Background to this call
This document provides further information to support applicants for the above call. Research is required to improve the commissioning and provision of health and social care services for Looked After Children and Young People (LAYP) as they transition to be users of these services as an adult on leaving care by social services.

Why is this important?
The role of birth parents in the management of childhood-onset long-term physical and mental health conditions is essential at many levels and continues throughout transition. For young people in local authority (LA) care, even if they have had a stable placement or social worker during their time in children's services, transition is a period when their social care support is likely to change. The status of the health service user changes at age 18, when the primary receiver of information is the young person, not their social worker or foster carer. Young people leave care at an earlier age, on average, than other young people leave home, giving them additional challenges to face, often with little support, and fearing the stigma of seeking help.

There is a need for new research on how health and social care services can better collaborate with the young person during transition, respecting their need for privacy but also enabling inter-agency communication when this is agreed by the young person.

The topic was referred from NICE as a Key Priority for research, based on NICE guideline NG43 Transition from children's to adults' services for young people using health or social care services (published February 2016) - Research recommendation 8 - What is the most effective way of supporting care leavers in transition from children's to adults’ health services? These topics have been identified as being of specific priority because looked after children undergo multiple transitions, have complex needs, fall through care gaps and can cost health and social care services considerable amounts of money.

1. Identified Service need
On March 31st 2016 there were 94,000 looked after young people in the UK, with 70,440 in England. Over half are in care due to abuse or neglect and 6% are unaccompanied asylum seekers. The best estimates are that 3.4% of adults have spent time in public care. Every year, around 6,000 looked-after children leave care for good; 21 per cent are 16, 17 per cent are 17 and 61 per cent are 18, while in the general population in 2010 the average age for leaving care for good was 24. In addition to the departure from care being premature for many young people, the process itself is compressed. There is evidence that care leavers living on their own face a range of emotional and psychological problems. Research suggests that some LAs tend to focus on practical issues, overlooking the need for emotional and psychological preparation for those on the verge of leaving care and living independently. Unaccompanied asylum seekers have additional problems of mental and physical trauma, and legal uncertainty regarding their future in the UK (Personal communication-Designated Doctor).

Poor (or no) transition between children’s and adults’ health and social care services is extremely costly. For example, a recent economic analysis calculated the total cost of immediate complications from poorly managed Type 1 diabetes among adolescents at transition age amounted to £9.5 million as a result of acute care admission due to Diabetic ketoacidosis (DKA), hypoglycaemia, and unknown diabetes related causes. In spite of a wealth of guidance on transition, poor practice is widespread; in particular, there is a ‘lack of appropriate services for young people to transition into, and evidence that young people may fail
to engage with services without proper support. In addition, while ‘person-centred’ transition has featured strongly in national policy, this principle is not being translated into practice; and, young people report not feeling as prepared for, or as involved in their transition.

Looked after children have specific problems accessing support, as do young people leaving residential schools. Many looked after young people must live independently sooner than young people living with their parents. This requires high levels of practical support but this is often not provided. The National Audit Office used, as an indicator of poor transition, the number of care leavers not in education, employment and training (NEET). On this basis, authors noted, ‘the lifetime cost of the current cohort of 19-year-old care leavers being NEET would be around £240 million, or £150 million more than if they had the same NEET rate as other 19-year-olds.’ Similarly, case study modelling by Hannon (2010) found that a young person who has an ‘unstable care journey’, including mental health problems and poor experiences of employment, will cost the state £91,805 more between the age of 16 and 30, than one who is able to be supported in care for longer, and then continues education and gains employment.

There is evidence that where care leavers are supported in foster care for longer, this can improve transition to adulthood. There is, however, limited effectiveness evidence about which models of support for transition work best under which circumstances. There is also no data routinely collected at the national level on economic activity of care leavers aged over 21 years.

Furthermore, it is well established that, in general, looked after young people are more likely to experience poor mental health than other young people, and that these needs are often not met. There is also evidence that looked after children experience a significant rise in mental health problems particularly after leaving care, attributed to the complexities of transition. This is in the context of users of Child and Adolescent Mental Health Services (CAMHS) in general being particularly at risk of poor or failed transition. Across health (e.g. immunisations), social and educational outcomes measured using Every Child Matters data young people in care have more physical and mental health issues than their peers and do less well educationally. As a group, they have poorer adult outcomes in social mobility, employment, mental health and criminality, though there are exceptions. Transition to adult health services for health problems other than mental health is challenging for young people, and as NICE has identified, there is a lack of evidence for how looked after children and young people should be supported by health services in transition.

