

Themes from engagement with a youth panel

Care leavers' experiences of health inequalities

Rachael McKeown, Ann Hagell,
Emma Hosking & Jeremy Sachs
September 2023



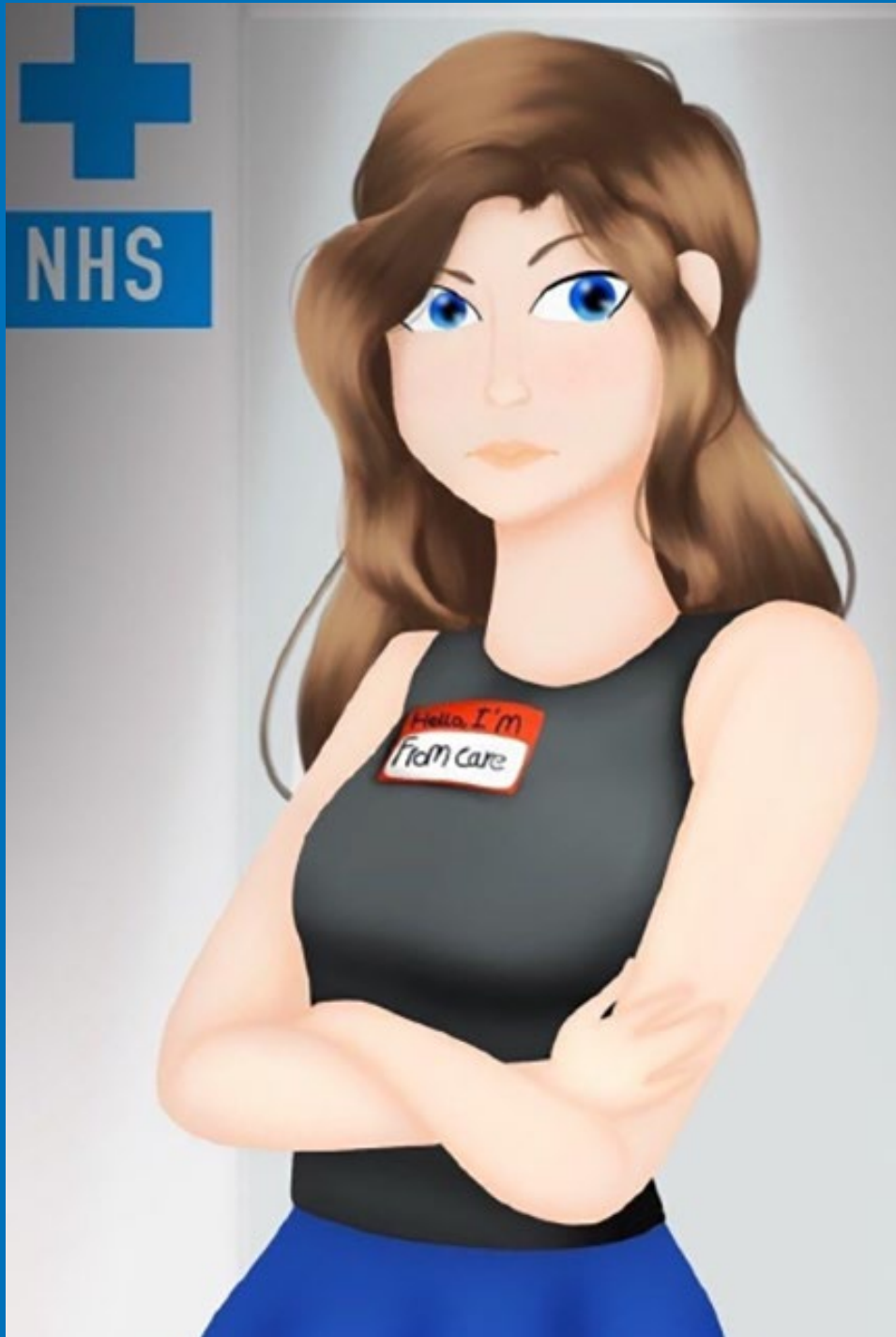
Supported by

Contents

Executive summary	4
Introduction	4
Methods	5
Everyday challenges	6
Experiences of stigma in everyday life	6
Challenges of transitioning out of care	6
Financial pressures	7
Accessibility of services and information	8
Factors that influence health outcomes	9
Lack of health literacy	9
The impact of mental health problems	9
Experiences of healthcare	10
Finance as a barrier to accessing healthcare services	11
Bureaucracy within the healthcare system	11
Recommendations from young people	12
Conclusions	13
References	13

