

CARING FOR BETTER HEALTH: An investigation into the health needs of care leavers

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This report is the culmination of a 3 year project conducted by The Care Leavers Association and funded by the Department of Health Voluntary Sector Investment Programme.

The Care Leavers Association is a national user-led charity working to improve the lives of care leavers of all ages. We take the voice and experiences of care leavers and use this to improve policy and practice and to better able organisations to support care leavers with a wide range of issues.

The project team consisted of Jakeb Braden and David Graham with data analysis conducted by Carla Cordner. Dr Jim Goddard also contributed, alongside the team, to the final written report.

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We would like to thank all the care leavers who attended and participated in the health forums. Your honesty and insights helped produce a number of project resources.

And last but not least we would to thank all the care leavers who took part in the health survey. Thank you for sharing all your experiences, no matter how painful they may have been.

As well as this report, we will work to ensure that your voices are heard loud and clear and it leads to real change in the world.

Table of Contents

Executive Summary	4
Section Two: Introduction and Objectives	8
Section Three: Methodology	11
Section Four: Adult Care Leaver Survey	13
Section Five: Forums	26
Section Six: Professionals Survey	30
Section Seven: Seminars with Professionals	34
Section Eight :Cradle to Grave: Discussion	37
Section Nine: Recommendations	41
Section Ten: Final Thoughts	44
References	45

When asked about experiencing low self-esteem during care 87% (312) said they had. 83% (295) said they experienced this after leaving care



Executive Summary

The health and wellbeing needs of care leavers of all ages are largely ignored. Research tells us that looked after children are far more likely to experience negative mental health and physical health issues than their non-care peers. Yet when that child in care becomes a care leaver, and the care leaver becomes an adult, any support that did exist stops. Services become tapered. Access criteria rise. Waiting lists go up. Its as if the state apparatus conveniently forgets everything that went on in the young persons life before and during care. A key conclusion from this project is that we must stop looking at the care system in silos and instead focus on the journey of a whole life and how everything joins and fits together.

We must think about the experiences of adult care leavers and work out how to prevent them earlier in childhood. Its not rocket science. But it requires effort and commitment.

This report attempts to address the problems that arise from this act of collective amnesia. It is a summary of work carried out by The Care Leavers Association, with funding from the UK Department of Health, during the period 2014-2017. We sought the views of both care leavers and professionals on how health services can be improved to better meet the needs of

care leavers of all ages. In stretching our focus across the life – well beyond the usual focus on care leavers between the ages of 16 and 25 - we offer unique insights into the long-term consequences of the relative neglect of health care issues for this group.

We aimed to work closely with ten CCGs by setting up local working groups to explore care leaver health needs in each area. We ended up working with more than ten CCGs, some for the full period of the project and others for less. The working groups also provided us with support in relation to other stages of the project and helped us to place our recommendations within a health commissioning context.

During the project, we developed the most comprehensive survey of its kind of the health needs of care leavers. This was completed by 418 care leavers of all ages. This report highlights some of our key initial findings and conclusions and more comprehensive treatment of the data will be released after further analysis. The high numbers in our survey who experienced low self-esteem, anxiety, depression and isolation are consistent with other research on care leavers and highlight the prominence of mental health issues in our findings. The continuation of these experiences over several decades, in some cases, highlights the importance of

addressing the causal factors as early as possible. In some cases, if young care leaver adults are given the skills, strategies and support to deal with mental distress it could significantly enhance their later lives.

We also listened to care leavers directly through our health forums and to professionals currently working in the field through our health seminars. Through both of these routes, some key themes arose. Both younger and older care leavers spoke repeatedly about the debilitating effects of feeling isolated from others and having limited social connections within the community. Transition periods were also highlighted as important, stages where an individual is more vulnerable but may receive less or insufficient support. Problems with accessing mental health services were also raised several times, with services either having too high access criteria or not able to adequately support care leavers. There was a broad sense amongst care leavers we spoke to that the health care system took inadequate account of the lifelong effects of trauma that is a frequent legacy of a child's journey into and through the care system. Support for adult care leavers in their thirties and beyond, for example, remains limited.

The combined findings of the research techniques deployed by this project has led to a number of recommendations designed to improve the commissioning process and improve health outcomes for care leavers:

1. The health needs of looked after children and care leavers to be a distinct section in the Joint Strategic Needs Assessment (JSNA). This should, if possible be extended to adults aged 25+
2. Each CCG area to conduct formal assessment of health needs of looked after children and care leavers
3. Commissioning of all mainstream health services to include targets for improving health outcomes for children in care and care leavers.
4. Commission a range of mental health and wellbeing services, from low level to psychiatric, that specifically support looked after children and care leavers.
5. Ensure that care leaver health needs are identified in broader commissioning processes.
6. That a young person in care has a comprehensive health assessment at entry into care which is then monitored and updated on a regular basis
7. Health assessments should focus on mental health and wellbeing as well as physical health.
8. All local authorities to appoint a Mental Health and Wellbeing lead
9. Implement a protocol to support placement stability

10. Improved training for all staff (social workers, foster carers, residential workers) to better respond to a young persons needs not their behaviour.
11. All social care professionals to have training on attachment and trauma theory.
12. Deliver a range of emotional wellbeing and self-development interventions to young people
13. Increase the availability of therapeutic placements.
14. Reduce waiting times and increase opportunities to access mental health intervention for looked after children and care leavers
15. All care leavers 18-25 to receive a health assessment as part of the pathway plan
16. Care leavers to be given priority status in relation to accessing health services
17. At 18 services continue and any young person in care is being treated with a stage not age approach so whether 17 or 20 they access the same service with the same access criteria.
18. Increase the status of the PA role and provide improved training and support to all PA's
19. All local authorities to have a mentoring/coaching/befriending service for care leavers
20. Increase the statutory requirement to provide accommodation for care leavers to 25
21. All care leavers to be provided with free access to health records alongside their social care file
22. Implement guidance on care leaver involvement and participation in the design and delivery of services
23. Deliver a range of emotional wellbeing and self-development interventions to young people
24. The health of adult care leavers (25+) to be recognised as a specific area of focus for mainstream health services.
25. All health services and professionals need to have an understanding of the care experience and how it can affect a persons health at any stage in life.
26. Develop guidance and support for health services in relation to working with adult care leavers.
27. Improved training on mental health needs and ACE's research for frontline health professionals
28. Increase access to IAPT services for adult care leavers.



29. **Fast track access to talking therapies for care leavers**
30. **All CCG's to appoint a champion for the health needs of care leavers (of all ages)**
31. **Commission a range of health and wellbeing support services for care leavers including emotional wellbeing, self-development interventions and mentoring/befriending**
32. **Commission services widely to reduce isolation**

There is much work to be done. Listening to some of the experiences from care leavers was extremely harrowing. Yet it was also inspiring to see the amount of people prepared to be courageous and attempt to make a difference to their own lives, no matter how challenging. Sometimes even though the system is well meaning it can do more harm. We must take stock and reverse this situation. We need to ensure that we view the path into, through and after care as a life journey and build our responses to meet needs throughout this life journey. All policy makers and practitioners must have a better understanding of the experiences of young people in care and care leavers. We must respond positively to what is really happening in the daily lives of care leavers. Service commissioning needs to be needs led, but it also must provide the best outcomes for care leavers. Historically this has not happened well enough. The health sector and the social care sector must get better at working together and developing joint initiatives that not only focus on care leavers health and wellbeing but provide positive, loving and nurturing opportunities.

We want thriving, not just surviving.

Section Two: Introduction and Objectives

Young people leaving care constitute one of the most vulnerable groups in our society. However, outcomes for care leavers remain much worse than for their counterparts in the general population (H.M. Government, 2016: 6)

A quote from the UK government's care leaver strategy from 2016 considers the need to improve health care support in relation to both physical and mental health, acknowledging that care leavers face a disproportionate range of challenges and issues in both areas. However, the government's approach is based on a limited understanding of the health issues that care leavers face and is only focussed on care leavers up to the age of 25. This report remedies those twin deficits by being the largest-ever investigation of the health needs and experiences of care leavers of all ages.

