

# How it works: children and young people's continuing care

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## Introduction

Children and young people's continuing care supports those under the age of 18 who have health needs that cannot be met by existing services. The relatively small number of children and young people in each clinical commissioning group that have these needs, means that few people have a full understanding of the process.

This briefing gives an overview of children and young people's continuing care, picking up some of the terms that are commonly used, but may not be fully understood. This guide is intended to give a basic understanding for those working in NHS finance teams. It should not be used to administer children and young people's continuing care. Links to further reading and guidance are provided in the final section.

## What is children and young people's continuing care?

Children and young people's continuing care is an ongoing package of care to meet health needs arising from disability, accident or illness that cannot be met by existing universal or specialist services alone. It covers young people up until their 18<sup>th</sup> birthday. After that point, the assessment framework for NHS continuing healthcare (NHS CHC) applies<sup>1</sup>.

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<sup>1</sup> Department of Health and Social Care *National framework for NHS continuing healthcare and NHS-funded nursing care*, October 2018

The child or young person's clinical commissioning group (CCG) is usually the responsible commissioner for their continuing care. There are circumstances where NHS England and NHS Improvement will hold this role, such as for children of service personnel, or for specialised services.

Continuing care is undertaken as a multi-agency, needs led approach; involving health, social care and education.

## The children and young people's continuing care process

### Identification

A child or young person should be assessed if it is thought that they may have additional health needs. The referral for assessment can be made by a variety of professionals working across health, social care or education. Some areas allow referrals from individual professionals, others take a multi-agency approach to identification. The referring professional should provide supporting evidence for the additional needs that prompted the referral, but this may not always be the case.

### Assessment

The assessment is led by a children and young people's health assessor who is nominated by the CCG and should be completed by someone who has experience of caring for children and understands child development. This person should not be an adult service practitioner, but care should be taken that the individual is not placed in a difficult position in relation to the families that they support on a day-to-day basis.

The assessment covers four areas:

- *The preferences of the child or young person and their family*  
Preferences of all family members should be taken into account as care provision can have a significant impact on the family home.
- *Holistic assessment of the child or young person*  
A health assessment should be undertaken, and other assessments should be collated. If social care or educational assessments have not been carried out, then these should be sought.
- *Reports and risk assessments from the professionals in the child's or young person's multidisciplinary team*  
The assessor should collate evidence from professionals involved with the child or young person across health, social care and education, particularly risk assessments and reports.
- *The decision support tool (DST) for children and young people*  
Drawing on evidence from each of the above, the decision support tool ensures that all needs are captured, assessed and described in a consistent way.

### Decision support tool

The decision support tool is a national tool designed to ensure that all relevant needs are captured and assessed, in a concise and consistent way. It should be used in conjunction with other information provided from the child or young person, their family and the professionals working with them across a range of settings.

The tool sets out needs across 10 domains, divided into different levels of need:

- breathing
- communication

- eating and drinking
- mobility
- continence and elimination
- skin and tissue viability
- drug therapies and medicines
- psychological and emotional needs
- seizures
- challenging behaviour

Professional judgment should be used to ensure that the tool adequately describes the needs of the child and young person, and that these needs are over and above what would normally be expected at that age. Both met and unmet current needs should be included, even if they can be met by routinely commissioned services.

## Recommendation and decision

Upon completion of the assessment, an evidenced recommendation should be made. The decision-making panel should include key CCG and local authority professionals and at least one clinician. It should be independent from those who carried out the assessment. Decisions must be made based on need and should not be financially led.

A decision should be made within six weeks of the assessment starting. The child or young person and their family should be informed of the decision with five days of it being taken. Key professionals and organisations, such as their GP, school and local authority, should also be notified.

## Arranging care

A package of continuing care should be put in place as soon as possible after a decision has been made. It must take account of other packages of care that the child or young person may have in place. It is important that this is done after the decision, so that the decision is based on need rather than the services that are available.

The child or young person and their family must be involved in the development of the package, particularly in respect of the parental role as carers. Professionals across the necessary range of disciplines and agencies should work together to develop the package required, taking the child or young person's preferences into account.

Decisions around residential or social care must be led by the local authority as lead commissioner, although residential care should only be considered where other interventions have failed. Joint commissioning or bi-partite agreements may be required in order to develop a package that meets all the identified needs across health and social care.

## Review

Needs should be reviewed after three months and annually thereafter, to ensure that the package of care is operating well and effectively. If the child or young person's health or function is known to have changed, then a review should also be carried out. If significant, this may require a full reassessment. A review can also be requested by the child or young person or their family.

Any review should be needs based and not financially motivated. If the child or young person has multiple packages of care, reviews should be synchronised where possible. The process should be transparent, with verbal and written reports supplied to the child or young person and their family.

Needs can change and continuing care may cease to be appropriate. In this case, the care team should support the child or young person and their family to transition back into universal or specialist health services.

## Children with special educational needs and disability (SEND)

Children and young people with complex needs may not just require support from health services, they may also have special educational needs. Since September 2014, the SEND framework<sup>2</sup> applies to children and young people with special educational needs and disability, up to the age of 25. This is an outcomes focused framework across education, health and care and has at its heart, an integrated education, health and care (EHC) plan.

It is important to note that the SEND framework will not apply to all children who are eligible for continuing care, nor do all those under the SEND framework have a need for continuing care.

The assessment for the EHC plan shares many common elements with the continuing care assessment. Health, education and social care should consider how to bring the two processes together to articulate a single set of needs and outcomes, reducing the assessment burden on the child or young person and their family. The same professionals should be involved in each one.

