The first step in the process should involve a qualified health or social care professional using a checklist to evaluate whether the person in need of care qualifies for a full assessment. The full assessment should be co-ordinated by the local CCG or the local authority within defined timescales. A team of professionals join together to conduct the full assessment. This group is called a multidisciplinary team (MDT) and should involve professionals from across health and social care who are familiar with the individual’s needs.

Gillian’s experience

“Mum has had Parkinson’s for a long time but was coping well until my dad passed away. After his death, she started going downhill. My brother and I stepped in to support her, but eventually her needs got too great and we had to acknowledge she needed round-the-clock care.

I found out about NHS CHC by accident. When it came to the assessment I was nervous they wouldn’t understand mum’s condition, and what it meant for her day to day. The team was made up of a group of professionals, including a Parkinson’s nurse. And to my surprise, the nurse assessor who co-ordinated the multidisciplinary team had just done a course on Parkinson’s herself, so she had a really good grasp of the issues. As a family we felt really involved in the assessment. It seemed to me that the MDT all worked together to make their decision, they also wrote a lot of notes. We were lucky, mum was awarded NHS CHC, but I think there is a real risk the wrong conclusion would have been drawn if mum hadn’t been assessed by people who were expert in her condition.

Positive progress

- The National Framework was introduced to ensure NHS CHC is implemented in the same way across the country. If every CCG, Commissioning Support Unit (CSU) and local authority followed this guidance CHC provision would more often be implemented to a satisfactory standard. The recommendations include:
  - Defining an MDT as a team of at least two professionals from either the health or social care professions, who have an up-to-date knowledge and understanding of the individual’s needs, potential and aspirations.
  - Advising that friends or family who care for the person applying should be included in the assessment process. Our survey results show 44% of respondents felt fully involved.
  - Stipulating that health and social care professionals with condition-specific expertise are involved when the person being assessed has a diagnosed condition. For example, an assessment of someone with Parkinson’s could include a Parkinson’s nurse or a neurological nurse. If this isn’t possible, every effort should be made to source specialist advice in advance, and this should be considered during the assessment.

- NHS England has developed e-learning training modules for professionals working in the NHS CHC system.

- In some areas of the country CHC teams sit in the local authority, while others are part of the CCG or CSU. When they work well, the nurse assessor works with the family, alongside health and care professionals, to co-ordinate a team of skilled experts to conduct an assessment. They also source evidence from specialists, taking into account the family’s views and keeping them updated on the outcome.
Current challenges

• Despite the National Framework being in place, some local decision makers appear to regard it as guidance, choosing which bits they intend to follow.

• Worryingly, 32% of survey respondents who had applied for NHS CHC told us the assessment was not conducted by an MDT.

• All of the MDT members involved in the assessment should have their opinions valued equally. However, 10% of professionals who completed our survey told us that opinions were not weighed equally during an MDT. An additional 40% said they had mixed experiences, where in some assessments opinions are weighed equally and in others they are not. 29% of people applying for NHS CHC who completed our survey told us that one member of the MDT had their opinion valued more highly than other members.

• The decision on whether someone is eligible for NHS CHC often depends on the quality of evidence. We know this varies greatly, with some assessments resulting in two lines of evidence, while others produce several pages.

• Despite national guidance stating that condition specialists should be included, 66% of survey respondents felt the professionals in the assessment did not possess any in-depth knowledge – or knew very little – about the condition of the person being assessed.

• We know some assessments take place where members of the MDT have never met the individual or family before.

• The role of the co-ordinating assessor, also known as the nurse assessor, is to co-ordinate the MDT and be impartial. They should not dominate discussions, and their opinion should not be afforded greater weighting than anyone else. However the alliance is aware of instances where this happens.

Emma’s experience

I’m a neurological conditions clinical nurse specialist. I work with people who live with conditions like multiple system atrophy (MSA), MND, progressive supranuclear palsy (PSP) and Huntington’s.

We have an NHS CHC co-ordination team based within my local CCG and they are fantastic. It’s very clear who to contact to start the assessment process. If I think someone is eligible, I’ll complete the checklist myself. This gets sent to the CHC team which is staffed by nurse assessors. The nurse assessors liaise with the individual and organise an assessment as quickly as possible. They have a can-do attitude and are very responsive. I let them know if I need to be part of the MDT, and they contact a cluster of other relevant professionals, while also ensuring the patient and their representatives are involved.

Sometimes a decision is made the same day, which means the families know there and then whether they qualify. When NHS CHC is awarded, the nurse assessors help co-ordinate the care package. My patients often have very complicated conditions which can mean they need to access hugely costly and complex care packages. If this is what is required, it is put in place. Often the agencies used are more expensive and specialist than the ones the council are able to employ. We are always driven by the need of the patient, rather than being led by the price of the care needed.
Chloe’s experience

“...I’m an occupational therapist and work with a team including physiotherapists and speech and language therapists. Many of my patients have deteriorating conditions. I am astounded by how few of them receive CHC funding, even when they are near the end of their lives. Being a health professional, I know what the NHS CHC criteria are and I won’t complete a checklist unless I believe someone qualifies. We don’t want to put these people through the lengthy assessment process if they are not likely to get a positive result.

We used to have a local CHC team, but then it got centralised and moved out of our area. Since then things have gone really downhill. The first major problem is that the nurse assessors often don’t tell us when the assessments are taking place. We only find out about them if we are told by chance, often by a patient or family member. We know that nurse assessors often assess people on their own and make decisions on eligibility. This should not be happening.

When we do attend assessments it can be extremely hard to make the nurse assessors understand why someone has complex health needs. I was recently working with a gentleman who had PSP. He couldn’t move and needed hoisting everywhere. His condition meant he often didn’t remember this limitation so he would often try to stand and then fall over. He had awful swallowing problems, where he had so much saliva it got into his lungs. This meant his mouth was constantly having to be cleared. He was fed through a tube eight times a day. His wife was providing all his essential care.

I was part of the MDT that graded him at the highest level for nearly half of the categories in the DST, which should have meant he qualified for NHS CHC.

When the case was reviewed the nurse assessor said he wasn’t eligible. We couldn’t believe it. They said they disagreed with how unpredictable his needs were. His application was rejected. We appealed the decision but he passed away two months later.

It’s vital that the treating professionals who see the person on a monthly basis and really understand their condition are listened to. In my experience the opinion of the nurse assessor has overruled other MDT members. It’s incredibly frustrating for us, and really distressing for the people involved.

What needs to happen?

• CCGs must ensure that MDTs always meet the minimum requirements of the National Framework, particularly in respect of including “those who have an up-to-date knowledge of the individual’s needs, potential and aspirations”⁵. Ideally this would apply to all the health and social care professionals involved in the care and treatment of the individual.

• CCGs must involve professionals with condition-specific expertise – preferably in person, or where this isn’t possible by requesting evidence and advice in advance – and demonstrably give due regard to this professional judgement.

• CCGs must ensure that the professional judgement of all MDT members is given equal weight alongside ensuring that nurse assessors fulfil the co-ordination role described in the National Framework, and do not inappropriately overrule other members of the MDT.

• CCGs must demonstrate that the person being assessed (where possible) and their carers are involved in the assessment and their opinions are given due regard.

• Professionals from the local authority must be aware at what level they are able to offer support for people. If the person’s healthcare needs exceed the level that the local authority can lawfully provide for, they should then be eligible for NHS CHC. This should be made explicit by professionals and be clearly documented.

⁵ National framework for NHS continuing healthcare and NHS funded nursing care (Nov 2012) Annex A