The vision of The Care Leavers

Association is the achievement of 'A good life in care and a good life after care' for all who go through the child care system. We are unique in being run by, and focussed on the needs and experiences of, care leavers of all ages. We recognise that many issues faced by care leavers, including physical and mental health, stretch across the life course and are best understood within that wider framework. This research report reflects that understanding.

Background

There is a relative lack of research on the health outcomes of care leavers, especially of those over the age of 25. There is more research into the health of looked after children and in particular their mental health. An influential study conducted by Meltzer and colleagues (2003) suggested that 45% of the looked after population could be diagnosed with at least one psychiatric diagnosis, rising to 72% for those in residential care, in comparison to around ten percent of the overall population of young people (Meltzer et al., 2000). It is safe to assume that a number of those looked after children will continue to experience mental health issues as care leavers.

Indeed there is research to show that a significant number of care leavers continue to experience mental health difficulties, such as depression, long after leaving the care system (her use of national child development data stretched up to age 33) and to a higher degree than other disadvantaged groups (Buchanan, 1999). The most recent study into the mental health needs of care leavers, a review by Barnardo's of 274 of their care leaver case files, showed high numbers (46%) with mental health needs (Smith, 2017). The Barnardo's report highlights issues with drugs, alcohol, self-harm and post-traumatic stress disorder and it emphasises the findings of several previous

studies (Lynes and Goddard, 1995; Richardson and Joughin, 2000; Broad, 2005; Goddard and Barrett, 2007). In short, we already know a great deal about the health problems that looked after children and young care leavers face.

Less well known is research on the long-term health experiences of adult care leavers. In truth, there is far less of such research. Aside from Buchanan's (1996) and recent studies of the long-term effects on survivors of abuse in the care system (e.g. Penglase, 2007). Those which have appeared have focussed on general issues or specific areas of the lives of care leavers that are either tangentially or unrelated to health issues (e.g. Murray, 2015).

However, research more broadly on the survival of childhood trauma has obvious relevance to adult care leavers and such research has mushroomed in recent years, partly fuelled by developments in neuroscience and their application to a spate of subject areas. The early work on Complex Post-traumatic Stress Disorder of Herman (Herman, 1992) and others has informed our analysis. Perhaps the best-known body of research is that conducted primarily in the USA under the banner of the ACE (Adverse Child Experiences) Study (e.g. Felitti et. al. 1998). These studies focus on health and disease in adulthood, and associated risky behaviours, and seek to explore the links between adult experiences and the exposure to childhood abuse, family dysfunction and trauma. Such sources have

also influenced our thinking and analysis.

The Project

The wider research findings concurred with our long experience of working with hundreds of adult care leavers over many years. We were aware, however, of a major gap in the research field with respect to care leavers beyond their mid-twenties (Buchanan's relatively small-scale study notwithstanding). For this reason, The Care Leavers Association applied to the Department of Health in 2013 for funding of a project designed to provide a research base for improving the physical and mental health of care leavers of all ages. A key project aim was to ensure that National Health Service (NHS) Clinical Commissioning Groups (CCGs) and other health professionals in a variety of contexts become more aware of the health issues facing care leavers of all ages and how best to address them. There were four main elements to the project:

- To work with 10 CCGs in England on increasing the awareness amongst their workforce of health issues affecting care leavers
- To conduct an in-depth survey of care leavers of all ages on the health needs of care leavers
- To establish user-voice care leaver forums across England, to provide further care leaver input into the project

- To produce resources and a final report that would encourage more effective support regarding the health care needs of care leavers

The project changed slightly in scope in response to circumstances. The main change was that it took longer than expected to start the project due to initial difficulties in engaging

Section Three: Methodology

In adopting a methodology for our research project we chose tools that would best achieve our objectives of understanding care leaver health issues across the life course and providing useful advice for health practitioners and policy-makers about how best to meet the needs of care leavers.

With that in mind, we adapted a multi-methods approach familiar to one of the authors (Lynes and Goddard, 1995; Goddard and Barrett, 2007) to surveying care leavers and looked after children to include a wider focus that included the views and experiences of health care practitioners. Central to our approach with adult care leavers was encouraging them to provide us with a narrative account of their perceived relationship between past and present with respect to health. To that end, we sought both quantitative and qualitative data. However, unlike the earlier surveys cited above, we also sought to survey health practitioners. In that, our approach was similar to that of Smith for Barnardo's (2017). However, we went much further than Barnardo's survey in our interaction with both care leavers and health practitioners. The basic approach is set out below.

1. An online survey (using Survey Monkey) sent to as many care leavers as possible. We used several sources for reaching our intended audience: a) our several hundred care leaver members, b) the several thousand care leaver members of our 'Careleaversreunited' web-

site, c) a range of related organisations who we encouraged to promote and forward our survey, d) various social media tools by which we seek to reach care leavers of all ages. As a result, we gained questionnaire responses from 418 care leavers of all ages. This result is unique in both the numbers of care leavers reached in a survey of this kind and in gaining responses from care leavers of all ages (almost half of the respondents were aged over 40).

2. Care leaver forums (we eschewed the term 'focus groups' as we wanted the discussions to be more free-ranging as befitted both subject and those surveyed). We established three of these; in Manchester, Birmingham and London. The groups met quarterly under the guidance of the key worker on the project, Jakeb Braden. Most meetings were held on weekday evenings and some on Saturdays. We invited respondents to the online health survey to attend the forums. In total, through this means, we engaged with 70 individuals.
3. An online survey of health professionals. The idea for this survey occurred after the surprisingly large number of care leaver responses was received. We believed that we could, by the same means, reach a significant number of health professionals. It helped that we were

already building up a healthy number of health service contacts through our work with the 10 CCGs we were already engaged with. The questionnaire used (see appendix) was developed with the help of health professionals and distributed both via CCGs and a number of other health networks that we were engaged with. We achieved 215 responses. The vast majority, as expected, worked in a health context either with looked after children, care leavers up to the age of 25 or both. Only a small number (13, or 6%) worked with care leavers over the age of 25.

Seminars with health and related professionals (such as leaving care workers). We held five of these across the UK at about the halfway stage of the project. We wanted to discuss our emerging findings, promote those findings and develop our thinking about the interaction between those findings and the work that health professionals were doing with care leavers. The seminars took place in London (two), Manchester, South Tees and Milton Keynes. A total of 63 people attended the seminars. Attendance included designated nurses, leaving care workers, mental health workers, Personal Advisers to care leavers and service commissioners.

These four sources of data were sought at various times from late 2015 through to mid-2017, with data analysis taking place throughout 2017.

Ethical Issues

The Care Leavers Association has long experience of working with care leavers of all ages. We have held many meetings of such care leavers, assisted them with individual problems and addressed sensitive issues in a variety of contexts. This means that we were already familiar with a variety of organisations to whom to refer care leavers in the event that his proved necessary. Very few challenges were thrown up in this respect.

Representativeness

With neither the care leaver survey nor the survey of professionals did we seek to stratify the sample. This is more pertinent to the survey of care leavers, since we were seeking a good deal of detail from them about their experiences across the life course. We can see from the responses that we got a wide range of ages, enabling us to analyse our data by comparing age groups. This is useful for assessing the persistence or otherwise of problems over time. The most obvious difference between our population of respondents and that of the population of care leavers as a whole relates to gender, where we had twice as many female respondents as male. This is a well-known phenomenon in surveys and its relevance here is that we know that health problems differ markedly by gender, particularly mental health problems.

Overall, our survey sought to develop a multi-faceted approach that would give us the best prospects of having sufficient data to be able to add fresh insight into the health problems of care leavers of all ages and fresh proposals as to how these might be addressed. As we can see in what follows and in our conclusions, we succeeded on both counts.

Section Four: Adult Care Leaver Survey

The centrepiece of our research was our survey of the views and experiences of adult care leavers. Given the large number of respondents, this was a uniquely valuable contribution to discussion about the health experiences and journeys of care leavers across the life course. As we will see, a good deal of the findings and discussion focus on mental health issues.

The health survey was completed by 418 care leavers. As noted in the methodology section, this was not a stratified sample so due caution needs to be adopted in interpreting the results. For example, an internet survey is, by its nature, biased in favour of technologically-literate respondents. However, the survey offers us the opportunity to see two things: 1) the wide range of health issues care leavers can experience, 2) how these health issues can evolve, persist and progress over time and how their etiology is perceived and explained by those experiencing them.