Acknowledgements

We would like to thank all of the young people involved in this engagement work, who dedicated their time to have these important conversations about their experiences of leaving care and the impact on their health and wellbeing. We are grateful for their thoughtful and considered opinions that have informed our work on health inequalities. We are also grateful to the funders of this project, the Health Foundation.



Note from the artist: “In the past when I have told people that I am a care leaver, especially when talking to professionals, I end up either getting strange looks, invasive questions and or discriminated against, for example I have been denied service at some shops because they have overheard me say that I’m from care.

In my time of this I have began to feel different and isolated because of my experience. So in my work I wanted to capture the feeling of trying to get help specifically within the NHS and the anxiety that comes with that as well as the roadblock in getting anywhere just because of the label care experienced.

Everyone including care experienced people deserve adequate care from the people who are supposed to help us and I feel that it is important for the NHS to know what they are doing at the moment and to work to improve for the future so that care experienced people get the same support and help as everyone else does” **(Ace)**

Executive summary

Young people who have been in the care of the local authority are, on average, at greater risk of poorer health outcomes than their peers. As part of our [wider health inequalities programme](#) we explored the views and experiences of care leavers about health, accessing healthcare services and health inequalities in order to understand the challenges better. In partnership with [Coram Voice](#), we completed a small-scale engagement project with young people in the UK, setting up a youth panel for discussions co-facilitated by a young person themselves.

The young people who took part shared a range of challenges and experiences they had faced as care leavers. Many of these related to general issues they faced that made everything – including healthcare – more difficult. In addition, they spoke about issues that might contribute specifically to health outcomes. The latter included a lack of health literacy, the impact of mental health problems, experiences of healthcare, finance as a barrier to accessing healthcare services and bureaucracy within the healthcare system.

The young people made a series of recommendations specifically in relation to reducing health inequalities for care experienced young people including financial help with prescriptions, making care leavers more aware of the support that is available, consideration of ways to alert healthcare systems to the needs of care experienced young people, improved training and education for healthcare providers, and an improved and targeted mental health support offer for care leavers.

Introduction

Through the course of our [health inequalities policy programme](#), we have sought to understand better which groups of young people are more likely to experience poorer health outcomes compared to others. Available data show the [impact of deprivation on health inequalities experienced by 10-25 year olds](#) (AYPH, 2022). However, much less is understood about the health inequalities experienced by care leavers. As a result we reviewed the available quantitative data specifically on the health outcomes of this group, which revealed worse outcomes for care experienced young people in comparison to others aged 16-24 (McKeown and Hagell, 2023)

In this report, we explore the views and experiences of care leavers about health, accessing healthcare services and health inequalities. We completed a small-scale engagement project with young people in the UK to hear their views. Our aim was not to provide a representative sample of views of care leavers. Instead we explored a select set of young people's views by working in an in-depth way with a small number of young people. We hope it forms a solid basis for future research on the health inequalities experienced by care leavers.

Methods

The Association for Young People's Health (AYPH) collaborated with Coram Voice to deliver this engagement work, which took place between January and May 2023. The aim of this project was to better understand young care leavers' views of:

- Opportunities for leading healthy lives
- Health inequalities
- Access to healthcare services
- Solutions for tackling inequalities.

To achieve this we set up a youth panel, which was co-facilitated with one young person who was appointed as a peer facilitator. Although we had an understanding of what we wanted to discuss, there were no set research questions and the content of each of the youth panel sessions was co-designed in close collaboration between AYPH, Coram Voice and the peer facilitator. We replicated an approach we had taken in 2022 when engaging with young people from ethnic minority backgrounds to hear their views of health and health inequalities (McKeown, 2023).

