Dysfunctional decisions: how the Decision Support Tool is used

The Decision Support Tool (DST) is the nationally mandated tool for assessing whether an individual's healthcare needs place them beyond what the local authority can legally provide. If their needs are high enough they should be eligible for NHS CHC. Completing the DST involves looking at the individual's care needs across 12 broad areas of care (care domains) and allocating a level of need in each. The care domains are designed to help assessors identify healthcare needs across a wide range of conditions. In each domain, examples are given that would typically represent the different levels of need.

However it's not only these scores that determine if the individual is eligible for NHS CHC. Professionals should also use the four key indicators where relevant.

The key indicators refer to the four key characteristics of need including nature, intensity, complexity and unpredictability. Each of the four key indicators may alone, or in combination, indicate a primary health need. The MDT should use their professional judgement to consider the combined need identified across the domains and indicators.

Positive progress

- The creation of the checklist and DST as part of the National Framework has meant that everyone is technically measured against the same criteria. However, in practice we know this assessment process is largely dependent on the team conducting the assessment.
- The four key indicators form part of the DST. This is a particularly important measurement for those who have cognitive impairments or fluctuating conditions.
- The NHS CHC operating model and assurance framework were created to:
  - improve the application of the DST assessment
  - measure CCG performance to improve consistency of assessments and outcomes across CCGs
  - use Quality Surveillance Groups to hold CCGs to account
  - involve the NHS England Directorate of Commissioning Operations to hold CCGs to account
- The DST allows someone to be assessed if they don't have any health needs, but instead have extremely challenging behaviour. This is a positive change, but sadly is not often taken into account.

THE LAW

Pamela Coughlan case

In 1999 Pamela Coughlan went to court after the NHS attempted to stop funding her care and pass it over to the local authority. She was tetraplegic, but could use a computer with voice technology and an electric wheelchair independently.

The court ruled that her healthcare needs were significant enough to be beyond what a local authority could reasonably be expected to provide, and were therefore the responsibility of the NHS.

Pamela Coughlan's case is significant because the health needs they identified were not that substantial.

The key question that the court had to decide was where the boundary between the responsibilities of a local authority and the NHS lies. In other words, how much care does an individual need in order to qualify for NHS CHC?

Pamela Coughlan's court case made case law. This should mean that if an individual has higher needs than Pamela Coughlan, but doesn't meet every threshold on the DST, they should still qualify.

Current challenges

- **80%** of professionals surveyed said the DST was not fit for purpose, or there was room for improvement in some areas.
- **73%** of survey respondents who applied for NHS CHC felt the DST did not ask relevant questions to elicit an accurate impression of a person's situation.
- Despite explicit guidance[6] to the contrary, there is evidence that assessors use the DST tool mechanistically, and do not apply their own professional judgment. The examples given in the DST often represent extreme failures, or an absence of appropriate care and support. These examples can prejudice assessors by artificially raising the eligibility threshold and making them believe people have to be worse than they do in reality. For example:
  - In the nutrition domain the descriptions of what would constitute a severe level of need are "unable to take food and drink by mouth. All nutritional requirements taken by artificial means requiring ongoing skilled professional intervention or monitoring over a 24 hour period to ensure nutrition/hydration, for example I.V. fluids **or** unable to take food and drink by mouth, intervention inappropriate or impossible." If this description is used as a benchmark by the assessment team, the person being assessed would have to be at the point of death in order to qualify. This is not the threshold at which CHC is intended to be made available

The DST is a guide. The court has set the level at which someone must receive NHS CHC. In the Pamela Coughlan judgment the judge decided that if healthcare is more than 'incidental or ancillary' it falls into the healthcare category rather than social care.

- People with well managed needs are often assessed as being ineligible despite having needs that qualify. The DST can often be used to measure the failure of care, rather than the care needs of the person. For example, if someone has serious bed sores where their skin has broken, this would qualify. Someone with the same health needs who was being regularly moved by trained professionals to avoid bed sores would, under this incorrect interpretation, not necessarily qualify.
- Some professionals have shared their frustration that less attention is paid to the four key indicators. It is absolutely crucial these are factored into the final decision. For example, if someone scored lower in one of the domains, they could still be found eligible based on the unpredictability and complexity of their needs.
- When being assessed someone's diagnosis should not be relevant. The assessment should be purely based on their needs. Despite this, the alliance hears evidence from people who tell us that they have been refused NHS CHC because their needs are a routine part of their condition(s) and its or their progression. Assessors therefore conclude, incorrectly, that those needs are outside the scope of NHS CHC.
- The alliance has seen situations where someone is assessed as having no emotional or psychological needs because they have a cognitive impairment which means they communicate differently.
- When an MDT makes a recommendation that someone should receive NHS CHC, the CCG should sign it off unless there are exceptional circumstances which should be for a clearly articulated reason. Such reasons can include missing evidence, or major differences between the evidence and the recommendation. However, the alliance knows that sometimes CCGs say that exceptional circumstances are simply that they disagree with the decision. This is not how the guidance should be interpreted. **35%** of survey respondents told us they had experienced the MDT awarding eligibility, only to have that rejected by the review panel. If this represents the numbers being turned down for that reason, these can in no way be considered exceptional.

[6] National framework for NHS continuing healthcare and NHS funded nursing care (Nov 2012) paragraph 88

Alison's experience

"My father-in-law, Tom, was an intelligent and independent man with an amazing memory. He graduated from Oxford, was an Artillery Instructor during the war, and then became a teacher. At 96, his health was going downhill. He had several mini strokes and developed vascular dementia. I enquired about applying for NHS CHC. I knew about it because I've been a nurse for more than 40 years.

An assessment took place while Tom was living in a nearby care home. At the time of the assessment he had no short-term memory, was immobile, deaf and partially sighted. He couldn't feed or wash himself, and he had a catheter fitted as he couldn't go to the loo. Having a catheter made him vulnerable to infection, so he often required medical attention to deal with that. He couldn't eat or drink independently and had lost lots of weight.

During the assessment they used the DST to assess the severity of Tom's needs. The criteria can be interpreted differently by the people conducting the assessment. I believe the team assessing Tom manipulated some of the information. For example, when assessing his mobility they decided that because he could shuffle about in bed, he was mobile and therefore did not qualify. What's their definition of mobility? He couldn't walk, stand or even turn over in bed, which I think means he was immobile. It was very clear to me that the assessment was a sham. It was awful to watch. Tom was completely reliant on others to provide his care. I felt the assessors seriously downplayed most of his problems.

Our application was turned down. If he wasn't eligible, I don't know who would be! We appealed their decision several times, and were finally successful four days before Tom passed away.

As well as being very concerned professionally by how this process was conducted, I worry about my own future as I have MND. The thought of being assessed through this process myself is terrifying.

What needs to happen?

- The checklist and Decision Support Tool should be rewritten so they more effectively measure individuals' healthcare needs against the lawful limit of care that the local authority can provide.
- CCGs and local authorities must ensure all staff who deal with NHS CHC have thorough training to understand the lawful limit of care that the local authority can provide regarding healthcare, as defined in the Coughlan judgment. The training should be mandatory.
- Until the assessment tools are rewritten, MDTs must adhere to the National Framework by not using the current tools mechanistically. Instead assessors must use the key indicators and their professional judgment[7] when deciding on an individual's eligibility for NHS CHC.

[7] National framework for NHS continuing healthcare and NHS funded nursing care (Nov 2012) paragraph 88