The information below sets out the demographic data we sought at the start of our survey (the actual questionnaire can be found in the appendices at the end of this report). Percentages have, where useful, been rounded up to whole numbers.

Gender

Male: 33% (134) Female: 67% (276)

Age

Under 16: 0.24% (1), 16-24:34%, (139)
25-30: 9% (37), 31-40:8% (34),
41-50: 17% (70), 51-60: 18% (73),
61-70: 7.76% (31), 70+: 6% (26)

Ethnicity

White British: 81% (332), Asian 2% (10),
Black 7.5% (31), Mixed 7.5% (31),
Other 2% (7)

Sexuality

Heterosexual: 86% (345), Gay: 4% (18),
Lesbian: 3% (13), Bisexual: 7% (27)

Disability

Yes: 3% (11), No: 70% (283)

Marital Status

Single:62%, (253), Married: 32% (130),
Civil Partnership:6% (26)

Placement

Foster care; 29% (119),
Residential care:32% (132), Both:39% (161)

Our Respondents

The question of how representative our sample is has been dealt with in the previous chapter. However, a few further points are worth emphasising here.

Firstly, most respondents being female marks a difference with the balance of genders in the care system both past and present (for example, data for England on looked after children shows a gender split of approximately 55% male and 45% female from 2013 to 2017). This is important for our findings since we know that male and female health issues, both mental and

physical, often differ markedly and this is reflected in the discussion of health problems by our respondents.

Secondly, the high number of our respondents aged over 40 (200) allows us to consider the lifelong persistence of health issues connected with the care experience. This is important given how little data we have on older care leavers generally, let alone on their health.

Thirdly, the relatively high number of our respondents who had experienced residential care reflects the wide age range of our sample. At least 30% of them would have been in care before the mid-1980s at the latest, when residential child care was far more extensive than at present. For example, in 1985 there were 69,000 looked after children in England. Of these, 34,800 were in foster care and 16,100 in residential care (Hayden and Goddard et. al., 36). This itself was a significant drop in the residential population over previous years.

Lastly, we had a higher representation of LGBT care leavers than is indicated in the general population. Again this gives us good data to inform discussions related to a particularly disadvantaged group within the care system.

Questionnaire Responses

We asked several questions related to aspects of mental and physical health, beginning with “have you experienced...”. We also asked care leavers to consider

the time before care, during care and after care. The ‘before care’ responses demand memories and knowledge (e.g. through care files) which many care leavers do not have. However, since most looked after children enter care due to abuse and/or neglect in the home we believed it important to allow our respondents to comment on their life before care and the care system response to this. We collated our data in two important ways:

- Unless before-care data seemed significant, we focussed on the in-care and post-care data since this was more readily available;
- We combined responses for experiencing an issue sometimes, often or all of the time unless this threatened to over-simplify the analysis.

We gave our respondents the opportunity to expand on their answers and many did so. This qualitative data highlights aspects of health journeys captured by no other research in this field; in particular, the persistence of some issues for decades after leaving care. As usual in such surveys, not all respondents answered all questions.

Health Questions

Here we have highlighted the most important responses in relation to the issues we were addressing through this research and which we are already familiar with from our work with adult care leavers over many years.

'I have experienced low self-esteem...'

Several factors affecting self-esteem are related to going into care (such as family breakdown, abuse and neglect), the experience of care (multiple moves, rejection, isolation, stigma, lack of personal care) and life after care (unemployment, lack of educational qualifications, isolation).

While we don't know if those with low self-esteem may have been more or less likely to answer questions on such a topic, these figures are hardly surprising in light of previous research.

What is more interesting is that our respondents frame their answers in complex ways and in many cases it quickly becomes clear that one physical or mental health or wellbeing issue is intimately interrelated with a range of others both past and present. As one respondent noted, leaving care itself can be an anxiety-provoking experience.

"As a vulnerable person i have always seeked acceptance & I have never believed in myself as my past trauma has lead me to always blame myself and put immense pressure on changing, working to better mental health when really a lot of situations are not fault of mine. I have lacked mental control ever since I remembered but now it causes me huge problems within spending uncontrollably & addictively repeating patterns in my day to day life."



"I had a really tough time in care, I fell in love! I was all over the national papers! Through no choice of mine! I still struggle to this day that he is living a lavish life and I've been left with a mental illness, sleepless nights, low self esteem, and totally over paranoid about my own daughter! It's soooo unfair."

Experiencing anxiety on occasion is a

"I think I would have benefited from having some therapy to help me process my mother deserting the family prior to my time in care... it was never talked about and many problems in adult life (low esteem etc) are connected to this experience."

normal part of life, of course, so these responses are likely to cover the range from normal to extreme degrees of anxiety. However, once again the details of the later qualitative responses reveal more about the contextual factors linked to the anxiety and the different ways in which such anxiety expresses itself,

One of the notable features of this and other responses is that the rate of experience of certain mental health difficulties differs little from the in-care period to the post-care period. Again, given we are covering care leavers across the life course and, given that almost half our respondents are aged over 40, this suggests that untreated abuse, neglect and other traumatic and damaging early childhood experiences can have major and lifelong consequences.

“We need support with the anxiety of leaving care and facing the world on your own.”

As noted earlier, one of the earliest discussions of mental health amongst older care leavers, that by Anne Buchanan (Buchanan, 1999), found that care leavers at the age of 33 were the socially disadvantaged group most likely to be experiencing depression at that age of 33 were the socially disadvantaged group most likely to be experiencing depression at that age.



“I have a diagnosis of anxiety and depression as a result of my abusive childhood”

“I get anxiety a lot when something stresses me out. I also find myself crying when I am by myself so I feel to need [for] company all the time.”

“I would like counselling to help me understand my anxiety but I cannot afford it. I think care leavers should have priority to counselling services.”



“I think I’ve probably lived with some sort of depression for most of my life, due in large part to my childhood having been spent in care. I recently acquired my care file, and a prevalent theme in the reports I’ve read is of me being described as a “Sad, little boy.” In truth, I don’t think anyone really knew just how sad I was. I had a big issue with drugs and alcohol for a long time, I’d cut myself a number of times, I’ve had a few panic attacks which resulted in me going to hospital as it felt like I was dying.”



Again, it is the meaning of isolation in the context of the care system that is most important here. Isolation experienced as a result of being in care can have multiple causes with compound effects. For example, a neglectful or abusive family home is often an isolating one and the subsequent admission to care often isolates children further from their previous family and neighbourhood. Other children in care are often non-siblings, thus creating the

illusion of family bonds where none exist, and problems of stigma and shame can produce further isolation at school. Unemployment and the relatively early age of leaving care can add further causes of isolation, until an isolated lifestyle becomes a habit rather than merely a difficult but temporary experience.

“I am appalled that there is so little support available for people who grew up in care and have been affected for life by their experiences. I feel very alone in the world. People go on all the time about the importance of family, and I feel like an outsider. Very few people understand the issues.”

“Well I feel utterly let down by the lack of support surrounding my health. Being diagnosed with Multiple Sclerosis at the age of 21 at a time where my health was deteriorating considerably, both physically and understandably mentally; I was told I was ‘too old’ for support. I felt utterly isolated and completely hopeless for my future. I asked to be put in touch with MH services and was told that there isn’t services available to me and I would have to go to the doctors for them to refer me to counselling. Leaving care is the worst time for you emotionally and is a time when you should be getting most support, not a lack of.”

“I’ve isolated myself from people and I do not socialise at all. I avoid busy times in town, or shops. I don’t drink often, and when I do I have to be in trusted company. I have persistent nightmares which wake me and I have trouble sleeping. This then effects the following day’s activities. There is a distinct failure, no a total lack of understanding of the lifelong effects of abuse and living in care issues. This is also true in the Mental Health I often hear this. Relationships are hard or impossible.”

