LOOKED AFTER MINDS

Prioritising the Mental Health of Care-Experienced Children and Young People

November 2019
NYAS (National Youth Advocacy Service) is a leading rights based charity providing independent advocacy support and legal representation to care experienced children and young people and vulnerable adults across England and Wales.

We listen to what children and young people want, care about what they say and do everything we can to empower them to have a voice and be heard when important decisions are being made which affect their future.

We influence and campaign to bring about positive changes and ensure children’s rights are upheld.
Mental health matters to care-experienced children and young people. It is consistently raised as one of the key priorities from young people themselves, but their calls for action are not being taken seriously enough and they are often left waiting for the support they need.

The risks of poor mental health faced by care-experienced children and young people are significantly greater than their peers.

NYAS’ Looked After Minds campaign is calling for the Governments of England and Wales to take urgent action to protect the mental health and well-being of care-experienced children and young people.

We need to move away from a mental health system that requires its patients to be in crisis, towards one that is truly proactive: advocating on behalf of care-experienced children and young people; supporting them through crucial times such as entering adulthood; addressing trauma at the earliest opportunity; and striving for childhoods that are full of positive experiences and love.

Mental health services and support in the UK must cope with pressures, overcome obstacles and meet real needs, but always in a way that preserves our commitment as a country to children’s rights. That is the basis of the principles set out in the Looked After Minds campaign:

- All children and young people have the right to have their voices heard in decisions made about them, including when understanding and navigating mental health services.
- When care-experienced children grow up, they continue to deserve the best possible protection and support for their mental health and well-being.
- Every opportunity must be taken to address and minimise the impact of traumatic experiences on the mental health and well-being of care-experienced children and young people.
- Everyone must have the opportunity to enjoy their childhood, not just survive it. We must build resilient networks and strive to enable positive experiences for care-experienced children and young people.

The recommendations in this report form the basis of NYAS’ campaigning efforts to encourage all relevant politicians and decision-makers to improve public policy and legislation relating to the mental health and well-being of care-experienced children and young people. This report is not intended to promote or support any particular political parties or candidates, and must not be used for this purpose.

NYAS’ message to all care-experienced people is that the Looked After Minds campaign hears you, and we will not stop working together to improve mental health and well-being policies.
For decades, NYAS has advocated on behalf of children and young people across England and Wales who are suffering from poor mental health or are struggling to engage with mental health services.

Prioritising the mental health of care-experienced children and young people

The risks of poor mental health faced by care-experienced children and young people are significantly greater than their peers. Children in care are four times more likely to have a mental health difficulty, which in many cases is attributed to isolation and loneliness.¹

For many children and young people that NYAS speaks to, entering the care system gave them the support and stability they needed to be able to begin to recover, build positive relationships and start to build their future. However, it is not enough just to take a child out of an adverse or traumatic environment and then assume their mental health will improve.

Currently, an estimated three quarters of children raised in local authority residential homes meet the criteria for a psychiatric diagnosis.² Even more starkly, young people who have left care and entered adulthood are between four and five times more likely than their peers to attempt suicide.³

That is why NYAS is calling for the Governments of England and Wales to take urgent action to protect the mental health and well-being of care-experienced children and young people. Elected representatives of the state, having taken these children into their care, must answer to whether these outcomes would be good enough for their children.

NYAS believes the lack of focus and priority given to children’s mental health, amounting to less than 1% of the NHS budget, is completely unacceptable.⁴ This is the case despite the fact that 50% of mental health problems in adult life (excluding dementia) start before 15 years of age, and 75% before 18.⁵ Only a fraction of this 1% is accessed by care-experienced children.

NYAS works with children and adults in mental health in-patient settings, and runs a project across Wales that supports care-experienced young people to access mental health support as they enter adulthood.

