

Young People's insight into bereavement support services





Who are Participation People?



Simply, we empower and enable young people to improve services they use.

Participation People believe services improve when you work creatively with the people who use them!

We care about IMPACT and the difference made to people's everyday lives. We want to help everyone:

- Improve service performance.
- Be agile and responsive to the changing needs of young people.
- Increase or repurpose resources to effectively meet the needs of young people.
- Improve service reputation.
- Improve satisfaction of services with children, young people, and families.

We are playful in practice and serious about solutions.

Our values are central to how we do our work:

- Have fun!
- Empower young people to develop a strong voice.
- Work with services to develop actionable plans.
- Challenge the views and perceptions of all those engaged.
- Build projects that are selfsustaining through building capacity, training and funding.

Methodology

Cruse Bereavement Services (CBS) commissioned Participation People to help them hear from young who had people experienced bereavement. Cruse Bereavement and Participation People met to begin the project in April 2023. CBS shared their desire to listen to young people aged 14-25 to understand how to better support young people who had experienced bereavement. We also discussed the types of young people we particularly wanted to hear from and some challenges we may face engaging these young people.

Participation People then began to design the research to reach the multiple audiences of young people we wanted to hear from. research auestions were COproduced with the help of Participation People's Consultants, who youth-proofed the questions for us.

We held focus group sessions and 1-2-1 sessions with young people over the course of 2 months. We allowed young people to define how they would like to engage. We incentivised participation with a £20 Amazon voucher.

Cruse
Bereavement
wanted to gain
valuable insights
and feedback on
what does and
doens't work for
young people

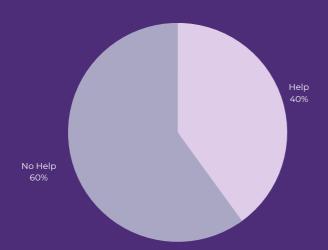
We engaged with a range of young people aged 14 - 25 who had experienced bereavement.

A few years ago, I lost my grandmother who I was very close to. Initially, it didn't feel real but starting to live a life knowing she was gone forever was the most difficult part. Although she was ill for quite a while, the thought of her gone was the most heartbreaking.

The Results

Young people who had experienced bereavement were invited to share their personal experiences of loss and coping and describe what they believe good bereavement services should look like. The young people had lost siblings, parents, grandparents and friends.

Regardless of who they lost, young people had a lot to say about their experiences, both positive and negative. The young people who were involved were keen to ensure that changes were made to ensure that young people would receive the right support moving forward. They felt like a number of little things would go a long way to making effective change.



We opened the conversation by enquiring about the support that they had received. 40% of the young people who we spoke to did not receive support immediately from anyone. They opted for 'dealing with it themselves'. Some only received support years later when they began to recognise they had not yet dealt with their loss.

The primary reason for young people not accessing support was not knowing where to go or who to speak to. They were also unaware of the benefits of accessing immediate support and would have appreciated more information on why seeking prompt help is important.

Those who did receive support found it was very inaccessible and difficult to navigate. Many commented on the cost of services and how they were unable to have regular support sessions due to the cost.

Many also spoke about how hard it was to find out where to go for help. All of the young people who spoke about receiving help were signposted by a family member, school or organisation. Several young people recommended more signposting in hospitals, schools and youth spaces that allowed them to seek help by themselves.

I did speak to a therapist and it did help but I think like she was quite expensive. My brother was paying for it, which was really nice of him. He's a lot older than me.

Who did you speak to?

Family

22/22

I would often go to my dad or a trusted family member/friend to speak about how I felt. Once people know what you are going through, they are able to support you in the best way they can and I often felt more comfortable reaching out when I needed help.

Friends

50%

I sought help from my other friends, as we were all grieving at the same time, through meeting up and phone and text conversations.

Professionals

30%

My granddad actually really, really struggled to find help. I know a little bit about it from from asking him. The day he went through the council, and he found that they weren't very helpful, and there was waiting lists of like, years and years long and obviously because it was such a traumatic loss, he didn't want to wait that long.

School

2 People We spoke about, you know, mental health services in schools and things like that. But ever since COVID-19, funding for these programmes, school nurses, and additional support is falling to pieces.

Who do you go to for help?

of the young people we spoke with confided in their families.

Because their family understood what they were going through, it was easier to speak to a family member than a 'stranger' who knew nothing about them or their situation.

The young people suggested that even if it was a friend that the family didn't know, they would still confide in their family because they knew them and they would know how to respond.

Two young people mentioned that they found it hard to speak to their families because they understood how much the loss had affected them and were unsure how they would respond. These young people spoke to friends instead.

Young people found it easier to speak to friends when they knew those friends had experienced bereavement before or when they also knew the person who had passed away.

There was significant conversation around the stigma attached to death and grieving. Many young people made it clear that they did not feel comfortable speaking to people because they were worried about what people may think or how they may react. The youngest people that we interviewed shared their experience of being in primary school and teachers and peers treated them as 'weird' after the loss of their brother. They did not know how to respond, which the young people found very difficult to navigate.

For some reason, I remember being embarrassed to tell people in school, but school didn't make it well advertised that there would have been any kind of support for that.

2 of the young people accessed non-bereavement-specific therapy either through preexisting enrolment in counselling services or referral to services like CAMHS. All of the young people were unsure who to speak to in their schools or universities to get support and what form that would take and, as a result, did not access any specialist support services.

Only 30% of young people had heard of any bereavement services, either through directly accessing services or through learning about them from others. There was no experience of flyers or social media posts making young people aware of bereavement services.

Everyone cries? I mean, but you see, not everyone is as fortunate to have such a stable background as I'm privileged with. And so I can speak on behalf of my community that there most certainly is a stigma attached, and people don't feel comfortable going to you know, counsellors.