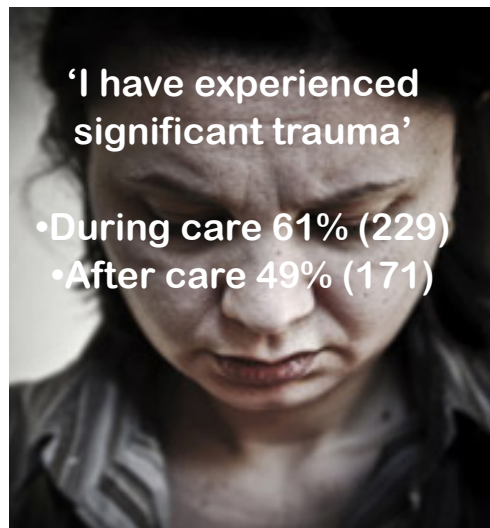


As noted elsewhere, emotional dysregulation is a common response to childhood abuse, neglect and trauma so it is no surprise to see anger management issues feature highly amongst our responses. Indeed, one of the primary roles of parents is to teach children how to regulate their emotions so the mere absence of personal care, even without subsequent abuse and neglect, is likely to lead to weaker emotional control.

“First of all about the anger. I worry all the time because although I have never lost my temper to the extent that I have been violent to others, I feel all the time that I am like a ticking bomb. The only reason I keep control because of fear that has been drilled into me. In Steal I was always falling down stairs and my sister was made to put my shoes on even though they were too small, when I was in the bath I had my feet scrubbed with a wooded brush till they bled”

Others provided examples of how such emotional control issues had continued long after the care experience, blighting their lives. For example:

“Into care when I was 6 after my mother had died and my father had been jailed for sexually abusing my sisters while my mum was dying of cancer... After living in four children’s homes and three foster placements (one of which was brilliant and life-changing). My social worker was excellent but I had suffered so much that I suffered from anger, anxiety and depression and general PTS until my mid 40s when I finally cracked and went for two years of self-funded psychotherapy costing £10,000). I get the odd bout of AAD and then but have largely recovered and met my current partner when I was 49 and the relationship works well. Two decades lost through to mental health problems that could have been dealt with much earlier on.”



Large-scale trauma before care is, of course, the major background to admission to the care system in the first place. The act of being admitted to care – the disruption of being removed from all or almost all social and neighbourhood ties – is a second experience of trauma. The history of the care system experienced by large numbers

of our respondents suggests many further opportunities for repeated trauma (such as amongst those who experience multiple moves). The more developed responses we received are consistent with academic studies of the nature and effects of trauma (e.g. Lanius et.al., 2010

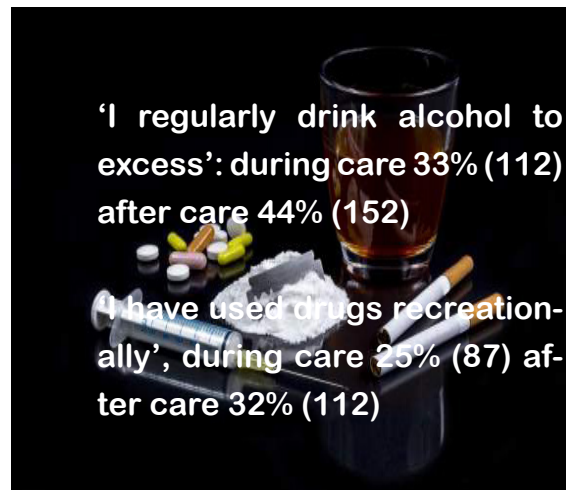
“Like I said in answer to a previous question, being taken into care, away from my home, family, friends and school, I was effectively punished for my father’s crimes. No one sought to correct that perception in my mind that I was somehow to blame, it was my fault. I’m still left with feelings of shame even now. And like I also said, I was the one who was left stigmatised, being a care leaver/ gym slip mum was held against me during care proceedings about my daughter, the fact that my father had battered me wasn’t held against him, he was still the model of ‘respectability’, being a working, married man, homeowner, etc. It’s so twisted, it’s really fucked up how care leavers end up being stigmatised, how there’s this taboo. And it doesn’t help to have been moved round like a piece of furniture, chucked out with your rubbish bags of all your worldly goods, treated like trash.”

“I do believe that the temporary and often mobile nature of my time in care in different homes made me feel a little like a traveller with nothing permanent - which might be why I joined the Army. My Army life was good, and while still very mobile, was relatively stable until I was married when things went downhill. I never sought help in those years, as the Army at the time, regarded anyone who came forward as a ‘welfare case’ which might have affected my career or promotion prospects. I can see in retrospect that this was a reaction to the nature of my childhood and time in care.”

“Because of the constant fear I had while in care and even since that time it has affected my ability to learn and remember (not to do with mini stroke).. It has therefore affected my confidence and in its own way creates it’s own mental health issues the mind just freezes up and it is practically impossible to remember and in turn to learn to it affects your education.”

Alcohol and Drug Use

We asked about alcohol and illegal drug use and got the following findings:



As noted earlier, excess consumption of alcohol has been reported in previous research on the health needs of care leavers. Qualitative contributions on the subject included the following:

"I became a mum at 17 found it stressfully at times, lived in a flat, shoplifting gang, drug, alcohol abuse, have many boyfriend, had depression, counselling, was very angry when younger, but I did have a good experience while in care, no aftercare support at all, found my way on my own by experience and mistakes, now I have a degree aged 45 and now work at clan. Admin, not watt I want but it's a decent pay. I'm seen as a role model in my local community, I never gave up and that education can open doors. Now I'm 48 and single again, must be attachment and relationship issues because if a boyfriend falls out with me I end it and move on emotionally very quickly."

"I was kicked out of SS care when I hit 16 as my "voluntary" care order was over. I was given no support and left to fend for myself. I quickly got heavily into drugs. Drugs have been a blight on much of my life, although they also helped me deal with the feelings of inadequacy that were left from my time spent in care."

“I feel grossly betrayed by the social service that was supposed to be acting with my best interests at heart. At times I feel like my particular case was too much of a hassle for their department to constantly deal with, and as such a slipped through the proverbial cracks and as soon as I reached 16 (even though I’d been showing signs for many years that I was on a steady decline) I was dropped like a hot coal, and simply left to my own devices. What followed was a tumultuous period of about 10 years during which, due to alcohol and drug abuse, I came very close to dying. I made it through, obviously, and I’m not doing too badly for myself now but none of that can be credited to the help or care I recieved.”

Alcohol and drug use could be linked to self-harm. One respondent linked them explicitly – “Self-harm, the way I took drugs n drink to get obliterated was my form of self-harm” – and in response to a general question - ‘



The links between the care experience and post-care life

The literature on the long-term effects of childhood trauma is now vast and demonstrates that cumulative childhood experiences of abuse, neglect and trauma can work themselves out through adult life

over several decades. The accounts of our respondents often concur with this literature. For example, in relation to Question 30, on the experience of physical health problems, several of our respondents made direct references to the links between past and present:

“I have several physical health issues as well as mental health. I would attribute some as a result of my experiences in care. Personally I felt I received an utter lack of support in and out of care.”

“Lack of dental treatment led to me losing all my teeth by age 27. I broke my arm very badly at aged 7 and it wasn’t set properly. Operated on when I was 11 but it was shorter by then so was bullied. I was always hungry at home. My periods were appalling and I had a hysterectomy at age 29 and several repairs to sort internal damage.”

“I have been diagnosed with fibromyalgia which I believe to be directly related to my early life trauma. I believe I have severe pain headaches etc the list is endless. I liken it this. When I was in care I was often locked in a shed. I can’t bear confined spaces. I used to be dragged up the stairs by my hair. I suffer daily headaches. Just those two things and there are several more, make me think that is why I can’t bear being in a locked room, and have headaches my hair actually hurts. Maybe someone should tell me why I believe it to be because of my experiences maybe I am wrong and they could give me an explanation as to why I would be wrong.”

With over 60% of children entering the care system due to neglect and abuse, this may well result in mental and physical illness at various stages in life. That being said, the care system itself can cause unintended harm to young people. Placement breakdown and frequent moves, a lack of care and attention, and the lack of voice and control in decision-making can all have an effect on a person’s mental and physical health. Furthermore, where issues do arise, they are often not picked up within the care system nor are they given sufficient attention and resolved.