Mental health has been raised by children and young people themselves as a priority issue for them.⁶ In 2018, NYAS Cymru hosted the first ever Youth Gender Equality Conference, where access to mental health services was identified as a key concern by the three hundred 14-21 year olds attending. The recent Care-Experienced Conference in Liverpool, which brought together 141 care-experienced people of all ages, also led to a call for mental health to be prioritised. Attendees felt this was the most important and urgent issue that needs to improve.⁷
The priorities outlined below reflect the experiences of mental health issues and services by the children and young people we’ve worked with in recent years.

This is not a quick fix, and there will be other ideas that can make a difference too. We have focused on four vital areas for improvement: advocacy, entering adulthood, responding to trauma and enabling positive childhood experiences. A golden thread throughout these areas is that mental health support must be child-centred and rights-based, recognising that mental health problems are preventable. If we get these areas right, then the improvement to the mental health and long term outcomes of care-experienced people would be significant.

Mental health and well-being are our biggest worries and the most important and urgent things that have to improve.

The Care-Experienced Conference

NYAS’ message to all care-experienced people is that the Looked After Minds campaign hears you, and we will not stop working together to improve mental health and well-being policies.
Anyone suffering from mental health issues must be made aware of their rights and be supported in expressing their wishes and feelings. All children and young people should therefore have the right to an independent advocate, not just in in-patient settings but in the community too. Advocates could:

1. Guarantee their right to have their wishes and feelings taken into account in decisions made about them.
2. Help them to navigate the system, and understand what is happening.
3. Hold CAMHS answerable on services and waiting times, using trends and issues raised through advocacy to lead to continual improvement in mental health services.

Whether children and young people are having difficulty accessing services, need support at mental health appointments or want to put their voice across in care plans, advocacy at that stage could prevent escalation of mental health issues and give individuals greater control in their lives.

In-patient advocacy is a vital service, but many of the challenges facing young people are in accessing treatment and support in the first place. Advocacy at an earlier stage of engagement with CAMHS, or in following patients’ recovery out into the community, would mean that a much larger number of children and young people would feel more confident in navigating the system and having their voices heard.

There are three groups of children and young people who already have the right to advocacy set out in law: in-patients in mental health settings, children in care, and care leavers up to the age of 21 (Wales) or 25 (England).
It appears common for children’s mental health to deteriorate while waiting for support from Child and Adolescent Mental Health Services (CAMHS), and most carers report that neither they nor their children were signposted to any other form of support during the time they were waiting to access CAMHS. Of more than 338,000 children referred to CAMHS last year, less than a third (31%) received treatment within the year. Another 37% were not accepted into treatment or discharged after an assessment appointment, and 32% were still on waiting lists at the end of the year.

That is why independent advocacy is needed to uphold rights for children and young people receiving any tier of mental health support. Currently, only ‘Tier 4’ highly specialised in-patient units and intensive community treatment services offer advocacy under the Mental Health Act 1983.

Care-experienced children and young people already have the right to an independent advocate, but this needs to be an ‘active offer’ if they engage with CAMHS so that they are made aware of their rights and can choose to opt out of an advocate if they do not want one. Given that an estimated 65% of young people who have a mental health need are not currently receiving any statutory service support, NYAS are also calling for this right to be extended to all children and young people. This would require an amendment to the Children Act 1989, or further legislation. In the interim, a pilot arrangement based on local policy could immediately offer support to young people in understanding their rights, expressing their wishes and feelings, and navigating mental health services in order to get the right support. NHS guidance promoting this as best practice would also be a welcome interim measure.

Advocacy case study

Sally, an in-patient at a mental health unit, was concerned that she didn’t need to be following a strict meal plan and had tried self-advocating to explain to staff why she believed she didn’t need certain foods they were insisting she had.

She was concerned the consultant she was meeting might be equally dismissive, so she requested advocacy support to explain the concerns on her behalf and then she would speak for herself. The consultant agreed that Sally no longer needed a meal plan which she was relieved to hear as not being listened had been frustrating and could have set back her recovery.