It is worth noting that this youth panel was not recruited on the basis of having a long term healthcare condition, but on the basis of being a care leaver between the ages of 16-25.

All of the youth panel sessions were hosted online, via Zoom, which enabled young people from across the UK to attend. There were a total of four youth panel meetings involving facilitated group discussions, each of which lasted 1.5 hours. There were also activities for young people to share their views via polls and in written feedback. We engaged with a total of 10 young people throughout the work.

Each of the youth panel meetings were transcribed. The qualitative data from the transcripts were thematically analysed using a coding framework to pull out the key messages within this report.

The young people who took part ranged in age from 17 to 25 years. The majority were young women, with one young man and one participant preferring they/ them pronouns. Five identified as white and five Black. They came from across England, including Dorset, Stockport, London, Scunthorpe, Manchester, Reading.

Everyday challenges

The young people who took part in our youth panel shared a range of challenges and experiences they had faced as care leavers. Many of these related to general issues they faced that made everything – including healthcare – more difficult. In addition, they spoke about issues that might contribute specifically to health outcomes. In the next section we summarise the themes they raised around everyday challenges. In the next we go on to look at issues in relation to looking after their health and accessing healthcare.

Experiences of stigma in everyday life

The youth panel members spoke of the ongoing stigma they experience in day to day life. They worried about being judged by others due to having been in care, due to negative stereotypes of children and care and care leavers. Representations of care experienced young people on TV and films were felt to be generally negative and often depicted care experienced young people as criminals. For the youth panel members, these stereotypes had fed into people's perceptions; *“being a care leaver, it's like everyone has this automatic assumption that you are some form of criminal.”* It was felt that these opinions were very common among the public and had spread by word of mouth. The youth panel recognised that these stereotypes are unfair – *“there's children who are not in care who do way worse things or whatever that care leavers don't do.”*

As a result, the young people we spoke to were reluctant to disclose their status as a care leaver. They would not tell their friends and potential employers over worries and fears about how people might react. The young people believed that employers would be unlikely to accept them for jobs. One young person said that their friends *“would struggle to relate to you”* as they wouldn't understand what it is like to be a care leaver.

“ The surprise because they don't fit the stereotype of what you think a care leaver should look like or somebody in care because they seem to think we're all incompetent or whatever I don't know. ”

Young person

Often these concerns were rooted in previous negative experiences they had had when they had told people that they were a care leaver. One young person said that they were left feeling *“abnormal”* when someone started asking *“strange questions”* about them having been in care. For another young person, they felt that people were often *“surprised”* to find out they were a care leaver as they didn't fit the stereotype they were expecting. The youth panel members felt that there should be a greater level of understanding among the public about the reality and differences of young people who have experienced care.

We discussed with the group how they would describe this collective experience of stigma. They likened it to micro-aggressions and unconscious bias faced by people from ethnic minority backgrounds. One young person noted that the repeated negative experiences had a negative impact on their self-esteem. We have previously heard the [views of young people from ethnic minority backgrounds about their experiences of health inequalities](#). They shared the commonality of micro-aggressions in everyday society. This points to a broader problem of attitudes and behaviours towards minoritised groups in society and recognises the intersectional experiences of young people. It is important to recognise that these young people may carry these pre-conceived ideas about how others view them throughout their life, impacting on all of their interactions with professionals and services.