As such we asked care leavers if they thought the care system had contributed to both mental and physical ill health (questions 20 and 29)

Mental Health	Physical Health
Yes 54% (192)	Yes 19% (64)
No 23% (82)	No 56% (187)
Don’t Know 23% (81)	Don’t Know 23% (81)

This result is both explains and justifies our methodology, reflecting the experience of the Care Leavers Association, over many years, of encountering care leaver of all ages ascribing some of the present problems to experiences in the care system. Of course, it is quite possible that the ascription of origin to care system experiences may be wrong, given the levels of abuse and neglect that often led to entry to care, but the narrative itself is important. We received the following elaborations on these responses:

“In the residential home I was placed in we were unable to leave the house unless accompanied by a member of staff. As there were never enough staff on duty this often meant we were forced to stay indoors. As a very active person I struggled with this, and the lack of physical activity or exercise we were able to do. Before being in care I was competing in a wide range of sports, however in care I was unable to do any of this, and gained a large amount of weight - which contributed to my low self-esteem- as I felt uncomfortable in myself and unable to do the things I enjoy”

“I have several physical health issues as well as mental health. I would attribute some as a result of my experiences in care. Personally I felt I received an utter lack of support in and out of care.”

Links between Growing Up in Care and Entering Custody

It has long been known that there are a disproportionate number of care leavers in the prison system, so we chose to ask a few questions related to custody and health. 33% (138) of respondents indicated they had experienced some form of custody. Of these, 65% indicated that they were not asked about their care status in custody, and 66% (94) reported that their mental health was not assessed at any time in

custody. This is not surprising, since it is only in recent years that links between care and prison have been addressed by researchers and policy-makers in the UK. A number of respondents expanded on how they saw the link between mental health issues and custody:

“I also spent some time in prison on remand, the prison did assess my mental health”

“I have been arrested in a police cell before due to my anger managements”

“I have been arrested on many occasions when my mental health is unwell, but I see them as safety and they won't hurt me”

Conclusion

We asked our respondents to suggest possible improvements and some of the feedback (88 responded to this request) confirmed our own experience of the inadequacies of past and present leaving care experiences and their long-term impact. Some spoke of being 'abandoned' and of the long-term development of young people being damaged by inadequate support. Others felt their health needs were ignored or mental health issues made worse.

The reasons for some of the problems are familiar from the wider leaving care literature – frequent moves, lack of consultation, stigma and isolation. The field of research linking the experience of childhood abuse to adult mental health problems is now vast (e.g. Herman, 1992; Felitti et. al., 1998).

That so many of our adult respondents of all ages were still dealing with the effects of childhood abuse is therefore unsurprising, but it raises the question of what mental health or therapeutic interventions took place whilst they were in care to address the known problems of abuse that had led many into the care system. Since it is only in recent decades that the mental health needs of children have begun to be addressed, it is unsurprising to find so much unmet mental health support needs amongst older respondents in our survey.

Section Five: Forums

A key element of the project centred on increasing the user voice to improve commissioning of health services for adult care leavers. To this end, we established three User Voice Forums in Manchester, Birmingham and London. Once established towards the end of Year 1 of the projects, the forums met quarterly. Most meetings were held on a weekday evening and some on a Saturday. We invited people to attend the forums from those who had undertaken the health survey, and through our website and networks. In total we engaged with 70 people.

Meetings were typically informal, with a city centre venue and refreshments provided. They would last for about two hours and discussion facilitated by the health project worker, who also took notes. Personal experiences were shared, but we also invited comments on our overall objects and the direction and early findings of the project. In the initial forums we explored the health journey of individual adult care leavers from care to adulthood. Issues discussed were in relation to specific questions that we repeated at all of the forums. The feedback we received at these meetings is summarised below each question.

What does good health mean to you?

- A large number of comments focussed on emotional wellbeing, such as: Emotional stability; Belonging; having Self-awareness, understanding and knowledge; having

choices over emotional, social and physical health; Permanence; Being in a good place physically and emotionally; Social health, social connection; thriving not surviving

- Other responses focussed on the activities of agencies: Not being pathologised; Having a voice; having choices; support to maintain that good health
- Others had specific goals: Good solid physical health; being healthy enough to do what I want to do

How would you describe your care experience?

Given the work of The Care Leavers' Association in this field over many years, few of the wide range of responses on this question surprised us. Two key themes that emerged were high degrees of emotional isolation and instability due to frequent moves:

- People doing things to you; being sent home to abusive parents at weekends; new kids coming and changing the dynamics of the home/family; unstable; residential care gave me some stability; traumatic first ten years; remote, cold, institutionalised; being moved without warning; friendships compromised by being moved around; profound emotional sadness; very good until a new foster child arrived we fought and I was sent to respite

How did your experience in care impact on your health?

We sought to explicitly address the central issue of the project and received the following responses. They confirmed the findings of our survey of adult care leavers and in some cases elaborated on them:

- Self-destruction; very ill; moving about a lot changing doctors etc.; low self-esteem; chronic illness (when I look back it's linked to childhood trauma); guilt and fear about being in care; physically there was no impact, but mentally and emotionally there was; mental health issues came out in care; self-harming; medication – being forced to take it, even though I didn't have the condition it was for; huge impact on my mental health.

How would you describe your health history?

Again, themes of isolation and disruption, particularly around the transition from being in care to leaving care emerged:

- With regards to physical health, a post-18 misdiagnosis on a couple of occasions; my care worker not supporting me post-18 (e.g. with doctor's appointments, advocacy etc.); dealing with all health issues on your own; no after-care support; next of kin – who do I put? Feeling like I am imposing on people; CAMHS gave me an ADHD diagnosis and a second opinion said I didn't have ADHD; the trauma of being in care; my children being taken away; transition being an issue, with

services ending at 18; being forced to take medication with no say in it; needing coordinated support; a lack of understanding about vulnerability; being passed from pillar to post; the transition - I didn't know I could still access some services

Where are there gaps in services?

We are seeking to identify solutions as well as problems, so we specifically asked our forum members to advise us on this:

- Access to services post-18, a 'stage not age' approach is needed; knowing what are the key health issues for care leavers; improving CAMHS and access to MH services; misdiagnosis seems very common, including the labelling of looked after children with a condition, e.g. ADHD; less reliance on medication and a more holistic approach, e.g. using art and drama therapy; remove the restrictions on how many support sessions you can have; the transition to adult care has so many gaps, issues and barriers.

Other Issues

As well as the specific points above, several other key themes emerged during the course of these discussions. Firstly, in looking back on their lives many of the care leavers we spoke with expressed anger at the process of going into care, claiming that it hadn't been explained properly to them or that they were not supported through it.

Some argued that the trauma of that experience was pushed under the emotional carpet and subsequently came out later in life as anger, grief and various forms of emotional distress. The term “institutionalisation” was frequently used. Many older care leavers described a care setting devoid of love, attention and other normal expectations of children. However, some younger care leavers also noted a lack of love and care in their care experience.

In relation to leaving care, the key issue raised was isolation. There was often a sense of “being left to fend for myself”. Care leavers talked of struggling to deal with everyday life and this having significant effects on their health. When they sought to access health support they perceived a lack of understanding of their care experience.

The forum meetings that we held towards the end of the project (i.e. in early 2017) concentrated on developing recommendations for the project report and on developing and designing a resource to improve commissioning.



Section Six: Professionals Survey

As well as surveying adult care leavers on their health experience, we felt it would be beneficial to explore the views of health professionals. We therefore undertook a similar online survey to evaluate the level of knowledge of care leaver health needs amongst those most likely to work with care leavers in a professional capacity.

We developed the questions with the advice health professionals and distributed the survey to members of the ten Clinical Commissioning Groups (CCGs) that we were working with as well as to other health professional through number of other professional networks. We kept the survey simple, asking six questions split equally between the health needs of care leavers and those of looked after children.

Of the 215 respondents the table is a breakdown of work areas engaged in by these professional

Care leavers 16-15	62% (134)
Care leavers 25+	6% (13)
Looked after children	43% (93)
Looked after children and care leavers	32% (69)

We asked on a scale of 0-5 how aware they were of the health needs of care leavers and looked after children, with 0 being 'not aware' and 5 'very aware'

	0	1	2	3	4	5
Mental health needs	0.5% (1)	0%	1% (2)	6% (13)	37% (76)	55% (115)
Physical health needs	0.5% (1)	0.5% (1)	3% (7)	13% (13)	33% (66)	50% (104)

We asked professionals to rank the top five issues affecting looked after children and care leavers. The responses were varied but the collated top five from all the responses were; mental health, general physical health, drug & alcohol issues, sexual health, and access to services.