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I didn’t realise mental health was the sort of thing that advocates could have helped with.
2. Entering Adulthood

**Our position...** When care-experienced children grow up, they continue to deserve the best possible protection and support for their mental health and well-being.

**Making it happen...** Every care-experienced young person’s Personal Adviser should prioritise support for the young person’s mental health and well-being as a key performance indicator. Mental health support must be proactive, preventative, and meet the mental health needs of the individual as they are leaving care. Where a child or young person is waiting for or denied access to CAMHS or adult mental health services, other support options must still be timely, tangible and led by a genuine dialogue with the young person.

A major challenge for care-experienced young people is leaving care between the ages of 16 and 18, when they are no longer legally ‘looked after’ by their Local Authority Children’s Services. For those experiencing poor mental health, this time can feel especially unstable because they are becoming too old for engagement with CAMHS too.

If young people do not meet the threshold for adult mental health services, which is higher than that for children, then CAMHS will make plans for discharge which should include referral to other agencies. However, the higher threshold for access to adult services can cause serious issues for care-experienced young people with lower tier mental health issues, who face this instability at the same time as they are leaving care.

Medically, there is no reason that a change in service support should happen at precisely the time when a young person is leaving care - there are no clear biological markers that indicate when transition to adulthood begins or is complete.

When entering adulthood works well, health professionals are present at meetings allowing for a full and comprehensive picture of the young person to be provided before they leave care. But NYAS hears from young people and partners that too often the support they receive when entering adulthood does not work well. Even if a young person’s transition successfully keeps them engaged with services, they are known to experience a dramatic culture shift between CAMHS and adult mental health services. Patients may experience contact with multiple clinicians during the transition to AMHS, and inadequate handover can lead to inefficiencies and patient dissatisfaction.
NHS England’s Director for Transition to Adulthood rightly points out that “The brain doesn’t finish developing until the age of 25, so there is an argument for building young adult services that meet the developmental needs of young people while they have so many changes in their lives.” NYAS welcomes NHS England’s Long Term Plan commitment to create a comprehensive mental and physical health model for 0-25 year olds to avoid the difficult transition into adult services at 18 years old. NYAS also welcomes Welsh Government plans for young people who are looked after or on the edge of care to be helped and supported to enjoy the same life chances as other children.

Once a young person has left care, they are entitled to a Personal Adviser up until they reach the age of 25 in England, or 21 in Wales. A Personal Adviser acts as a focal point to ensure a care leaver is provided with the correct level of support. While there are pockets of best practice, NYAS believe linking a Personal Adviser’s performance to the mental health and well-being of their young people would ensure better access to services and support during the transition to adulthood.

An example of best practice is in the Welsh Government-funded NYAS Cymru ‘Newydd Project’, which provides additional support to care-experienced young people transitioning from CAMHS to adult mental health services or the community. Intensive advocacy when entering adulthood enables a continued and familiar source of support, help understanding the change in systems, and increased involvement in care planning. It also helps to avoid the ‘cliff edge’ of support young people in care face as they transition from both mental health services and care, and therefore the recommendation on advocacy in section one of this report is highly relevant to young people moving on from CAMHS.

Entering Adulthood case study

Beth was very happy with her weekly therapy but had been told this had to end due to lack of private funding and she would need to access therapy through CAMHS.

Due to previous family history with CAMHS, Beth did not have any trust in their service. These arrangements were made without consulting Beth and no support was offered to address the trust issues.

I turn 18 in a few months’ time but after meeting with doctors I was told I wouldn’t get any therapy from adult services and I’d be on a waiting list for at least a year. They couldn’t say how many meetings they could offer in the community, and I’ve still not met my care co-ordinator. They still haven’t said what they are going to offer when I am discharged. I feel completely numb and overwhelmed, hopeless to be honest.

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A major step forward will be when the NHS England’s Long Term Plan delivers its promise of a designated physical and mental health keyworker for those who face multiple vulnerabilities, including care-experienced children in transition between services. Their target is for this to happen by 2023/24.