Challenges of transitioning out of care

All of the youth panel members agreed that transitioning out of the care system is challenging and impacts on young people's mental health and wellbeing. Going into independent / semi-independent living was difficult as young people felt that they lost their support system and were largely left to fend for themselves. The young people we spoke to found the transition out of care to be a largely negative experience. Having to do things by yourself led to *“feelings of loneliness and anxiety”* as they were unable to access the support mechanisms they had once had. Another young person described, *“once you turn 18 they'll drop you and the effect that has is it just leaves you quite worthless. It leaves you on your own, you're unsure where to go.”*

“ You’re covered with a warm blanket and then you reach 18 and the blanket is ripped from you and no one tells you how to get warm. ”

Young person

Although there are initiatives in place to support care leavers navigating this period of transition, the young people we spoke to did not feel that they were wholly effective or their leaving care advisors did not utilise the available schemes. One young person explained that while the Staying Put Scheme intends to provide care leavers with lessons on budgeting and cooking, they personally received this too late at just one week before they left care. Another person explained *“I find it really stupid, so that’s the official plan when you’re hitting independence, but they don’t really properly prepare you.”*

Every care leaver is appointed a personal advisor (or leaving care worker) to support their independent living. For the majority of the young people we spoke to, personal advisors were *“not good enough”* and did not know about what support was available, leaving young people to feel like they have to do it on their own. One young person described, *“it never felt like extra support, it felt like the quicker I could get rid of them the better because that was causing more stress.”* There was variation between different advisors who changed roles often. Young people mentioned the importance of building trusting relationships to allow the care leaver to open up and ask their advisor for support.

The transition out of care exacerbated the youth panel members feeling of difference to other people their own age. Having to manage the practicalities and realities of leaving care whilst externally appearing as a “normal” teenager is difficult and places a lot of pressure on young people. As one young person described, *“it’s restricting and it’s difficult and you can’t be your authentic self ... Yeah you want to feel somewhat normal and it’s difficult.”* Some of the youth panel members reflected that going through adolescence and teenage transitions is difficult for all young people, but there are added stresses and challenges for care leavers.

The youth panel members have built up their own support networks, usually consisting of good friends and partners. Friends could cheer up the young people and give them positive energy. As one young person described, *“no one is really independent, everybody needs someone.”* But other care leavers struggled to find time or money to socialise, which left them isolated. Others felt that it was down to luck whether you found your own social support system – *“it is hit and miss”*.

Financial pressures

Most of the young people discussed finances in comparison to other young people. They felt that, as a care leaver, you are more likely to be in financial stress at an earlier age as you have responsibility for paying either all or a combination of rent, bills, food and hobbies/socialising. They were aware that other young people don’t have to pay for these things, and they can *“ask their parents if they could borrow some money”*. Care leavers do not have a familial financial safety net. One young person commented that a young person’s parents *“want to ensure your health”* and so would pay for private counselling or therapy sessions, but care leavers often have to pay for this themselves.

As a result, care leavers have had to learn budgeting skills from a young age. This was particularly difficult to manage when unexpected expenses came up, for example one young person had to pay £1,000 for carpets in their property. This kind of financial stress had a negative impact on the mental health and wellbeing of the young people we spoke to. It meant that some young people could not see their friends as often as they would like, as they could not afford it. One young person described the stress of managing bills that had spiralled into debt, which left them feeling *“helpless”*.

“ Just trying to have normality whilst also going through one of the most abnormal things a person can go through, managing that can be really difficult. ”

Young person

Some of the young people we spoke to had received financial support from their local authority to help with their education, university degrees or have received reduced rent through social housing. However, the young people discussed the difficulty they faced when the bursaries or support was removed, as it felt like a cliff edge. As one young person describes, *“having no financial support and kind of I didn't feel prepared for it and that was kind of quite a sharp change.”* Another young person had five different jobs in order to fund their master's degree, a stark contrast to the financial support they had received for their undergraduate studies. The young person described the pressure as *“overwhelming and daunting”*. Other young people spoke about the burden of finding out what financial support is available sitting with the young person themselves, who is not likely to be aware of financial support services that are available.