We also asked these professionals to think about key areas of need that, in their view, are either supported or not supported in relation to health service responses to looked after children and care leavers. The responses are as follows:

Are not supported for children in care	Are not supported for care leavers
Mental health Physical health Transition Sexual Health	Mental health Transition General support Housing Access to services

Are supported for children in care	Are well supported for care leavers
Looked After Children Nurses/Doctors Annual health assessments General health support	Looked After Children Nurses (where they work with care leavers)

We then asked these professionals to give us examples of what needs to be done to improve support for meeting the health needs of looked after children and care leavers. Below are some of those thoughts in their own words. We have grouped them in relation to clear themes that emerged, though some clearly overlap:

Accessibility of Services:

- Direct access to a mental health crisis service
- A mental health service that is easily accessible to young people including better routes to making self-referrals, less waiting times and shorter waiting times between appointments and being offered appointments.
- Accessible, dedicated holistic services across the country integrating a holistic approach to emotional, physical, mental health, housing, education and support within creative communities. As well as dedicated services helping children overcome the traumatic impact of abuse

and neglect and education of wider professionals, for example in schools how this may be played out in their behaviour.

- A mental health service that is easily accessible to young people including better routes to making self-referrals, less waiting times and shorter waiting times between appointments and being offered appointments.

Responsiveness to the Specific Needs of this Group:

- Patience and an understanding of the journey care leavers have made. They are often cautious and weary of professional input. Professionals need to have more patience and understanding of the needs of these YP who have been assessed throughout their lives and are at a transitional stage of being able to make their own decisions. I do think more time should be given before a case is closed. At times MH professionals do not have enough empathy or understanding of our care leavers.
- More targeted provision
- Local drop in centre, outreach health initiatives to target specific health related issues
- Develop Care Leavers health services with specific roles within Looked After Children health teams to contribute to pathway plans and develop transition services.

Help from Outside the Health Care System

- Addressing the poor social care context around these young people. How can they have positive health when being asked to leave their foster placements or children's homes at 18 without anything close to resembling a family to support and contain them?
- Consideration of developing peer support groups for care leavers.
- Life coaching
- Assessment of emotional health needs on entering care, specialist services with enough capacity to help, helping young people build their own resilience to life.

Improved Training and Services Generally

- Clinical Commissioning groups need to commit to offering services to children and young people. Better support needs to be in place to allow children and young people to share their worries and concerns and obtain the right support for their needs. There could be extension of the lac nurse role to include care leavers. I have seen LA's where this has worked.
- Effective working together. Integrating commissioning between CCG's and local authority - implementation of the intercollegiate guidance re staffing level

- ensuring Named Nurse in post and more specialist provision. Better information sharing across multi agency groups.

- Better training for staff and carers. More creative resources for young people to access support.

Discussion

It was clear from the professional survey that there are some knowledgeable and dedicated health professionals throughout the sector who are keen to see improvements in the services that support the health of care leavers. They also have considerable insight that could be used to help improve services. Many wanted to see service commissioners take a more evidence-based approach to commissioning services for this group.

There is a perceived tension between the need to deliver specific targeted services for care leavers and a broader focus on their ability to access good quality generic health care. Several of our respondents suggested that targeted services can be helpful.

Problems with accessing services is a point raised by both care leavers and professionals, with suggestions that referral pathways need to be clearer and the opportunity for self-referral highlighted. Consideration also needs to be given to place and environment, given the vulnerability of some individuals. Services are more accessible if they feel safe and welcoming.

The main focus of the professional discussion was, as expected, children in the care system and care leavers up to the age of 25. However, we know that health issues related to care backgrounds continue to affect care leavers into adulthood. Health services that currently support children in care and care leavers have experience and knowledge that can and should be stretched to encompass the needs of adult care leavers through greater integration and education of adult services and professionals.

Section Seven: Seminars with Professionals

At the halfway stage of the project, during 2016, we held five seminars in the local areas of some of the Clinical Commissioning Groups we were working with. The aim of these seminars was to bring together health professionals to identify problems we were already aware of, issues that were emerging and possible solutions from within their professional experience and perspectives. The seminars took place in London (two), Manchester, South Tees and Milton Keynes. We had a total of 63 people attend which was made up of designated nurses, leaving care workers, mental health workers, personal advisors, and commissioners.

We split the sessions into two parts. Firstly we presented both the national picture of care leaver health and the early findings from our care leaver health survey. Participants then worked in groups to identify some of the problems highlighted from the presentations and develop solutions to those problems and issues. We present, below, a summary of those discussions.

Problems

- Transition from CAMHS to adult services
- Slow and inadequate response of adult services
- Adult services thresholds and criteria for access
- Care leaver feelings of abandonment and isolation and experience of lack of stability
- The need to address attachment issues
- The need for services to respond to individual care leavers rather than focussing on professional solutions
- Early independence
- Care leaver reluctance to be identified as such and issues of stigma
- The effects of institutionalisation
- Lack of Life skills work and Life story work
- The lack of targeted provision for this group
- Carers not supporting or recognising the importance of health assessments
- Issues with use of drugs and alcohol

Solutions

- A dedicated CAHMS member of staff in a leaving care team who is integrated as a looked after child practitioner
- Social contact through support groups

- A 16 – 25 service for all care leavers, including a care leaver passport to services and a regular review of Health Care Plans
- Training and education of carers and health workers and greater stability of staff
- A care leaver support fund for life, Personal Health Budgets
- Commissioning of Health services to include specific provision for care leavers
- Consultation; empowering the voice of the care leaver (through training if needed)
- Every care leaver should have a mentor, possibly a peer mentor
- A mental health assessment when a child enters care
- Improved support when transitioning to independent living (such as through the use of practice flats)
- The identification of looked after children and care leavers on presenting to health
- Life story work
- The opportunity to re-engage with previous workers

Wider Discussion

At these sessions, there was disappointment expressed by several attendees that over thirty years of solid research saying that mental health is a significant issue affecting care leavers and looked after children have led to little action to improve health outcomes for care leavers. Some of those who attended were already aware that having designated nurses was supportive to looked after children but recognised that such children didn't get as much nursing support as much they would like and there was little time for deeper work in areas such as mental health. Several key issues were highlighted throughout the seminars:

Transition

There was broad agreement on the importance of this issue, where many young care leavers fall through gaps in services. This especially applies at three key ages (18, 21 and 25) where some support stops and given that the criteria to get mental health support is much higher at 18. Given that 18 is also the age at which care leavers typically become independent, there is the potential for severe strain on their emotional and mental wellbeing. A 'stage not age' approach to service provision was recommended by some with respect to 18-25 support. Others argued that care leavers and looked after children should be fast-tracked through CAMHS services and the benchmark for support reduced for them.

Isolation

Many in attendance noted that large numbers of care leavers are housed in inadequate accommodation without social and family networks to provide a sense of connection. This can lead to poor mental health outcomes, resulting in difficulties in everyday life. There was general acceptance that peer support and mentoring services would benefit care leavers.

Access to CAMHS and mental health services

Waiting lists can be long and access criteria high. With many care leavers not having support networks, they are especially vulnerable and this can lead to self-harming behaviour and other mental health issues. There was also a consensus that services were too formalised and did not relate well to care leavers

Section Eight: Cradle to Grave - Discussion

In this section of the report we use the data and knowledge acquired throughout the project to discuss some of the key issues in relation to the health of care leavers.

Reasons for entry into care

The numbers of young people going into care has been increasing over the last few years, 72,670 in the 12 months to March 2017 – marking the biggest annual surge of children in care in seven years.

2011 - 65,510

2012 - 67,070

2013 - 68,060

2014 - 68,800

2015 - 69,540

2016 - 72,670 (Department of education)

This will mean that future numbers of young people leaving care each year will also rise. The present situation facing care leavers and their health, especially their mental health, will only going to get worse if we do not act now.

