Executive summary

Key problems

The Continuing Healthcare Alliance believes that NHS continuing healthcare (NHS CHC) is failing people across England. The current system attempts to artificially divide the care and support that sick and disabled people need into 'health' care and 'social' care. For example, eating and drinking is considered a social care need while nutrition is a healthcare need. As a result the dividing line between a healthcare need and a social care need is fundamentally blurred. If someone is unable to eat and drink for a sustained period, they wouldn't live for long unless they received medical intervention. Due to flawed processes, many people who should be found eligible are being denied this much-needed support.

Alongside this, those who *are* granted NHS CHC funding are often given inadequate care packages that don't meet their needs.

To provide an accurate picture of how the system works, we've gathered evidence from across England. As well as speaking to people individually, we created two surveys: one for individuals who had applied for NHS CHC, the second for professionals who work on NHS CHC. We also conducted a Freedom of Information (FOI) request that was sent to every Clinical Commissioning Group (CCG) in England[3].

Vision for the future

We strongly recommend that NHS England and the Department of Health consider how CHC will operate in the NHS after the implementation of the *Five Year Forward View*, and prepare to make any changes necessary. Patients should be closely consulted during this process to ensure the system operates effectively, and does not continue to be blighted by the failings identified in this report.

The Continuing Healthcare Alliance wishes to support NHS England and the Department of Health with this important task.

Our findings confirm that the system is letting people down:

- **40%** of professionals who completed our survey told us that their experience of decision making in a multidisciplinary team (MDT) can be very mixed. In some assessments opinions are weighted equally, while in others they are not.
- **66%** of survey respondents felt the professionals in the assessment did not possess any in-depth knowledge – or knew very little – about the condition the person being assessed was living with.
- **80%** of professionals surveyed said the Decision Support Tool (DST) was not fit for purpose, or there was room for improvement in some areas.
- Those with well-managed needs are often assessed as being ineligible despite having needs that qualify. Denial or withdrawal of care could result in making their needs worse.
- **42%** of survey respondents who had applied for NHS CHC told us they waited more than 28 days (the deadline set by the National Framework) to receive their final decision regarding eligibility.
- **35%** of survey respondents told us they had been told by the multidisciplinary team that eligibility would be recommended, only to have that decision rejected by the review panel.
- Some CCGs are introducing policies that force people into care homes if the cost of their care is more than a residential care package, irrespective of whether this approach meets their assessed needs.
- When less funding is received patients can be transferred to another care company, resulting in the loss of professional carers that the person and their family know and trust.
- **44%** of people surveyed had gone through at least one reassessment after being awarded NHS CHC.

[3] See appendices 2-4 for more information on these surveys and the FOI.

Susan's experience

"I met my husband, Bob, while at university. After getting his PhD in applied sciences, he became an engineer and went to work for the Ministry of Defence. He worked through the Gulf War, commissioning special equipment for desert conditions. He got the Queen's Commendation. In his early sixties, Bob was diagnosed with an aggressive form of Parkinson's. Within six years he went from being independent to needing a wheelchair, hallucinating, having short-term memory loss, being awake all night and having bowel collapses. I was caring for Bob alone until our Parkinson's nurse suggested we apply for NHS CHC. I had never heard of it so didn't know where to start. She helped me fill in the forms, but I didn't hear anything for four months. When I phoned, the CCG always said they were waiting for more information, but didn't say what. I was shoved from pillar to post. It didn't feel like anyone knew what was going on.

Bob had to move into a nursing home, and passed away aged 70. The day after his death the CHC assessor knocked on my door to conduct his assessment. I explained the situation and she said she'd conduct a retrospective assessment. Seven months later, I received a 64 page document. It came with a covering letter asking me to read through the information and provide comment. I didn't really understand what I was reading, but having to focus on details of Bob's condition was painful and I got very weepy. When I finally got to the end, on the final page it said their decision had already been made, and they were rejecting our application. I couldn't believe it! Surely they should have told me that upfront before I started? The whole process was dreadful. I'm an educated and capable person but I was exhausted and really angry. They seemed to forget they were dealing with real people.

Key recommendations

For NHS CHC to improve, the Department of Health, NHS England, CCGs and local authorities should initiate the following changes:

- Ensure multidisciplinary teams are composed of professionals who are experienced when making decisions around NHS CHC, with knowledge of the person, their condition(s), needs and aspirations.
- Design and deliver a mandatory programme of training for professionals who organise and assess people for NHS CHC to ensure they understand the eligibility criteria and how to use the current decision tools.
- Rewrite the checklist and Decision Support Tool so they more effectively measure individuals' healthcare needs against the lawful limit of care that the local authority can provide.
- Introduce an option for professionals to select if they agree that someone should not be reassessed for eligibility of NHS CHC. For people marked down as permanently eligible, reviews should only look at changing needs, for example, where someone may need increased support.
- Prevent people with long-term, serious health conditions being forced into residential care, or living at home with unsafe levels of care, by ensuring packages of care are needs-driven and not purely financially motivated.
- Publish data on how many people apply for NHS CHC – whether they are successful or not – as well as the number of people who proceed past the checklist stage to the full assessment.