Availability of services and information

A key general issue that the youth panel raised was the variation in terms of what support and services are available to care leavers in different areas. Access to many of these services would contribute to young people's ability to lead healthy lives. Every local authority provides a 'leaving care offer', which includes various entitlements. This complements the role of the personal advisor, which every care leaver is entitled to for guidance in their transition out of care. While some of the care leavers we spoke to had access to a free gym membership and prescriptions, others did not. One young person described the variation between places as *“a lottery of experiences.”*

Many care experienced young people have moved areas and placements quite a lot. This meant that many of the young people we spoke to were unaware of what support services were available to them in their area. On top of this, some young people were worried about their medical notes being lost within the system when they changed locations. Moving also had an impact on the sense of belonging to a place for care leavers, which might impact on their wellbeing.

Factors that influence health outcomes

The participants in the project raised a number of issues that could specifically impact on the health outcomes of care experienced young people.

Lack of health literacy

Participants commented that the challenges of transitioning out of care, living independently and lack of support meant that care experienced young people might lack the skills or confidence to lead healthy lives, or to navigate the healthcare system. This is often referred to as health literacy, but this wasn't a term that was known or used by the young people themselves.

A number of young people explained that they did not know about how or when to access different health services. They felt that they didn't understand when they should be using the pharmacy and when they should contact their GP, due to a lack of guidance. There was also confusion around whether certain sexual health clinics or counselling services would be available to them for free as a care leaver. This lack of understanding filtered into the young people's confidence levels, as one young person said that they didn't "feel brave enough" to access health services independently. Feelings of uncertainty around accessing services were also heightened by worries about being mistreated by health professionals, which were either rooted in personal negative experiences that have happened in the past or stories from others about their negative experiences.

One young person stated that they did not have enough information on what makes up a healthy diet. This is important as many care leavers are responsible for cooking their own meals.

The impact of mental health problems

Nearly all of the young people we spoke to said that mental health problems were a recurring challenge they had faced throughout life, particularly exacerbated during the transition out of the care system. A number of the young people shared that they suffered with anxiety and loneliness, which impacted on their ability to lead a healthy life. For many of the young people, experiences in their childhood such as neglect and adversity had contributed to poor mental health and these

feelings were often triggered during periods of high stress. The youth panel shared how increased anxiety led to health anxiety and worries about their physical health but also impacted on their confidence in reaching out and speaking to healthcare professionals.

“ Isolated is the emotion I'd go with. That's how I feel in some situations, isolated and strange. Even though obviously it's not my fault. ”

Young person

As discussed, loneliness can be triggered during the transition out of care and the loss of support networks, potentially leading to depression or depressive symptoms. There was an assumption from some of the young people that if they were to struggle with their mental health during this period then they wouldn't have the support system to help them. One young person described their own experience as, "...trying to remain calm and put together as possible because if you break and if you whatever, really and truly it's only you than can bring you back up."

The youth panel members struggled to access mental health support due to waiting lists and thresholds. One young person complained that although they had started IAPT (Improving Access to Psychological Therapies) treatment, there was only a small number of sessions available on the NHS, which wasn't enough. There were problems associated with waiting lists and moving address, which would put you to the bottom of waiting lists rather than transferring your care. A small number of the youth panel were funding private therapy sessions but others commented that they couldn't afford it. There was a clear sense of injustice

“ Everyone else around you is probably 10 steps ahead of you, calm and getting there slowly and then you're just down and getting lonelier and lonelier and eventually falling into a depression. ”

Young person

surrounding the lack of support set against the reasons why care leavers may require mental health support. As one young person described, *“it’s not my fault that my parents traumatised me and I have to pay for therapy, like so where’s the support? Sorry, that’s a bit matter of fact about it. I want to bill my parents to be honest, but I can’t, so can I bill someone?”* However, one young person mentioned that their local authority had employed a psychiatrist specifically to support care leavers in their borough, who is able to provide help for them. This highlights an earlier point regarding variation between places in terms of what support is available to care leavers.