In the interim, Personal Advisers and independent advocates should have a role in checking that NICE guidelines on transition to UK adult services are being followed.

When I hit 18, all support stopped. Suddenly I was being signposted from pillar to post but everyone seemed to be palming me off. Nobody wanted to put the time in to help me. I feel like you need more stepping stones before everything just falls away.

NICE guidelines (2016) on transition to UK adult services:

- Involve young people in the transition process, decision-making and goal-setting
- Ensure transition of support is developmentally appropriate and tailored to the patient
- Address all relevant outcomes (education, employment, health, independence, etc)
- CAMHS and AMHS should work together to make the process of transition smoother
- Transition planning should take place early; the point of transfer should not be based on a rigid age threshold
- A named worker should co-ordinate transition of care and support
- Parents and carers should be involved, if possible
Every child has the right to the best possible health. This includes Governments providing treatment for children, but this right is not always the reality for those with trauma-related mental health needs. We know that many children and young people are struggling to access mental health services, even once they’ve been referred by professionals. And we know that when they do access mental health services, there is little evidence that they are receiving NICE recommended treatments.

Care-experienced children usually haven’t gone through a short period of adversity, or a one-off incident. The majority have been in a traumatic environment for most of their lives, throughout their formative years. These circumstances leading to poor mental health would not be inevitable if such trauma-related issues were quickly identified, understood and treated.

Unaddressed trauma does not disappear with age. Today, one in three adult mental health problems relate directly to adverse childhood experiences. A parliamentary committee concluded that provision for care-experienced children with mental health concerns is often poor, inconsistent and inflexible, made worse by the denial of services to children who do not meet high thresholds.

It is important to remember that not all children who have suffered trauma will go on to develop related mental health issues. But it is also true that abuse and neglect are the most common reasons for children to enter the care system, and under the current system nine out of ten children who have been abused or neglected at a young age currently go on to develop a mental health problem by the age of 18.

Our position... Every opportunity must be taken to address and minimise the impact of trauma on the mental health and well-being of care-experienced children and young people.

Making it happen... Every care-experienced child and young person must have timely access to evidence-based support and understanding for trauma-related mental health needs. Social care staff should receive mandatory evidence-based training around the potential influence of trauma exposure on children’s development and well-being. Further, any service offering trauma-related mental health support to care-experienced children and young people should ensure assessments and treatments are evidence-based, including as captured by NICE guidelines.

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Mental health support must be immediate, at the point of a child entering care or even sooner where possible. Assessment and intervention must also remain proactive. Children who have experienced maltreatment may present with an absence of clinical-level problems for many years, but later develop significant mental health issues as a result of their earlier trauma.28

Trauma-related mental health difficulties, like post-traumatic stress disorder (PTSD), commonly result in children suffering internalising problems such as anxiety or depression, or externalising behaviour such as aggression.29 If left untreated, symptoms can be seriously debilitating for young people. Looked After Children nurses have shared with NYAS their frustrations that trauma is not always being recognised as a contributing factor to mental health that needs addressing, so diagnoses can focus too much on the symptoms rather than the cause of problems.

PTSD is seriously under-diagnosed for care-experienced children and young people.30 It can lead to children feeling unsafe at all times, which can be so destructive to their mental health. But PTSD is not a lifelong diagnosis if properly treated. Related issues can disappear with the right treatment, which is why NYAS feels that early identification and evidence-based treatment are crucial.

While some young people we work with still talk about the stigma associated with mental health, it is young people themselves who seem to be leading the conversation on it. While stigma has rightly been brought into the open and challenged, this has raised expectations that talking about mental health issues will result in effective support and treatment. In many cases, children and young people tell us that this expectation is far from the reality.

Responding to trauma case study

Social care were considering moving Michael (aged 16) to a specialised boarding school for emotional and educational needs which they felt were not being met by his current school and home. Due to a very traumatic childhood, Michael was desperate to stay with his foster carers whom he had lived with for several years.