Disputes around whether a need is primarily health or educational, should be resolved between the relevant commissioners without disrupting the provision of care.

## Personal health budgets

Since October 2014, people in receipt of continuing care for children and young people, or NHS continuing healthcare have had the 'right to have' a personal health budget in law.

A personal health budget, often referred to as a PHB, is an amount of money to support a person's identified healthcare and wellbeing needs. It is based on a personalised care and support plan, which is planned and agreed between the person, or their representative, and the CCG. It is not new money, but a different way of commissioning and spending health funding to better meet a person's needs.

A personal health budget can be used to pay for a broad range of goods and services that have been agreed to meet health and wellbeing outcomes through the personalised care and support planning process.

### Case study: Declan's story<sup>3</sup>

Declan had a diagnosis of Duchenne Muscular Dystrophy. He was completely immobile and relied on two carers for all moving and handling needs. He required frequent repositioning day and night to protect his skin and needed breathing support at night.

Declan and his mother were very reliant on each other, and he had very little independence. Declan's mother provided a lot of support, but she had her own medical problems, and there was no wider family support. He had access to respite/day care provision, but he reported that he strongly disliked attending this as he felt that the carers there didn't know him well or understand his needs. He preferred to be at home surrounded by familiar things, with his mum.

At this point, Declan was also accessing a package of support through social care for two overnight stays for one carer. This was not working well for him, as his mum was having to be a second carer throughout the night for repositioning needs. Restrictions on shift times impacted his

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<sup>2</sup> Department for Education and Department of Health, *Special educational needs and disability code of practice: 0 to 25 years*, January 2015

<sup>3</sup> NHS England, *Declan's story*, 2019

life as a late teenager; he did not want to go to bed at the time they arrived or indeed get up when they left.

Following his referral to the children's continuing care team, a visit to the family was arranged and the family expressed an interest in having a personal health budget.

The personal health budget enabled both Declan and his mother to achieve much greater independence. Declan built up confidence in the carers supporting him and built up a friendship with them rather than a more traditional carer relationship. They were similar in age and enjoyed encouraging Declan to access social activities he wouldn't have previously considered.

The original outcomes developed into much more than the family had hoped for. Declan's self-care, hygiene and dignity were achieved but he also grew in confidence and in his aspirations for achievement, seeing exciting possibilities for himself.

Personal health budgets can be made available in three ways; all three options must be available to the person who can choose one, or a combination, of methods. In all cases, the CCG retains responsibility for the provision of appropriate support for the individual, although delivery may be delegated.

1. **Notional budget** –the NHS holds the money on behalf of the individual. The person knows how much their budget is and discusses with the NHS the care and support they require to meet their needs. The NHS purchases the agreed care and support.
2. **Third party budget** – an organisation independent of the NHS commissioner and the person manages the budget and arranges the care and support for the person, working in partnership with the person to achieve the agreed outcomes. This organisation is often from the third sector but could also be an NHS provider, if conflicts of interest are appropriately managed. Some CCGs choose to offer third party budgets through a framework agreement where the contract of supply is between the CCG and the third-party provider, but the person can choose which provider to use. Other CCGs do not enter into these arrangements and the contract of supply is between the individual and the third-party provider. Third party budgets are particularly helpful when a person:
  - a. does not want to manage a direct payment
  - b. does not wish to take on employer responsibilities for personal assistants
  - c. lacks capacity or is otherwise not in a position to manage their own budget.
3. **Direct payment** – the person, or their representative, has the money in a bank account or on a pre-paid card and takes responsibility for organising their own care and support. Payments to the account are usually made monthly, in advance. A CCG can delegate delivery of direct payments to another organisation, such as a local authority who has the processes already in place to carry out this task, but the CCG retains responsibility for the payments.

More information about personal health budgets can be found in the HFMA's publication *How it works – personal health budgets and integrated personal budgets*<sup>4</sup>

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<sup>4</sup> HFMA, *How it works – personal health budgets and integrated personal budgets*, November 2018

## Transition to NHS continuing healthcare

Eligibility for children and young people's continuing care does not automatically mean that the person will be eligible for NHS CHC when they turn 18, as the legislation and associated criteria are quite different.

Where it is anticipated that NHS CHC may be appropriate in adulthood, children's services should notify the responsible CCG when the child reaches the age of 14. A formal referral for screening for NHS CHC will be made when the person reaches 16, with a full assessment of eligibility after their 17<sup>th</sup> birthday. This timescale ensures that packages of care can be commissioned and in place by the time the individual reaches their 18<sup>th</sup> birthday.

Further information about NHS CHC is available in the HFMA's publication *How it works – NHS continuing healthcare*<sup>5</sup>.

## Conclusion

Children and young people's continuing care supports those under the age of 18, and their families, where existing health services cannot meet their needs effectively. It can draw together health, social care and education in order to provide a rounded package of care.

It is important that NHS finance staff understand children and young people's continuing care to ask questions of those involved and assist the service to deliver the care and support that people need, while making the most effective use of resources. An understanding of the challenges encountered for children and families when they transition between services due to age and the difficulties of varying age boundaries, depending upon service and sector, can inform future service development and audit processes.

This guide gives NHS finance staff an overview of children and young people's continuing care. It should not be used as an implementation guide or to administer continuing care processes.

## Further information

- This briefing has made extensive use of the Department of Health *National framework for children and young people's continuing care* which can be found at <https://www.gov.uk/government/publications/children-and-young-peoples-continuing-care-national-framework>

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<sup>5</sup> HFMA, *How it works – NHS continuing healthcare*, May 2019