EYC staff, in several ways. One was the need to pay attention to transitions over the lifetime of sibling carers, as the SYC's understanding of their situation is subject to change through life. Mirroring the voices of sibling young carers, staff spoke of the need to support sibling young carers as they worked through different extremes of emotion, with the potential to get lost in the caring role or to reject it and then feel guilt. This could also change over time. In addition, minor transitions happen on a daily basis as SYCs move between home, where they might have an adult role, and school, where they are in a child role, sometimes leading to challenges with peers and staff.



The main emphasis on this theme, raised by several members of EYC staff, was transition to adulthood as a significant period for SYCs, requiring continuing support and awareness of how the caring role could affect the young carer's decision-making, as well as understanding how the caring role can change as the cared-for person reaches adulthood as well. Key conversations could raise previously unasked questions for sibling young carers in particular:

At high school, it's future destinations conversations that can kick start moments of realisation. They become aware of the barriers they are likely to face. (Professional interview)

In the preparation meeting for our large group session, we asked young teenage sibling carers to help us with the questions for the younger sibling carers, and whether there should be a question about growing up as a SYC:

Yeah, cos they want to have their own life and maybe they still have to be there for their brother or sister. If they want to have a girlfriend or boyfriend and they want to have their own life, but they have a brother or sister that they have to think about. (Sibling young carer in large group session)

EYC staff emphasised the need to reassure the SYC that they can think about their own needs as part of planning for the future:

Transitions come up in counselling. Who will do the caring? There are often close sibling bonds, especially with autism. We look at pros and cons when considering the future and they need reassurance to consider their own needs. And to give themselves permission. (Professional interview)

Transitions were also a very significant theme in our conversations with two young carers (and their mothers in interviews). They were older teenagers with cared for siblings of a similar age. Their families were pursuing guardianship for the sibling. (A guardianship order is a court appointment authorising someone to act on behalf of an adult without capacity). This was raising questions about the future and what options might be available to them.

Because I'm now down as X's next of kin and it is funny thinking that way and you think 'God I've got that responsibility. If anything happens to my parents, I'll be next in line', and it's not the nicest feeling.... I think there is also this thing about what care is there. Social workers say there will be care for her, but I don't think that is going to happen. (Sibling young carer in large group session)

The mothers of these two sibling carers also identified guardianship as a significant challenge for their daughters. This suggests that support for SYCs and sibling young adult carers must recognise the need for age-appropriate information about these likely transitions to support and inform them through this stage of caring and decision-making.





## The Pandemic: Life for a Sibling Young Carer

The pandemic impacted on all families in our research, as well as influencing our methods. We include key reports published during the pandemic, to put our findings in context.

### The Pandemic: Being at Home 24/7

Being constantly at home during COVID-19 presented significant challenges to some SYCs. A report from Kassa & Pavlopoulou (2021) looked at the impact of lockdown on siblings of disabled children, findings that 81% of siblings surveyed were experiencing worse mental health during this period.

While Edinburgh schools being open to vulnerable children was identified as beneficial to some, there was concern that this was 'by no means' covering all children in need. Similarly, the lack of being able to go to school was a very significant change for some of those who previously viewed school as a break from caring. For EYC staff noted that the SYCs were caring more than before, as other support services had closed down, a finding echoed by Kassa & Pavlopoulou (2021).

Lockdown also meant that those who usually enjoyed seeing friends were less able to do so. Reduced connections and increased isolation were also noted by the Carers Trust (2020) and Kassa & Pavlopoulou (2021). One SYC told us:

I think like...especially in Covid, it's been amplified how much going out with your friends can help you take a break. For example, I always go over to my friend's house for a sleepover or something... and just, like... you know, be myself, have a break and go have fun or something. And now, it's like I'm just stuck at home all the time ...it just shows how important having that like emotional aid is sometimes. (Sibling young carer in focus group)

There were exceptions to this, as with the following SYC who was able to maintain some peer contact within the limitations of lockdown rules:

I have a friend who lives quite close so we go on walks like twice a week, which I like because I go for about an hour, get some headspace (Sibling young carer in focus group)

some SYCs, the pandemic had changed their domestic situation in ways that presented new opportunities and benefits. Quite a few mentioned that their sibling had been given a place in school hubs due to being vulnerable, while they had continued schooling at home. Where this had happened, the benefits were highlighted by siblings:

Sometimes it's kinda hard to find time to spend with my parents because they're really busy and all that. But now, my brother, because of the whole current situation, I am at home, but my brother because of his needs, he is still going to school. So basically until 3pm I am with my mum and I am getting more attention than I was before [chuckles] (Sibling young carer in focus group)

The following EYC worker also identified 'some positives' from not having to go to school:

There are positives. The pressure to get to school can be significant for young carers. That and the bullying and teasing for many are not an issue in lockdown (Professional interview)

### The Pandemic: Being Supported Online

The pandemic was identified as significantly impacting SYCs by all groups of respondents.

EYC staff were all working online as required to maintain contact with the young carers. Two new staff were trying to get to know children in a virtual world and finding this challenging. Virtual contact was not the most popular option with any of the staff: "In terms of really building confidence, it has to be face to face." The same person noted that providing emotional support while on screen is "really, yeah, exhausting" (Professional interview)

Children themselves also identified limitations of online support.

- It is more challenging to be present online while at home due to clashes with family activities and because "anyone can burst into the room at any time" as we saw
- Feeling more pressure to talk as "online everyone is looking at you and listening to everything you say all the time" compared to being able to chat offside to one or two people in real life
- Because emotions are less visible, this made one young carer want to hide their emotions even further
- Playing games face to face is more fun than online

Some work was stalled during lockdowns, such as the "Happy Heids" wellbeing group for very young carers caring for a parent with substance use, and all other services had to be adapted overnight – including moving awareness raising and professional training online.

We waited until face to face was possible [for Happy Heids] as this seemed essential for building trusting relationships, developing social skills and providing genuine and full respite from home. (Professional interview)

The Carers Trust (2020) also highlighted the difficulties in maintaining digital support during lockdown. However, 74% of young carers who were accessing support pre-pandemic, continued to access them online. The main challenge for families, noted in this research too, was that only 1% of young carers surveyed by the Carers Trust had a paid care worker or assistant to provide support for the cared-for person in the home during lockdown.

### Challenges in the Wider Service Context: "Fine Lines" for EYC Staff

Most of the comments regarding the wider service context were made by adults, namely support staff at EYC or parents. EYC staff made frequent reference to gaps in other support services being available to families, such as adequate respite and support for the person(s) with disabilities in the family. Parents identified consequent pressures on young carers.

An additional pressure for us right now is that Edinburgh day services are not reopening after COVID. Some strong-minded parents are fighting this. I hope they succeed. (Parent telephone interview)

Five members of staff identified concerns about the changing role of their service in the context of reductions in statutory services. The staff did not blame their colleagues within the statutory sector, but identified that reductions in services in CAMHS and social work were creating gaps and impacting on outcomes for the SYCs. Similarly, families had to work harder to access support and respite for the cared-for sibling, with implications for outcomes for the whole family. Due to service reductions, social work were identified as having pulled back from working with families they would previously have supported:

There is a big difference in the services available to families who are struggling compared to ten years ago. Preventative services disappeared overnight in many cases, and we see [statutory service] waiting lists keep growing. (Professional interview)

The role of EYC has expanded in recent years and there was a sense of a 'fine line' existing in some families between children identified as being a young carer and children whose families need significant external support to improve outcomes, without which support for the young carer alone won't improve the situation. This places significant demands on EYC staff who are working with families with increasingly complex needs and sometimes high levels of risk. Staff identified that primary aged children had experience of often inappropriate caring roles such as putting their parent in the recovery position, of having to phone an ambulance and of living in volatile and chaotic situations.