Policy context:
Looked After Children and Young People (LAYP) are some of the most vulnerable children in society, typically residing in foster care or residential care with the majority having entered care from a background of abuse or neglect. The Care Act (2014) and Children and Families Act (2014) place responsibilities on local authorities to promote choice and control over care and support for young people and families, extending responsibilities to age 25 in the latter act, emphasising outcomes, personalisation and service integration, aligning with other guidance and legislation supporting better transitions. At 18 years, a significant legal and social care transition takes place: the move from being a LAYP supported by a social worker to an independent care-leaver eligible for assistance from a LA Aftercare advisor. The LA has a duty to keep in touch with and assist care-leavers until age 21 years (24 years if in education or training before age 21 years). The Designated Doctor and team undertake regular assessments of health needs until age 18 when the GP takes on this role. A “passport” is made available to the young person to summarise their medical history. The transition planning process should begin at age 16 years, and be guided and supported by a Pathway Plan, detailing each young person’s current and predicted needs in relation to: health and development; education, training and employment; emotional and behavioural development; identity; family and social relationships; social presentation and self-care skills; support; family and environmental factors; and accommodation and how these needs will be met. The Children and Families Act 2014 enables young people in foster placements to remain with their carers up to 21 years of age rather than having to leave at the age of 18 years if both parties are willing. In England, 123 councils have now signed up to the ‘Care leavers’ charter’, pledging to provide care-leavers with comprehensive support and advice until they reach their 25th birthday; however, this only applies to those in or wishing to return to education. DfE funded the New Belongings (NB) programme delivered by the
Care Leavers’ Foundation. The programme began in March 2013 and ran for 18 months until October 2014 (Phase 1) and originally worked with nine LAs. It was then extended for a further 12 months (Phase 2) to run from April 2015 to March 2016. Phase 2 set out to both expand the reach of the programme to a larger number of LAs, as well as to support the original nine authorities to maintain and develop their progress. These LAs aimed to improve their leaving care services by refining the design and delivery of services to care leavers across key life areas such as accommodation, education, employment and health and wellbeing. It did this by using the experiences and knowledge of care leavers to inform and shape decisions about service delivery and improvement. An evaluation published in 2016 took place across the English LAs that participated in the programme and found variation across the LAs in the extent to which they were able or willing to commit to the NB programme and, consequently, there was a diverse picture in terms of how fully and successfully the NB methodology was utilised. Though it was apparent that the programme had not worked as well for some, there was clear evidence that in most LAs, the programme (or certainly particular components within it) had been embraced. Some recommendations from the evaluation included that authorities should continue to work closely with their care leaver groups to identify strategies for reaching more young people; increasing diversity of the groups; consider ways to facilitate partnership working and opportunities to share practice and learning; effective systems are put in place for sharing resources and ideas across all LAs taking part, to promote learning during the life of the programme.

Recognising the likelihood, costs and impact of poor outcomes among looked after young people and care leavers, these groups are currently high priority in national policy. In the Government’s response to the report Education Committee of the House of Commons, financial investment in 2016/17 and the next 3 years was targeted on improved mental health support for the most vulnerable looked-after children and young people, those who are looked-after in secure children’s homes, and the new Children and Social Work Act (2017) requires local authorities to have regard to a set of clear ‘corporate parenting principles’ including acting in the best interests of looked after children, and promoting their health and well-being. The response rejects several recommendations in the report, and has referred questions such as who should assess a CYP’s mental and other health needs on entering care, access to mental health services for expert advice, access up to age 25 to CAMHS services. The response supports better integration and single of point of access between schools and mental health services, and a pilot is being evaluated. There was some level of agreement that system leadership via Health & Well Being Boards should be firmed up, along with Local Transformation Plans that should specifically state the plans and funds for LAC. The Government acknowledges some 85% of plans included specific activity or plans for looked after children and/or care leavers. The analysis shows the level of detail in plans and the local approaches varies between areas. DH established with NHSE and HEE a new Expert Working Group for Looked-after Children in 2016 to consider how to improve the mental health and well-being of looked-after children, children adopted from care, care leavers and children leaving care under a special Guardianship Order or Child Arrangements Order.

There is guidance on commissioning transition services for young people with mental health problems. It notes LAYP are particularly vulnerable, with a five-fold increased risk of any childhood mental disorder and four- to five-fold increased risk of suicide attempt as an adult, but makes no specific recommendations for transition services for this group. Health strategies in England, Scotland, Wales and Northern Ireland all include plans to deliver better mental health outcomes for LAYP.

