COMMISSIONING TOOL KIT FOR CARE LEAVERS (up to end of life)

This booklet has been developed by The Care Leavers Association as part of a Department of Health funded project to improve commissioning and health outcomes for care leavers. It can be used as a stand-alone toolkit or seen in conjunction with the report Caring For Better Health which can be downloaded from The CLA website at www.careleavers.com

The Care Leavers Association is a user-led charity established to improve the lives of people who have spent time in the care of the state. Its vision is for “a good life in care, a good life after care. It does this by bringing together the voices of care leavers of all ages to improve the current care system, improve the quality of life of care leavers throughout the life course and change for the better society’s perception of people who have been in care.

The Department of Health funding was received through the Voluntary Sector Investment programme, Strategic Development Fund.
There is widespread agreement in the literature and research that care leavers of all ages experience poorer outcomes than the non-care population. Some of these poorer outcomes are related to mental and physical health.

A care leaver is anyone who spent any time in the care of the state (such as foster care or residential children’s homes).

The majority of young people enter into care having experienced abuse and neglect in the family setting. On top of this the care system and process itself, although well-meaning, can cause the individual to experience psychological, emotional and physical ill health. The result of both of these points is that care leavers can be faced with a range of mental and physical health issues that continue into adulthood and can have an effect throughout their entire lives.

The challenge for commissioners is to find a way of providing services for this section of the community that improve health outcomes.

In addition to this, and service that are likely to be accessed by care leavers should be required by the CCG to monitoring data on and be asked what positive actions are being taken to encourage care leavers to access services and to have their needs met.

**Why use this tool kit**

There is some 30+ years of research into the health of looked after children. However there has been limited research into the health of care leavers. The CLA aims to partly rectify this situation by undertaking extensive research (CLA Health Report) and consultation nationally with care leavers of all ages.

This tool kit will guide you to better meet the needs of care leavers through the commission process and lay out some guidance on what to do, and how to go about either commissioning a care leaver specific service or guiding generic services on how they can better meet the needs of care leavers.

**Health and young people in care**

The research conducted on the health of looked after children is stark. An influential study into the mental health of looked after children 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).
Research shows that a significant number of those looked after children continue to experience mental health difficulties, such as depression, long after leaving the care system and to a higher degree than other disadvantaged groups (Buchanan, 1999). A recent study into the mental health needs of care leavers 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. In doing so, 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) work. 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. 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. They find that care leavers are significantly more likely to experience physical ill health in adulthood compared to the general population.

**Key Issues affecting care leavers**

**Isolation**

In our research we found that a significantly high numbers of care leavers (78%) felt isolated some, most or all of the time while they were in care. This dropped to only 75% once they left care. From the qualitative data we collected and through the numerous consultation events we facilitated, time and time again the issue arose of the challenge in maintaining friendships and relationships. For many this was the result of having developed difficulties in trusting people during their care experience. Added to this many have no family support networks in place. Nobody to go to for emotional support. And when you take into context the high levels of depression and anxiety experienced by care leavers, this only compounds the feelings of isolation.

Being isolated from others isn't just lonely — it may increase your chances of an early death.
Social interactions play an important role in health. In fact, studies have found that a lack of social connections can increase the risk of death by at least 50%, and in some circumstances, by more than 90%. (Social Relationships and Mortality Risk: A Meta-analytic Review)

“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.” (CLA Health Report)

Poor mental health

Many care leavers live throughout their lives with their experience of the trauma, neglect and abuse that took them into care. Prior to The Children Act 1989 there was very little coordinated mental health support for people in care. A large number of care leavers who left care before 2000 were generally unsupported emotionally during their time in care and very few had access to MH support unless they had significant MH issues. In this situation care leavers can find it difficult to navigate within the world. Many do go on to form positive relationships, have families of their own and live successful lives. However, it can often not be easy and research into mental health shows there is still an underlying sense of abandonment and fear of connection. This can manifest in a variety of ways, often with the individual having limited understanding of exactly what is going on.