An advocate supported him to write a letter of complaint about his wishes not being considered. As a result, he was allowed to stay in his foster placement but has still not been provided with the therapy he needs to deal with his childhood trauma.

I lose count of how many different social workers I’ve had. My entire life has been one big game of pass the parcel.
This is most clear when calling for ‘trauma-informed’ practices, which NYAS and many other charities have done. It is vital that services around young people, such as schools, social workers, police and carers, recognise and better manage the behavioural difficulties that can arise from trauma-related mental health issues. It must be recognised that trauma can increase young people’s vulnerability to gang involvement and exposure to violence, abuse and exploitation, which in turn can cause long term damage to their mental health and well-being.31

While there has been recent progress to make these services trauma-informed, more remains to be done. Without access to evidence-based treatments for trauma-related mental health issues, the efforts of schools and homes being trauma-informed will not be enough.

Young Minds are rightly calling for a national focus on preventing and addressing trauma and adverse childhood experiences, which NYAS supports.32
4. Positive childhood experiences

Our position... Everyone must have the opportunity to enjoy their childhood, not just survive it. We must build resilient networks and strive to enable positive experiences for care-experienced children and young people.

Making it happen... The Department for Education (England) and the Welsh Government (Wales) must create statutory guidance for professionals and carers on Positive Childhood Experiences. As part of that guidance, a ‘do no harm’ principle for services working with care-experienced children and young people should be introduced that recognises which professional decisions can harm mental health. This guidance should have an explicit focus on supporting care-experienced children and young people to lead fulfilling lives and reach their potential.

Adverse Childhood Experiences and Positive Childhood Experiences are two sides of the same coin - it is not enough just to take a child out of an adverse or traumatic environment and then assume their mental health will improve. Children need love and support in order to flourish.

Recent research in the USA showed that seven ‘Positive Childhood Experiences’ focused on safe, stable and nurturing relationships for children, can reduce the risk of poor mental health in adulthood.\(^{33}\)
Positive childhood experiences case study

Anna (aged 15) struggles with depression and mental health and experienced problems getting the necessary permission from social care to take a holiday with her parents as a reward after completing her GCSE exams. During these exam months Anna had a change in IRO (Independent Reviewing Officer), several changes in social worker and a change in the head of the social care department dealing with the permission decision.

After an advocate supported Anna with her complaint, it became clear that she did not have any Pathway Plan or a Personal Adviser, despite the law entitling her to both. After a lot of upset and anxiety, Anna was eventually given permission to go on holiday. All the additional stress had an impact on Anna's mental health and she felt she could have done better in her exams had the situation been handled better.

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These experiences improve the child’s ability to recover from or successfully cope with significant stresses, both within themselves or external to them, also known as becoming ‘resilient’. This does not mean it is up to children to become resilient themselves, but instead adults must look to build resilient networks of stability and support that target the child’s needs and give them the safety and opportunity to enjoy their childhood. If the Department for Education and Welsh Government introduced statutory guidance on Positive Childhood Experiences for corporate parents, professionals would be well equipped to both tackle adversity and give children and young people a springboard from which to flourish.

This is to recognise that even once removed from an adverse home environment, many children and young people in care continue to face instability that can negatively affect their mental health and ability to be resilient. Last year, 1 in 10 children in care experienced two or more home moves during the year, and just over 1 in 4 experienced two or more changes of social worker. Only 1 in 6 children in care experienced no change of home, school or social worker in the last two years. Their social support, considered important for young people who have experienced trauma, is often disrupted or inconsistent while they are in care.

That is why NYAS believes there must be a ‘do no harm’ principle for professionals supporting care-experienced children and young people, where guaranteed stability and support ensures that no child has their mental health negatively impacted by decisions made about them.

Just as doctors sign up to the principle of primum non nocere (“first, do no harm”), corporate parents should take a similar approach to protecting the mental health of their children. They have the resources and evidence-base needed to reduce instability, so recognising the serious harm that unstable environments can cause is an important step from adversity to positivity.