2. Identified Research need

The concept of transition has two distinct meanings: developmental transition and healthcare transition. From a developmental perspective, adolescence is a crucial stage of emotional, psychosocial, personal and physiological developments as young people embark on adult roles through tasks such as separating from family, deciding on a career path and defining self in a social context. From a healthcare perspective, young people with on-going health problems have to move from one service to another upon reaching certain age milestones. For young people who have lived in tertiary health settings for most of their lives this can be particularly difficult. While some services are flexible about the time of transition, for others these two transitions usually occur simultaneously, but needs related to developmental transition may
remain unmet if transition is seen simply as an administrative healthcare event\(^4\). Transition is often too focused on service transfer rather being part of a holistic process of moving to adulthood and independence\(^5\). The need for improved transitions for service users of health and care services is evidenced in the NICE NG43 guideline, which provides important context and models of transition. An evidence synthesis in 2010\(^1\) found that for physical health, there are emerging models of practice to improve the process and outcomes of transition, but there is very little comparable literature in mental health care. Service protocols were reviewed in London, and found to be focussed on only a limited set of enduring mental conditions. Singh et al’s (2008) study of young people’s transitions from CAMHS to AMHS found that two thirds of teenagers are either ‘lost’ from or interrupted in their care during this time\(^6\), which is likely to have serious consequences, especially if needs are unmet. Moreover, those that do make a transition can still experience poorer quality of care. For example, research such as the NIHR HS&DR TRACK study has shown that only 4% of young people experienced their ‘ideal’ transition from CAMHS to AMHS. The study also highlighted care leavers as a vulnerable group with greater mental health transition care needs\(^7\). NICE NG43 includes a body of research on the challenges faced by young people and families, and poor outcomes and costs to services, for young people with physical health problems, and learning disabilities. The guideline provides evidence for overarching principles of better transition (such as co-production of policies and strategies, personalisation, ensuring transition support is strengths based and tailored to the individual’s support network, user-centred, with mechanisms for service integration; and principles for transition planning and how this can be achieved and by whom (such as named workers, peer support groups). Further guidance for looked after young people in transition is in NICE Guideline PH28, updated in 2015, which includes transition to mental health and substance misuse services\(^8\).

NICE NG43 reviewed the evidence for transition services for all young people in health and social care services, including early transition planning, joint working or protocols between children’s and adults’ services, and signposting young people to, or offering them support from, the voluntary and community sectors; interventions such as peer support groups and transition clinics; and transition training for staff. NICE identified many research gaps around the most effective service models, and how practitioners can implement them effectively.

A review in 2011 of seven studies, only one in the UK, of transition support services found no effect on mental health outcomes, and recommended research is needed. Further high-quality, robust research to evaluate the effectiveness of TSSs on adult outcomes for young people in the short, medium and longer term\(^2\).

Below are some studies, which focus specifically on models of transition in those with physical care needs, and those focussed on looked after young people.

A realist evaluation of service models of transition from paediatric to adult diabetes services provides found models with high levels of relational, flexible and cultural continuity achieve smooth transition with relatively informal, low cost informational and management continuity mechanisms. Models with more complex divisions of labour and low levels of relational and longitudinal continuity need to invest in more formal interventions to facilitate management, flexible and informational continuity to ensure smooth transition is not compromised\(^5\). See also HS&DR 08/1109/011 for a study of models of transition, in this case for CYP with disabilities\(^5\). NICE NG43 includes five reviews of transition from paediatric to adult services, often in diabetes, with evidence the role of transition clinics, and studies of implementation of interventions \(^5\) and a UK study of transition of young people with complex needs, supporting the need for person and carer centred planning user and a dedicated transition team in health services\(^5\), and Watson et al (2011) review of studies of transition informed by Normalisation Process Theory\(^55\).

NICE NG43 reviews studies of young people’s and cares experiences, and included one review and three UK studies\(^7\)–\(^10\). A synthesis of 47 studies published since 2001 of care leavers’ experience. The influence of past experiences on social support in the present, Supportive relationships during the transition from care, relationships with birth families, the crucial role of practical support and the lived experience of
leaving care. There was frequently a tension between needing support and not wanting to ask for, or in some cases accept, support. A number of studies recommended harnessing the strengths of peer relationships and setting up intentional peer mentoring programme. A small-scale study of care leaver experience in Southern England highlighted the discontinuities of providers and funding, leading to recommendation for a longer term, lifespan approach to personal budgets, and to research into longer term outcomes rather than a focus just on transition. Another small-scale study evaluated a transition service with extended foster care beyond 18 years on their involvement in transition planning and self-reported outcomes. A study by Barn (2006) of the transition and post care experience of 261 care leaver found a similar profile of need across different ethnicities, with in-care experience being a key factor in better life opportunities. The overall better experience of Asian and African young people contrasted with the experience, and longer and earlier care experiences and multiple deprivations of White and Caribbean ethnic young people. None of these studies focussed on health transitions.