There is a crisis of mental health amongst all young people and this is particularly acute with care leavers. Getting the right support from CAMHS within an appropriate timeframe

Some general statistics

- Care leavers are 7x more likely to die before the age of 25 then the general population (Department of Education 2017)
- 25 x more likely to be homeless (National Audit Office 2015, 25% of homeless population had at some point been in care, 1% of population are looked after)
- 33 x more like to be involved with sex work (Home Office’s Paying the Price: A Coordinated Prostitution Strategy)
- Up to 27 x more likely to be in the criminal justice system (HMIP 2011)
The CLA Health Research 2017.

In 2016/2017 The Care Leavers Association carried out in depth research of care leavers of all ages on a range of health and wellbeing issues. From our sample of 420 responses some of the key results:

- 88% of care leavers felt depressed, some, most or all of the time while they were in care, falling to 87% after leaving care.
- 55% of care leavers attributed their mental health issues to their care experience
- 42% reported being diagnosed with depression and 19% being diagnosed with more than one mental health condition.
- 78% of care leavers felt isolated some, most or all of the time while they were in care, falling to 75% after leaving care

Principles for Commissioning

The knowledge and understanding we have received from care leavers has lead us to believe that for health services to be effective in meeting the needs of care leavers, they must be based on a set of overarching principles.

- **Fully meeting corporate parenting principles by offering Cradle to Grave support for care leavers.** Health issues developed during time in care do not stop when a person leaves care. Health issues manifesting in adulthood may be related to time in care. Work in a holistic manner and see the life of a care leaver as a joined up journey.

- **Whatever the health issue, the individual can be the expert in what works for them.** Recognise the expert knowledge a person can contribute to their treatment and support. Involve people at all stages of service development and delivery.

- **Take a holistic view of the persons needs.** Do not always focus on symptoms and place treatment and support in the context of a whole life.

- **Peer support can be key.** Supporting care leavers to support themselves and each other can have very beneficial outcomes.
What care leavers say CCGS should do to improve the health of care leavers?

In 2016 and 2017 The Care Leavers Association held a variety of consultation events with care leavers around their health needs where we asked what they thought CCGs should do to improve the health of care leavers. This is what they said.

**Care Leavers 16-25**

- A holistic health assessment that is part of the pathway plan and is regularly updated
- Systems in place to ensure the seamless delivery of care and support when a care leaver moves area
- Care leavers are treated with a stage not age approach, staying in a service from 16 to 25
- Care leavers given a resource which includes details of all available health services. It should be written in a jargon free way and contain information on access and referral processes
- Free access to health records
- A guided and supported transition to adult services

**Care leavers of all ages**

- Reduce access criteria to talking therapies
- Fast track access to talking therapies
- Offer longer set of sessions based on needs of the individual
- Training for MH services on needs and issues of care leavers
- Access to Mentoring / coaching / befriending support
- Access to Self-esteem, confidence building and assertiveness courses
- Increased use of creative therapies
- Commission services to tackle isolation
- Monitor physical health more closely and more robust checks ups
- Free access to health records.
The Commissioning Journey (London Borough of Sutton)

We are using this model as a standard commissioning process to give examples of how it can be related to commissioning services for care leavers.
Initiate & Investigate with Collaborate & Incubate

Bring together key professionals from across health and social care with good knowledge of the issues facing care leavers. As well as primary and secondary health professionals involve leaving care teams, housing, mental health services and a wide range of third sector organisations. Discussions with existing service providers, especially those more likely to be accessed by care leavers. Bring together available data on care leavers. Undertake audits of care leaver needs especially in services that do not monitor care leaver usage. Establish regular monitoring of care leaver usage in all services. Develop an understanding of pathways taken by care leavers across health and social care. Share information on the main issues affecting care leavers.

Talk with and listen to care leavers locally about their needs and experiences. Utilise existing structures and make sure you listen to those who do not have a voice Talk to national organisations.

Develop and outcomes framework that will change the lives of care leavers for the better and can be monitored and measured.

Develop joined up plans to respond to the health needs of care leavers. Look at holistic picture how health is informed by other life experiences. Consider wider, asset based responses to health and wellbeing situations.