The caring roles now can be very inappropriate. Ten years ago, we could focus on just caring. Now there is a pile of things going on with families. Situations that would have been a social work case years ago have been moved on to us. We say "we are part of the plan, we cannot be the only plan" and that needs to continue. Staff have burnt out along the way. (Professional interview)

The need to ensure that young carers support services remain a part of the support plan for SYCs, and are not relied on as the only plan, is pertinent given evidence over many years in the UK of reductions in local authority funding, impacting on preventative services and with an expectation that the voluntary sector fills the gaps (Joseph Rowntree Foundation, 2015). There is wider evidence of a shift in child welfare services away from support to compliance, with less attention paid to the material needs of families (Featherstone, et al., 2019).

The Carers Act (Scotland) 2016, is one of the most important developments of legislation for young carers and young adult carers in recent years. The legislation aims to improve outcomes for young carers, ensure they have a life outside of their caring role, and indeed have the right to stop caring if they wish to.



## Recommendations for Change

### What do these voices tell us and what are the implications?

One of the striking features of feedback was the level of agreement between the views of SYCs, their families and staff. Within EYC there is a clear, shared understanding of the specific pressures faced by these children and their families, and indeed of their strengths. Given that most of families had a child with autism and/or other developmental delays, this possibly created a stronger coherence of views than might otherwise have been. In any case, family life, wellbeing, friendships and school were common concerns, and therefore form the basis of a set of recommendations that we urge stakeholders to take immediate action on.

### Recommendation 1

There is a need to raise awareness of the needs of SYCs, including for many, a feeling of being ignored and of being voiceless and for some, having a parenting role. This corresponds with SYCs often being attuned to the needs of others, to being adult-like and sometimes taking control. This report should be used to raise awareness along with the young siblings section of the [Sibs website](#).

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### Recommendation 2

Sibling Young Carers should be recognised and reflected within the paperwork, processes and policies of all young carer supports – including Edinburgh Young Carers, other young carer support services, and within the requirements of the Carers (Scotland) Act 2016 and Getting it Right for Every Child. This includes ensuring that all local authority Young Carer Statements address the issues, needs and rights of sibling young carers. Where appropriate and with permissions, Young Carer Statements can be shared with professionals supporting the family and the cared-for sibling, as well as SYC support workers and education staff to further improve support and recognition.

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### Recommendation 3

There is a need to combat the bullying that many SYCs live in fear of. This is a much wider responsibility for all agencies working with children, including schools. The [Respect Me](#) organisation could be approached to support a specific campaign for SYCs.

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## Recommendation 4

There is a need for a whole family focus, also promoted by [The Promise](#), to be reflected in the respite, support and interventions of services with a remit for supporting children/families. Health, social care, education, CAMHS and other relevant statutory services, must pledge to work holistically to provide appropriate support to the family and around the SYC, acknowledging and including SYCs in discussions and decisions about them and their cared-for sibling. Services must continue to support families as a whole, ensuring appropriate support at the earliest possible opportunity, to prevent SYCs from taking on inappropriate caring roles or reaching crisis. EYC and other young carer services should explore the feasibility of working in partnership with organisations to increase the opportunities available for families to access respite activities together.

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## Recommendation 5

EYC, and other young carers services across the country, should adopt a trauma-informed approach, using national resources such as the Trauma Informed Practice Toolkit for Scotland by NES. This includes adopting a trauma-informed approach to staff support too, ensuring that this supported and healthy workforce can continue to deliver and increase services that excel at supporting the emotional health and wellbeing of sibling young carers.

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## Recommendation 6

In practice, SYC's should be offered more emotional support and, where required, therapeutic support through counselling or other mental health interventions. The Scottish Government has made promises to invest in the mental health of children and young people both pre-pandemic and more recently to help recovery from coronavirus ((Scottish Government, 2019) and (Scottish Government, 2020)). Sibling young carers need recognition by the Scottish Government and local authorities to access early and meaningful support for their emotional wellbeing and mental health.