When I was a teenager I overdosed and was taken to hospital. I was discharged the following day. This was nearly four years ago and I still have not had any follow-up from professionals about my mental health. Social services have never spoken to me about it at all and I was left to my own devices. For my mental health I’ve had to be independent and resilient, and I’m so lucky to have had my foster family, friends and other people supporting me through it all. I really worry for those who aren’t so fortunate.
Moving home and carer while in care, known by professionals as ‘placement breakdown’, can lead to a cycle that further undermines a child’s resilience. More challenging or complex mental health and behavioural problems increase the risk of placement breakdown, and placement breakdown and moving to a new caregiver potentially further exacerbates insecurity and mental health problems. A University of Bath study recently found that instability in living arrangements was closely associated with long-term mental health issues for children, even above the risk from experiencing maltreatment.

There are also longer term consequences of professionals causing instability. As well as increasing the risk of a child experiencing sexual exploitation, moving children more frequently from their accommodation raises the chances of them going on to experience abuse in intimate relationships in early adulthood. It also makes it more likely that the young person is not going to be in education or employment. Each of these situations are linked to poor mental health, and so the professional decision to move a child must be mindful of the potential to directly cause poor mental health and poor outcomes for that child.

That is why, to repeat the view of a recent Chief Medical Officer, Governments in England and Wales need to invest in the protective factors that can act as a strong foundation for good mental health throughout our lives.

Appropriate relationships, including the unconditional love of a carer, act as a shield that provides the best possible protection from the risks of poor mental health.

Equipped with this, we can be sure that all care-experienced children and young people are supported to lead fulfilling lives and reach their potential.

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**Positive childhood experiences case study**

John, aged 16, was informed by children’s services that due to the compulsory closure of his local authority residential home, where he was very settled, he would need to move. John agreed to move into another residential home because he did not feel ready for semi-independent accommodation.

However, John really wanted to stay with the manager of his previous home who had opened a new home with a private provider. But he didn’t know he could speak up and ask for something different. Following the move, John became very isolated and withdrawn and advocacy support was offered to empower John to explain how he was feeling. The advocate supported John through a very lengthy complaints procedure where John showed children’s services the negative impact of the move. Due to the intervention of the advocate John was eventually allowed to move into the home with the previous manager and staff who were familiar to him, and is now thriving as a result of his positive living arrangements.
Recommendations

1. Advocacy

Our position... All children and young people have the right to have their voices heard in decisions made about them, including when understanding and navigating mental health services.

Making it happen... All children and young people receiving any tier of mental health support services should have an active (opt-out) offer of independent advocacy services, enshrined in legislation through amendments to the Children Act 1989 or Mental Health Act 1983. This offer of advocacy should also be available to all young people throughout their transition from Child and Adolescent Mental Health Services (CAMHS) to Adult Mental Health Services or support in the community.

2. Entering adulthood

Our position... When care-experienced children grow up, they continue to deserve the best possible protection and support for their mental health and well-being.

Making it happen... Every care-experienced young person’s Personal Adviser should prioritise support for the young person’s mental health and well-being as a key performance indicator. Mental health support must be proactive, preventative, and meet the mental health needs of the individual as they are leaving care. Where a child or young person is waiting for or denied access to CAMHS or adult mental health services, other support options must still be timely, tangible and led by a genuine dialogue with the young person.

3. Responding to trauma

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NYAS would like to acknowledge the time and effort of NYAS’ campaigns advisers in shaping this campaign, and using their own experiences of the care system to promote the well-being of all care-experienced children and young people.

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Consultant Child and Adolescent Psychiatrist, UCL Institute of Child Health

Danielle Shaw
Former Mental Health Project Worker, NYAS
This document aims to encourage all relevant politicians and decision-makers to improve public policy and legislation relating to the mental health and well-being of care-experienced children and young people. It is not intended to promote or support any particular political parties or candidates, and must not be used for this purpose.

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