Other young people had experienced negative interactions with healthcare professionals as a result of their mental health diagnosis. Healthcare professionals hadn’t believed the validity of their physical health conditions, as physical symptoms had been attributed to anxiety or mental health. On occasion, this had resulted in young people receiving inappropriate treatment. One young person described, *“all tests were showing I’ve got physical symptoms but they’re just blaming it on the fact that just because I’ve got anxiety and depression, it must just be anxiety.”*

Experiences of healthcare

Many of the members of our youth panel had

A quick Zoom poll during one of the youth panel meetings revealed that 100% of the group had been made to feel unhappy or annoyed by a previous GP appointment and 100% felt that doctors or nurses had made assumptions based on their identity as a care leaver.



gone through negative experiences within healthcare settings or with healthcare professionals, which made them reluctant to use health services. This usually stemmed from mistrust and wariness.

As discussed, the group generally felt that they faced a certain stigma in wider society and this had permeated into their perceptions of healthcare professionals. It was felt that negative stereotypes and stigma had been passed down from older health professionals to their students.

Many of the young people we spoke to felt that health

“ The healthcare professional doesn’t want to find out what is wrong as they are pushing you from one person to another without finding out the main issue. ”

Young person

professionals did not believe them and that they were *“seen as a liar”* or that *“the condition is in your head and not real.”* One young person described how they saw six different doctors before receiving a diagnosis and treatment for their condition. This fed into an idea that health professionals were judging them as care leavers, or *“looking down”* on them. When pressed on how health professionals portrayed this, one young person explained that it was in the tone, body language, facial expressions and communication style used. Another young person stated that professionals have previously made *“comments that imply you’re paranoid or over-exaggerating ... ‘Don’t believe everything you read on the internet’, things like that.”* Some doctors have asked care leavers about their family history of medical conditions when they do not know the answer.

“ It’s like you’re a five-year-old and you’re immature and they don’t take a word that you say basically. ”

Young person

This mistrust made young people feel like they did not want to reach out to services. One young person described how they would delay accessing health services – “I wait until I’m basically on death’s door before I actually go back in.” This highlights the need to develop supporting and trusting relationships between care leavers and health professionals, and an awareness of the pressures these young people are under.

In one specific example of how mistrust might build, a young mother on the panel explained that if you are pregnant around the time of leaving care you must participate in a social services assessment of parenting capacity. The youth panel questioned the necessity of the assessment and highlighted it as a specific difference (or micro-aggression) faced by care leavers in comparison to other young people. The young mum reflected that some care leavers might require extra support during their pregnancy, especially for their mental health. However, going through the assessment “feels like extra scrutiny” rather than support. It made them feel judged by professionals who were assuming they would be a bad parent, and thus perhaps less likely to seek help when they could benefit from it.

“ Instead of spending on your rent you’ll have to spend it on the travelling, you’ll have to spend it on the actual prescription itself. You’ll be losing money if you’re taking time off work. So worst case scenario you could end up unable to pay your rent. You might have to take time off college to do more work. So there’s quite a lot of implications it could have. ”

Young person

Finance as a barrier to accessing healthcare services

Despite the NHS being free at the point of access, the youth panel members raised a number of associated costs that can prevent care leavers from accessing services. These included the cost of transport to and from appointments, the cost of prescriptions and the cost of dental care. While some local authorities offer free prescriptions for care leavers, this is not universal. The young people also discussed time as a hidden cost for attending healthcare appointments, as they would often have to take time off work and lose out on pay. As a result, these young people had to make difficult decisions about whether to attend appointments or not. One young person noted that their local GP service sends text messages to patients outlining that it costs £250 for every missed appointment. They explained that this is intended to pressure you to attend but it doesn’t take into account the cost to the patients.

Bureaucracy within the healthcare system

The youth panel highlighted a number of administrative / bureaucratic frustrations that can act as barriers to young people accessing healthcare services. Importantly for care leavers who have moved location frequently, they have experienced medical notes being lost between different health settings and having to repeat processes in order to get repeat prescription medication. One young person also described that some healthcare forms can be extensive and difficult to complete, especially if a care leaver is completing the form without any support.

Recommendations

The youth panel had a number of recommendations that related to improving the experience of care leavers, including the guarantee of a universal basic income, more national policies to avoid regional differences, and provision of trips or holidays for care leavers who could not afford these otherwise. They also suggested there should be more opportunities for peer support for care leavers, to reduce isolation and improve mental health. Opportunities for advocacy work had also been a positive experience for some in the group.