Attention especially needs to be paid to the reasons for children entering care. The dominant and well-known fact here is that the majority entering care have always done so due to various forms of neglect and/or abuse at home. The consequences of this neglect/abuse need to be dealt with during their time in care or there is a strong likelihood of significant detriment to their

long-term health and wellbeing, a detriment often picked up by adult services.

However, our research shows that adult services often fail to pick up these issues and adult care leavers are left to fend for themselves.

A key tenet of the care system should be to not cause the young person additional harm. However, there are multiple examples where this is breached. Systems must be improved and service providers need to do more than talk about placing the young person at the heart of everything.

Mental health support

Entry into care

Being taken into care can be a traumatic event no matter how traumatic home life is. In our focus groups of adult care leavers, many said they were never told why they went into care and if they were it was done in a matter of fact of way with little regard for feelings. Many were never given the opportunity to ask questions. Having a sense of identity is an important part of being a fully functioning adult and it is therefore essential that care leavers have an understanding of the reasons behind their entry into care. Many adult care leavers only discover key facts about their time in care when they access their social care file later in life. This can often trigger feelings of loss and abandonment.

Trauma in care

Many adult care leavers, through the questionnaires and forums, reported to us that they were sexually, physically, emotionally and mentally abused by those paid to support and help them, something which added to mental health issues or created new ones. The current government inquiry into institutional abuse is partly a reflection of the high degree of child abuse in the history of the UK child care system.

Trauma in general

Childhood experiences, both positive and negative, have a major impact on lifelong health and opportunity. Early life experiences are therefore an important public health issue. Much of the foundational research in this area, conducted chiefly in the USA, has been conducted under the banner of the Adverse Childhood Experiences (ACEs) studies. Adverse Childhood Experiences have been linked to risky health behaviours, chronic health conditions, low life potential, and early death. This research shows that as the number of ACEs increases so does the risk of these outcomes. Abuse and neglect in childhood can have a range of long-lasting effects: poor brain development, impaired cognitive functioning (and learning ability), poorer social and emotional skills, poorer language development, higher risk for heart, lung and liver diseases, obesity, cancer, high blood pressure and high cholesterol, anxiety, smoking, alcoholism and drug abuse (see

e.g. Felitte et. al. 1998). To prevent such outcomes, young people in care and care leavers need to have regular access to detailed health assessments and support to monitor the impact their early years development is having on their health.

Placement Stability

Human beings without a secure base are more likely to have a range of emotional wellbeing issues. Research also shows that the more placement moves a young person has in care the worse their mental and emotional wellbeing will be. A vicious cycle can develop whereby a young person's behavioural responses result in a placement move which then precipitates more misunderstood behaviour responses. We clearly need to improve the placement process to achieve a greater number of successful placements. We can do this by ensuring that foster and residential carers are better supported to manage placement challenges and that all care professionals have a better understanding of child development.

Emotional support

Our research tells us that there is inconsistent emotional support given to young people throughout their full time in care. For those given a mental health diagnosis there can be relevant support services. All care and leaving care placements require a focus on providing warm and nurturing emotional support but

many placements both now and in the past have focused more on ‘managing’ a child.

Transition out of care

Older care leavers

For many who grew up in care during the 1950s, 1960s, 1970s and 1980s mental health support was non-existent. This was highlighted in both the forums and qualitative data. Some of this group of adult care leaver left when no financial or practical support was given so they experienced a triple disadvantage of having been in care, being ill-equipped to live independently at such a young age and having to cope with mental health difficulties. Adult services in the health and social care sector need to be more aware of this context and thus better able to support adult care leavers.

Life skills

For some care leavers who left care prior to the 1989 Children Act implementation, leaving care could be an especially challenging experience. Since the 1989 Act and later legislation, degrees of support have improved. However, poor housing for care leavers persists. Sometimes permanent accommodation can be miles away from social networks a young person has built up, or in rundown areas with challenging neighbours. Alongside the stress of managing a tenancy and money at a young age, this can exacerbate existing

mental health issue or prompt new ones.

Managing adult life without support

Navigating adult life can be a difficult process for anyone, however doing it having had a care experience and with limited support networks in place is even more challenging. Our research showed that for some care leavers there was an increase in anxiety about having to cope with day to day living issues. This stress added to underlying and unresolved mental and emotional wellbeing issues. Experience from care leavers tells us that support services are not geared up to provide help in this situation.

Relationship Building

Care leavers tell us that sometimes as adults developing and maintaining relationships can be a problem. This could come as no surprise if you have had a history of being passed about from placement to placement from person to person. A lack of stability in childhood can manifest in negative ways as an adult. Younger care leavers told us that they felt a degree of resignation in the fact that all relationships were temporary so they just didn’t try. And in the forums and qualitative data care leavers of all ages told us that trust was an issue. They found it difficult to trust people and as such experienced more isolation. This had a negative effect on their mental health.

Isolation

A significant number of care leavers told us that they felt isolated whilst in care. Those who experience multiple placement changes or are placed out of area were often more so. Once isolation is established at a younger age connections of all sorts can become more and more difficult to make and physical health often deteriorates as a result of the isolation.

Diagnosed Mental Health Conditions

Depression, anxiety and PTSD were the most common mental health diagnosis for care leavers in our research. Multiple diagnosis was also high at 10%. Anxiety and depression were the two most common features of multiple-diagnosis. Other research has shown high rates of diagnosable mental health conditions in both children in care and care leavers. Mental health professionals need to be more aware of how the care experience can both affect the individual and their condition. We hear too often stories from care leavers who are left with no control or say over their treatment plan and are left feeling even more helpless and angry.

Some of the treatment choices for mental health conditions need to be placed within a wider discussion about the social/medical dialectic surrounding the root causes of mental ill health. A significant number of children in care are diagnosed with conduct behaviour disorders. Young people in care could be

exhibiting specific behaviours in response to their external environment. Looking back on their adolescent lives, some care leavers told us they felt angry at times, didn't know what was happening to them and couldn't explain it to other people.

Access to Mental Health Services

Almost a third of care leavers we spoke to told us they had experienced difficulties accessing mental health services. The key issues were access criteria, assessment, waiting times and available interventions.

Criteria for accessing services is often set too high and too rigidly. Often it doesn't take into account the needs of care leavers and the fact they can have no other support networks. Often the refusal of CAMHS to provide treatment until the young person is in a settled placement is a particular issue. Our preference is for treatment to start as soon as possible which will then lead to more stability. However more support needs to be offered to the care leaver to help them address the often chaotic nature of their life and thus support them to access the service.

Adult mental health services needs to have a much better understanding of the issues that care leavers can experience in adulthood. Assessments and service criteria need to be developed to respond to this particular set of needs. The Mental Health sector needs to recognise that there is a community of people who are not currently being supported.

The statutory requirement to undertake a health assessment ends at 18. This is another example of government short-sightedness where the investment made to support a young person in care's health is not followed through as an adult. Health assessments need to be developed and offered for adult care leavers that can identify issues and offer appropriate support.

Waiting times to access mental health services can be significant. We know this is a nationwide issue. However, care leavers are already a vulnerable group who having found their voice to ask for help can feel knocked back because of the waiting times.

The availability of a variety of interventions remains a problem. Most support offered CBT based which can be useful for many. However the lack of choice is unhelpful. Also mental health services on the NHS are unsuitable for trauma-based care. In our forums it was mentioned that generic mental services are rigid and it was suggested that a wider variety of ways of dealing with and supporting mental health were needed (such as art groups, or drama therapy, walking groups etc)

Physical Health

The incidence of physical health issues was lower than those of mental health. This goes against the current statutory focus on physical over mental health. However we believe that the focus is slowly shifting so that mental health is gradually being given

the focus it deserves. That said, physical health can be an issue for some.

Socio-economic factors

Throughout the literature there is evidence that care leavers are often from lower socio-economic groups. This can have an effect on health and the financial ability to look after health. We often heard in the narrative answers of the survey of respondents not being able to afford certain treatment or procedures. It also meant people were unable to seek any private health support, particularly in relation to therapy.

Supporting care leavers to support themselves

With isolation being a core issue faced by care leavers it is not surprising that 50% of care leavers who completed the survey said they would find it beneficial to be in touch with other care leavers. Care leavers who attended our forums indicated that it was good to meet other care leavers and talk about and explore how being in care affected them and how they dealt with issues on a day to day basis.