Transparency

In every interview and focus group, it was clear that young people wanted society to be more proactive in supporting them. Each young person that we spoke to was vocal about wanting and needing help when everything felt very confusing and overwhelming.

There was a strong consensus on a lack of understanding and explanation surrounding bereavement and counselling. Several young people commented on being in counselling sessions and not fully understanding the purpose; many felt their counsellor was not being direct which made it difficult to speak to them.

Furthermore, they would have appreciated more background into what counselling is and how that would help them with what they were going through.

I felt like it was to me at the time kind of confusing, there wasn't really an explanation. I didn't understand what they were doing. There wasn't really that kind of support. It was just almost like, assessing me. He was kind of very medical and meticulous in a way.

However, some young people had more positive counselling experiences and shared the qualities which made someone easy to talk to:

- Empathy
- Experience
- Relatable
- Approachable
- Supportive
- Good listener
- Give you space to go through the healing stages

5 of the young people who did access support used more than one organisation. Reasons included funding running out with one organisation and having to find another service, or because the specialist they were referred to only allowed a limited number of sessions.

The young people tended to have a better experience with one service over the other and attributed the difference between their experiences to the above characteristics.

What can schools do to be more supportive?



Workload

Schools and universities can provide counselling, be lenient with deadlines and expectations, and develop a care plan to support young people with their workload.



Signposting

Offer young
people the option
to have extra
support and
sharing resources
with them, as
bereavement can
affect their focus
in class and
learning in
general



Accessibility

"In my school, originally, it was always you are referred to your school counsellor.
You can't just go in and say, Hi, I want to talk to you."



No Stigma

"They need to actually advertise bereavement support.
I think they don't want to address or advertise it because they assume it's a tough topic to tackle."



Training

"Teachers, I guess should know about support. Because often, I think teachers are probably the person that someone might go to."



Communication

"I think they should encourage parents to tell the school, so if the child doesn't want to speak up they're still getting support and people know."

What are good places to put printed information so it reaches young people?

There were in-depth conversations on how and where young people access information and where they spend their time. Each person that we spoke to had very limited knowledge of where to potentially go for support and what support could look like for them.

All the young people noted that information needed to be in spaces they were already in if they weren't aware of support and were unlikely to be proactively seeking services.

So, we asked the young people what would be good places and ways to promote information. Here is what they said:



"Something that even if they don't go and look for, meets them exactly where they are."

Support

When looking at how young people access support and in what spaces, the most important aspect for them was anonymity. Young people wanted to have the freedom to access support when and how they felt comfortable without feeling like they were being watched or judged.

Most young people would prefer to have a session online for similar reasons they felt like they could get support in the comfort of their own homes, where they felt safe. without feeling like they were being watched.

However, some young people were on the complete opposite side of the spectrum: they preferred to have in-person sessions, as they felt that was more personal and helped them relate to the professional better.

When discussing what would catch a young person's attention in terms of bereavement support, young people want to see...

- Misconceptions around grief (fact or false)
- Testimonials about how people have made it through
- Tools, tricks and tips, e.g., 5 ways to get out of bed in the morning
- Real stories that allow you to relate and know that you can make it through
- 'Are you depressed?' direct questions addressing how they may be feeling
- People in the same boat depicted

Young people had mixed views around whether they would like to speak to someone who had previously experienced bereavement. Some felt it was useful to confide in a friend who had been in the same position before. However, others felt as if people did not always understand their situation and, for example, compared the loss of a sibling to the loss of their dog. This discouraged some young people from speaking to others about their experiences again.

Young people really loved the idea of being able to preserve the memory of a loved one through memory boxes. This was a very popular idea and everyone thought it would have been nice to have been given the opportunity to do this.

Conclusions

Whoever the young person lost, the death had a significant impact on the young person's life. They reported that the effect was greater than they had imagined, and only in hindsight did they realise how beneficial receiving support would have been.

When looking at important adults in their life, young people felt most comfortable speaking to a family member. Those who were referred to counselling felt communication was unclear, and so they did not fully understand why they were meeting this 'stranger' or how this person was supposed to help them.

Furthermore, when reviewing the support that schools offered, none of the young people felt their schools took the right approach. Some made a fuss so that it appeared they were being proactive; others barely recognised the young person's loss. All of the young people desired that schools did more to support young people better.

Lots of the young people recognised that mental health is intertwined with bereavement and grief but mentioned that mental health is rarely spoken about in the context of grieving. They suggested that general wellbeing support would go a long way.

Looking at media representation, young people were keen to have to have animations, so they could relate readily to the content, and practical tips on coping with everyday life in addition to emotional support. They thought images of older people on resources, or large blocks of text, to be unappealing.

The young people highlighted the importance of short videos which appear on their social media feeds and remind them they are not alone. However, they also supported putting flyers and posters in a wide range of spaces; it is key to reach the right people readily instead of being reliant on referral to a service or having to seek out support which they aren't sure exists.

Despite the number of negative experiences that the young people had with professionals and the accessibility of support, the young people appreciated the efforts being made to ensure that support is effective and accessible in future Here are their recommendations.

Recommendations



Training

Teachers are the first point of call for most young people who have experienced bereavement. But many of the young people reported that schools and universities didn't know how to respond appropriately, therefore training staff would be beneficial.



Collaboration

Young people felt like they were passed around a lot and there was no direction in terms of where they should go or why they were there. If schools and organisations could work closer together with families, it would reduce this.



Be Human

Young people expressed the importance of having access to support without judgement, so it is key to provide a safe space that allows young people to come and heal in their own way.



Meet us where we are at

It should not be a treasure hunt to be able to find services that are able to support a young person through a difficult time. Flyers and posters should be in places everyone sees and be short, quick, and engaging to catch young people's attention.