A more recent study of care leavers and practitioners in England in the 24 care leavers. Ten young people described receiving specialist health services for a physical condition, and of thee, seven had moved or were about to move from paediatrics to adult health services, and three were diagnosed with a physical health condition while in the process of transitioning into adult health services. Nine care leavers were in contact with CAMHS, two had transferred from CAMHS to adult services and two had mental health needs first addressed after transition. They found gaps in health care and exceptional care were both described. But young care leavers prioritized housing, education and financial support. The process was experienced as a transfer rather than gradual transition in which they were fully involved, some felt unprepared to take on the “adult” role of their own care co-ordination, others suggested adult service practitioners needed training to understand their needs better. The authors advise that better tailored services are needed that involve young people over a period of their care, not more services.

An NIHR funded study (LYNC) is a mixed methods study in one LA of 12 care leavers and 12 staff, and analysis of 40 care records. They found that care leavers with mental health problems face multiple transitions associated with low trust of professionals, reluctance to disclose their care needs, and they felt unsupported by social and mental health services, became disconnected from services at the time of transition from social care to independence, and from CAMHS to AMHS. Staff said transitions were often poorly delivered. Young people often fell into a “care gap” between services with different thresholds. They wanted a needs-led and preference-led, rather than age and diagnoses-related services, which should be non-stigmatising, flexible and responsive. There is a need for support to prepare for the transition from care to adulthood; as well as relational continuity and greater placement stability. They said that inter-agency working was weak, without a shared protocol or information sharing or a collaborative approach to care. Recommendations for improving transition include joint commissioning across the transition period, continuity between child and adult services, staff training, care-leavers active involvement, identification and evaluation of best practice models, giving continuity of care during mental health and social care transitions could be improved by providing more age-appropriate, accessible mental health services along the lines of the youth model for young people aged 12–25 years. However, this model has not been evaluated, although it has informed a newly commissioned service in Birmingham. The researchers recommend research is needed to develop and rigorously evaluate models of transitional care that promote mental health and wellbeing.

There are a range of different service models to support LAYP engage in their care process and advocacy. There are agreed knowledge, skills and competencies for healthcare staff working with looked after young people. Local authorities have children’s rights officers, and a Children in Care Council, feeding back on services, and some provide advocacy, all have a designated medical officer, and some provide a healthcare team for those in care. An exemplar is the Children's Active Involvement Service (CAIS) for all children who have social workers, and those Looked After by Islington Children's Social Care and care leavers. There is a lack of robust evidence to determine which models are most effective for improving transitions to adult health and cares services.
Relevant work in the HS&DR portfolio and wider NIHR

Ongoing

HS&DR 14/21/52: Young people with Attention Deficit Hyperactivity Disorder (ADHD) in transition from children’s services to adult services (Catch-uS): a mixed methods project using national surveillance, qualitative and mapping studies. Active. Professor Tamsin Ford. Due to publish May 2019. http://www.nets.nihr.ac.uk/projects/hsdr/142152


Published/In editorial


PRP 109/0001/926 Transitions for young people with long-term conditions, disabilities and those looked after using health and social care services. Children's Policy research Unit Professor Helen Roberts. http://www.ucl.ac.uk/children-policy-research/documents/publications/case-studies/Sociology_and_Illness_V9.1_WEB_FINAL.pdf

HS&DR Transition from CAMHS to adult mental health services (TRACK): a study of policies, process and user and carer perspective. Professor Swaran Singh. Published 2010. https://www.journalslibrary.nihr.ac.uk/programmes/hsdr/081613117/#/


HTA 08/20/03: Developing and piloting a peer mentoring intervention to reduce teenage pregnancy in looked-after children and care leavers. Professor Gillian Mezey. Published. https://www.journalslibrary.nihr.ac.uk/programmes/hta/082003/#/


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29. Royal College of General Practitioners, Royal College of Nursing, Health RCoPaC. Looked after children: Knowledge, skills and competences of health care staff INTERCOLLEGIATE ROLE FRAMEWORK. London: Royal College of Paediatrics and Child Health; 2015.


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50. NICE. Looked-after children and young people PH28; 2008.


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