Peer support & befriending

Again, feedback and input from the forums was that peer support would be great, be this a cup of tea and a chat or something. The following is a series of recommendations developed in response to

more regular that gave those needing support the chance and opportunity to share experiences and coping mechanisms. As a user-led group, The Care Leavers Association passionately supports increased use of peer support mechanisms.

Section 9: Recommendations

The following is a series of the survey data and discussions from the forums and professionals. Recommendations are split into sections and each recommendation has a rationale. Some of the recommendations will be just as valid for looked after children, care leavers and adults.

Commissioning health services

1. The health needs of looked after children and care leavers to be a distinct section in the Joint Strategic Needs Assessment (JSNA). This should, if possible be extended to adults aged 25+

This will ensure that LA's take a thoughtful and planned approach to meeting the health needs of their young people in care. It will also help to monitor and measure improvements in health outcomes and give direction to the commissioning of services.

2. Each CCG area to conduct formal assessment of health needs of looked after children and care leavers

In order to know what services are required there needs to be an accurate description of needs in each area.

3. Commissioning of all mainstream health services to include targets for improving health outcomes for children in care and care leavers.

Specialist services on their own cannot

bring about a broad increase in health outcomes for people who have been in care. Major improvements can only be achieved if the mainstream health services are on board and offering appropriate support.

4. Commission a range of mental health and wellbeing services, from low level to psychiatric, that specifically support looked after children and care leavers.

Whilst higher end mental health and psychiatric issues are supported by services, there are significant gaps in provision of support for the whole range of mental health and emotional wellbeing issues.

5. Ensure that care leaver health needs are identified in broader commissioning processes.

Health needs do not just have to be addressed through health services. There are a variety of community and local services that could support emotional health and wellbeing needs if they were encouraged to do so.

Looked after children

1. That a young person in care has a comprehensive health assessment at entry into care which is then monitored and updated on a regular basis

The health and wellbeing of a person in care is of paramount importance. It is too important to leave to chance. It should be monitored and nurtured in planned manner. Health assessments should focus on mental health and wellbeing as well as physical health. They should be carried out in a holistic manner. Where age appropriate they should be as person centred as possible. They should be constantly reviewed in relation to any changes in circumstances. They should be shared with all the relevant support people.

2. All local authorities to appoint a Mental Health and Wellbeing lead

For too long the mental health and wellbeing needs of young people in care have been ignored. Decisions are made about a young persons life without due regard to their emotional wellbeing. A lead in each area would act as champion and ensure that emotional wellbeing needs were being met.

3. Implement a protocol to support placement stability

Too often placement breakdown and resulting moves can be the trigger for a decrease in a young persons mental wellbeing. LA's and placement providers need to be supported to deal with and resolve breakdowns.

4. Improved training for all staff (social workers, foster carers, residential workers) to better respond to a young persons needs not their behaviour. All social care professionals to have training on attachment and trauma theory.

The effects of trauma and of care can have an influence on a young persons ability to communicate and on their ability to understand their own desires. They need more support to help them understand themselves and to communicate more effectively. This will also help make placements more stable

5. Deliver a range of emotional wellbeing and self-development interventions to young people

All young people need help to better understand themselves and the world around them. This is even more important for young people in care. We have to give them the tools for them to be able to make sense of what is happening to them. Without some of these skills all other interventions are doomed to failure. Our research showed high levels of low self-esteem throughout time in care – this has to be changed.

6. Increase the availability of therapeutic placements.

Too often placements are see as accommodation to manage an individual. More need to be focus on improving the wellbeing of the individual.

7. Reduce waiting times and increase opportunities to access mental health intervention for looked after children and care leavers

Too many young people are having to wait for assessment and treatment. This only makes the problems worse.

Care Leavers

1. All care leavers 18-25 to receive a health assessment as part of the pathway plan

We invest a lot of time and resources to support young people in care. Why should this investment stop at 18. Health does not stop at 18. Health assessment and support should continue with the care leaver having the option to opt out if they wish. The assessment plan should have clear referral links to adult support services

2. Care leavers to be given priority status in relation to accessing health services

As a corporate parent the state has a responsibility to ensure that care leavers get timely access to support that meets their needs.

3. At 18 services continue and any young person in care is being treated with a stage not age approach so whether 17 or 20 they access the same service with the same access criteria.

There is mounting evidence to show that the transition from children to adult services can cause a breakdown in accessing services leading to worse

health outcomes. Remaining in the same service provides continuity of care and ensures needs are met.

4. Increase the status of the PA role and provide improved training and support to all PA's

The PA role is central to ensuring successful outcomes for care leavers. It needs to be seen as having the same degree of importance and responsibilities as a social worker. PA's need to be empowered to work with care leavers to help them access the full range of support and opportunities in their local community

5. All local authorities to have a mentoring/coaching/befriending service for care leavers

Isolation is a key issue facing all care leavers. Care leavers also recognise the value of peer support. Mentoring type initiatives can help produce a range of positive outcomes in different life areas.

6. Increase the statutory requirement to provide accommodation for care leavers to 25.

Having a settled base from which to grow and develop is key to any individual. Increasing support in this area would allow care leavers that additional chance. Accommodation needs to be of a high standard and in good areas. Support also needs to be provided to help with independent living. This will in turn provide better health outcomes.

7. All care leavers to be provided with free access to health records alongside their social care file

It is extremely important that care leavers have an understanding of their own and family health history. This should also be coupled with an understanding of their care history.

8. Implement guidance on care leaver involvement and participation in the design and delivery of services

Service user involvement is often not done very well and needs to improve.

9. Deliver a range of emotional wellbeing and self-development interventions to young people

All young people need help to better understand themselves and the world around them. This is even more important for young people in care. We have to give them the tools for them to be able to make sense of what is happening to them. Without some of these skills all other interventions are doomed to failure. Our research showed high levels of low self-esteem throughout time in care – this has to be changed.

Adult care leavers 25+

1. The health of adult care leavers (25+) to be recognised as a specific area of focus for mainstream health services. Health issues that are affected by going into and being care do not stop just because a person is over 25. All health services and professionals need to have an understanding of the care experience and how it can affect a persons health at any stage in life.

2. Develop guidance and support for health services in relation to working with adult care leavers.

Our research and experience tells us that although there are some knowledgeable professionals in the field, many do not have access to the correct knowledge.

3. Improved training on mental health needs and ACE's research for frontline health professionals

As we become more aware of the effects of Adverse Childhood Experiences on health it is important that this information is shared with all professionals

4. Increase access to IAPT services for adult care leavers and fast track access to talking therapies

Throughout our research we received reports of care leavers being unable to access talking therapies because of access criteria or waiting lists. As a corporate parent, the state needs to

recognise that emotional health and wellbeing issues do not stop at 25 and adult care leavers needs additional support. Some care leavers do not have extended family support circles to turn to for support. This makes access to services more critical.

5. All CCG's to appoint a champion for the health needs of care leavers (of all ages)

There is a general lack of awareness about the health needs of care leavers amongst professionals. A champion could provide leadership and coordinate sector learning. In the first instance, this role would need to focus on improving knowledge of mental health and emotional wellbeing.

6. Commission a range of health and wellbeing support services for care leavers including emotional wellbeing, self-development interventions and mentoring/befriending

Adult care leavers need access to a variety of support times at all stages in life.

7. Commission services widely to reduce isolation

Isolation was the main issue presented by care leavers. Services need to offer support that is connected to the wider community and builds connections and relationships

Section 10: Final Thoughts

Health outcomes for care leavers are poorer than non-care peers. And this goes for care leavers of all ages. We have to pay more attention to this situation, focusing on why this is and what can we do to make an improvement. We also have to think longer term. What happens to us before and during care can have long lasting effects.

Services and interventions must not just be quick fixes but provide lasting solutions. More focus needs to be placed on mental health which includes emotional well-being. Many care leavers we encountered did not have diagnosed mental health issues, but had serious well-being issues that prevented them from living life fully.

Care leavers have every right to lead a happy and fulfilling life.

Thriving, not just surviving.

We must all work harder to make this happen.

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