Desired outcome

Care leaver health needs are championed in the local area.
Relevant Services are aware of the health issues facing care leavers.
JSNA describe needs and gaps the health of care leavers.
An understanding of the health needs of care leavers locally.
A sufficiency plan of services is created to respond to those needs.
Relevant services are have an action plan to meet the needs of care leavers.
Care leavers are consulted and are included in the commissioning process.
**Negotiate and Activate**

Build relationships with potential providers and the wider services and communities supporting care leavers. Implement protocols for mainstream health services to focus on and support care leavers of all ages. Ensure that referral and transition systems are simple and effective. Involve care leavers in service design and delivery. Consider delivery environments and access requirements for services. Ensure regular open feedback channels are available within the delivery model. Promote services widely in the community with messages specifically for care leavers.

**Desired outcome**
A wide range of services and opportunities are offered to meet care leaver health needs.
Care leavers understand and use services available.

**Consolidate and Evaluate**

Involve a varied range of care leavers in the review and evaluation of services. Review and evaluate based on agreed outcomes. Monitor and measure softer outcomes as well as hard and diagnostic based outcomes. Bring together wide range of health and social care organisations to review. Input review and evaluation outcomes into planning process to improve services.

**Desired outcome**
The care leaver voice and experience is central to service improvement.
A range of outcome are measured.
Individual improvement is seen in a winder context (change may be gradual).
## Commissioning Recommendations

As part of the 3 year Department of Health project we produced a final report with recommendations (details on the front page). Below is a summary of the recommendations.

<table>
<thead>
<tr>
<th>COMMISSIONING</th>
<th>LOOKED AFTER CHILDREN</th>
<th>Reduce waiting times and increase opportunities to access mental health intervention for looked after children and care leavers</th>
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<tbody>
<tr>
<td>The health needs of looked after children and care leavers to be a distinct</td>
<td>That a young person in care has a comprehensive health assessment at entry into care</td>
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<tr>
<td>section in the Joint Strategic Needs Assessment (JSNA). This should, if</td>
<td>which is then monitored and updated on a regular basis</td>
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<td>possible be extended to adults aged 25+</td>
<td>All local authorities to appoint a Mental Health and Wellbeing lead</td>
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<td>Each CCG area to conduct formal assessment of health needs of looked after</td>
<td>Implement a protocol to support placement stability</td>
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<td>children and care leavers</td>
<td>Improved training for all staff (social workers, foster carers, residential workers)</td>
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<td>Commissioning of all mainstream health services to include targets for</td>
<td>All social care professionals to have training on attachment and trauma theory.</td>
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<td>improving health outcomes for children in care and care leavers.</td>
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<tr>
<td>Commission a range of mental health and wellbeing services, from low level to</td>
<td>Deliver a range of emotional wellbeing and self-development interventions to young</td>
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<td>psychiatric, that specifically support looked after children and care leavers.</td>
<td>people</td>
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<td>Ensure that care leaver health needs are identified in broader commissioning</td>
<td>Increase the availability of therapeutic placements.</td>
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<td>processes.</td>
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### CARE LEAVERS 16-25

- All care leavers 18-25 to receive a health assessment as part of the pathway plan
- Care leavers to be given priority status in relation to accessing health services
- 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.
- Increase the status of the PA role and provide improved training and support to all PA’s
- All local authorities to have a mentoring/coaching/befriending service for care leavers
- Increase the statutory requirement to provide accommodation for care leavers to 25
- All care leavers to be provided with free access to health records alongside their social care file
- Implement guidance on care leaver involvement and participation in the design and delivery of services
- Deliver a range of emotional wellbeing and self-development interventions to young people

### CARE LEAVERS 25+

- The health of adult care leavers (25+) to be recognised as a specific area of focus for mainstream health services.
- Develop guidance and support for health services in relation to working with adult care leavers.
- Improved training on mental health needs and ACE’s research for frontline health professionals
- Increase access to IAPT services for adult care leavers.
- Fast track access to talking therapies
- All CCG’s to appoint a champion for the health needs of care leavers (of all ages)
- Commission a range of health and wellbeing support services for care leavers including emotional wellbeing, self-development interventions and mentoring/befriending
- Commission interventions to tackle isolation for all ages