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## Recommendation 7

Sibling Young Carers should receive dedicated and specific guidance and support at times of transition, especially around the transitions into young adulthood for themselves and the cared-for sibling. Organisations supporting young carers and the cared-for sibling should plan and deliver this support at the earliest appropriate stage to reduce anxieties and establish holistic support and emergency plans. This should include providing sibling young carers with access to an advocacy service to help represent their views in decisions which affect them.

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## Recommendation 8

There is a clear need at a macro level for kindness and compassion to be adopted as organisational principles across statutory and voluntary services in Scotland, particularly in the context of pandemic recovery, which could also help to counter a pervasive culture of bullying amongst children and young people.

## Acknowledgements

Huge thanks are due to the sibling young carers who contributed to the shaping and content of this report. It was an absolute pleasure to work with you all. Much gratitude is also due to the loving parents who responded to the survey and subsequent telephone interviews for giving us their precious time. And to EYC and education staff who care so much for the children they support. Here's to better times ahead and continued recovery from Covid.

## Appendix 1: Methods

During the research period (October 2020 – May 2021), the researcher worked closely with an EYC manager and two Development Workers, who work with the sibling young carers groups. We had frequent meetings on zoom throughout the period which kept the momentum going, and helped us respond quickly to the changing circumstances of the pandemic. We were able to have face to face contact with the young carers in Autumn, and the remaining research was undertaken remotely.

The staff at EYC were preparing for this research project since April 2019, but were faced with delays, including COVID-19 and before this in finding a researcher. However, the team at EYC had been keeping the young carers and their families up to date with the plans for the research project, and providing them with resources and support tools relevant to their role as SYCs from April – September 2020, in addition to their normal support activities.

From October 2020, 18 sibling young carers took part in the research project, aged 8 to 21 years old. EYC workers were always involved in the communication about the groups and attended research activities to support the young carers to tell their stories. It was also important that SYCs knew that their attendance and involvement in the project was optional at all times, and in planning the research activities, it remained a priority for EYC staff not to clash with any of the SYCs respite groups or ask anything too time-intensive of them.

The following is a timeline of the main research activities:

October 2020: We produced information and consent sheets for all participating young carers, parents and staff. This informed all participants of the purpose of the evaluation and that they could remain anonymous and seeking consent to audio record to help with accurate notes. As the project was an evaluation we did not require ethical approval from Strathclyde university but we did inform the university ethics committee of our approach.

November 2020: Two outdoor meetings with sibling young carers: one with the primary age group (8 attended) and one with the 12 plus group (6 attended) to introduce the researcher and the research idea.

November 2020 – December 2020: Three further research events took place for each of the groups (six events in total), which were led by EYC staff and planned in advance with the researcher. The events were a balance between fun activities and respite, peer support and research techniques.

December 2020: One indoor workshop in EYC premises with both groups of sibling young carers (16 attended). This included a pre-meeting with the older group to help them plan their research activity. There was a Christmas themed activity, a craft activity and a research table, which the SYCs rotated around. The older group members interview younger ones with their predetermined questions, with 9 SYCs opting to be interviewed.

February 2021: Eight zoom interviews with EYC staff and two interviews with teachers.

Feb-March 2021: Four digital focus groups were held on Zoom, with a total of 11 sibling young carers of mixed ages, hosted by the EYC team and the researcher. We showed an animation of a 22 year-old sibling carer describing impacts of her caring role. We asked the SYCs to tell us whether they recognised themselves in the film *My name's Lottie* – YouTube



A questionnaire was sent to parents, with 16 responses. Follow up interviews were held by telephone with the researcher with 4 parents who had expressed interest in doing so.

March 2021: The EYC team and researcher transcribed the audio from the focus groups and shared our thoughts about what we had heard, developed initial themes and recommendations. The researcher then reviewed all the information gathered and drafted this report.

April 2021: Two evaluation sessions were held at face to face events with 8 sibling young carers, where they adapted and amended the themes and the recommendations of the report through activities and discussion. The SYCs all recognised their own voices and lived experiences within the report which they were proud of. The sessions were planned and delivered by EYC staff.

May 2021: The researcher and EYC staff finalised the report and recommendations based on the SYC feedback.

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