The top recommendations from the youth panel specifically in relation to reducing health inequalities for care experienced young people included:

- **Free prescriptions for care leavers**
Young people felt that “...they should be free, they’re really expensive” as one step towards countering the financial constraints they faced in their everyday lives.
- **Making care leavers aware of support that is available**
In one example, a young person noted “I found this sort of stuff through going on the Care Leaver Covenant app but I only went on it once and realised all of this was available but without doing that I wouldn’t have known. So now I’m trying to get my local authority to get all the care leavers into all this stuff and to know about it but it’s just a shame that everyone misses out and doesn’t know about all this stuff that’s actually available for us.”
- **Flagging a care leaver in healthcare/GP systems**
Consideration for a flag in healthcare/GP systems that the young person is a care leaver. This might make some young people feel more comfortable and less stressed. However, not all young people want others to know about their care status, so this would require a careful consent procedure.
- **Improving training and education for healthcare professionals on care leavers’ experiences**
This should be available to all staff, not just one named person, and more training would benefit all young people, not just care leavers. The problem with having nominated specialists in care experience is that this may not trickle down to the rest of the team.
- **Improving the mental health offer to care leavers**
Panel members commented that “Because is it something like only six sessions of counselling are funded with the NHS, maybe you could fund more sessions or maybe you could skip the waiting list because I know waiting lists can be years long. I think that would be quite helpful”; “Care leavers have been through a lot of traumatic experiences and counselling would be quite helpful for that. So maybe just having the counselling easier access, quicker access to counselling and more sessions”, and “My borough has obviously hired a specific psychologist for care leavers, that would be a really important thing to have nationwide again.”

Conclusion

The young people who shared their experiences with us for this project were clear that the general life circumstances of care leavers could create challenges that might predispose them to health problems. As they noted, they had to become independent younger, without the family resources usually available, and often in the face of severe financial constraints and ongoing stress. Their experiences of the stigma of living in care, the lack of support, and a gap in health literacy caused by the disruptions of their lives mean that they were both more likely to need help, and less

likely to know how to seek it. They felt they were often met with a lack of understanding and empathy, and that this exacerbated barriers to accessing healthcare services.

They saw a number of ways in which the situation could be improved. In particular they suggested a need for improved understanding about the situation they were in from healthcare professionals, and for targeted efforts to reduce the barriers to good healthcare that they faced.

References

Association for Young People's Health (AYPH) (2022) Youth health data hub – Health Inequalities [Available online at: <https://ayph-youthhealthdata.org.uk/health-inequalities/> Accessed on 17/5/23]

Sacker, A. (2021) *The lifelong health and well-being of care leavers*. Policy Briefing. London: Nuffield Foundation.

McKeown, R. (2023) *The importance of ethnicity for understanding young people's experiences of health inequalities: Themes from available data*. London: Association for Young People's Health.

McKeown R and Hagell A (2023) *Care leavers' experiences of health inequalities: Themes from available data and literature*. London: Association for Young People's Health



More information

Association for Young People's Health

AYPH is the leading independent voice for young people's health in the UK.

To find out more about our work visit www.ayph.org.uk

Contact: info@ayph.org.uk @AYPHcharity

Coram Voice

Coram Voice works in a variety of different areas in order to support children and young people in care and care leavers. Coram Voice is part of the Coram Group of charities. www.coramvoice.org.uk

Contact: ANV@coramvoice.org.uk @CoramVoice

About the Health Inequalities Policy Programme

The **AYPH Health Inequalities Policy Programme** shines a light on young people's specific experiences of health. As well as speaking to specific groups of young people about their lived experiences we have collated data and evidence. We have also worked with key, influential stakeholders who have the power to help make a difference.

The project has developed a range of resources to support the delivery of change within both policy and practice. The project was part of the action phase of the Health Foundation's 'Young people's future health inquiry', which funded a range of projects to build the policy agenda and amplify the voices of young people.