

The Unfair Lottery of Continuing Health Care: Is CHC Failing People and Practitioners?



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Executive Summary

Key Findings

- **CHC funding is harder to get:** The number of people receiving Standard CHC has fallen by 3,300 in seven years, despite an ageing population.
- **£270m annual cost shift:** Fewer CHC approvals mean costs fall to councils and families. This equates to £1.8m per year per upper-tier authority.
- **Unfair variation:** People's chance of receiving CHC depends on where they live. The highest-rate ICB area funds 3.5 times more people than the lowest, with no clear link to health need.
- **Practitioner frustration:** Checklists are inconsistent, quality is variable, and rework is common. Both social workers and nurse assessors feel the process is burdensome and strained.
- **Impact on families:** People report the process as “appalling and gruelling,” with some giving up entirely.

Why This Matters

- **Adult Social Care:** Rising costs and stretched budgets mean unfairly low CHC rates directly undermine financial sustainability.
- **ICBs:** Inconsistent, poor-quality Checklists slow down decision-making and increase disputes.
- **People:** Families face unnecessary stress and gaps in care at the most difficult times of life.

The Solution: CHC Plus

CHC Plus is an AI-enabled tool co-created with councils to improve the quality, speed, and consistency of CHC Checklists.

- **Saves time:** Produces a high-quality draft Checklist in minutes.
- **Improves quality:** Trained on good practice, ensuring clear, evidence-based submissions.
- **Builds confidence:** Supports social workers to complete Checklists they may otherwise avoid.
- **Strengthens relationships:** Creates shared data and evidence for local authorities and ICBs, reducing disputes.
- **Supports finance control:** Tracks volumes, outcomes, and rework, providing real performance data.

What Leaders Can Do

- **Adopt CHC Plus** to improve quality and free up practitioner time.
- **Use the data** to monitor fairness, challenge inconsistency, and reset relationships with ICBs.
- **Reduce financial risk** by maximising rightful access to NHS-funded care.

 To explore CHC Plus for your area, contact: Emma Ockelford – Outcomes Matter Consulting
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“[The assessor] had obviously been instructed to refuse cases wherever possible.”
“I was warned that it was almost impossible to get full CHC funding.”
“No reason [was] given officially but [I was] told because budget insufficient and others worse”.

These statements reflect the experience of people going through the Continuing Healthcare (CHC) process. CHC funding supports some of the most vulnerable people, including those with significant health needs and at the end of their lives.

When the process is difficult, complicated and confusing it compounds what are often distressing experiences of giving and receiving care as illness escalates.

Talk to practitioners and you hear a similar story about a system that is not working.

They say that CHC funding is getting harder to get and that decisions are inconsistent. Social workers tell us about being left out of the process, and ICB nurse assessors about the poor-quality referrals they receive.

This is not despite effort. The costs involved are huge; the NHS budget for 2023 was

£6.5bn.



Extensive resource is invested by local authorities, ICBs and other care professionals to administer the process, as well as by families to gather information.

CHC is the process by which a person with “primary health needs” receives full NHS funding of their care and support, including personal care and support needs that a local authority might pay for. It has two streams – Fast track for people in the last few months of life, and Standard for everyone else. Although it does vary nationally, with Standard CHC, a social worker or professional in the community typically completes a CHC Checklist, with an ICB nurse assessor then completing a full assessment.

In this report, we assess the state of Standard CHC. We use national data, reports by other organisations and our own research to assess the truth in some perceptions within the system and suggest a way forward. **We ask: Is Standard CHC funding getting harder to get? Is Standard CHC fair? What does it mean for people and practitioners? How can we make it better?**



Question 1: Is CHC funding harder to get?

✚ Government data suggests that councils are correct in their assessment that funding is harder to get. According to central government figures, 33,827 people were receiving standard CHC funding on 31 March 2025. 7 years earlier, it was 37,116.

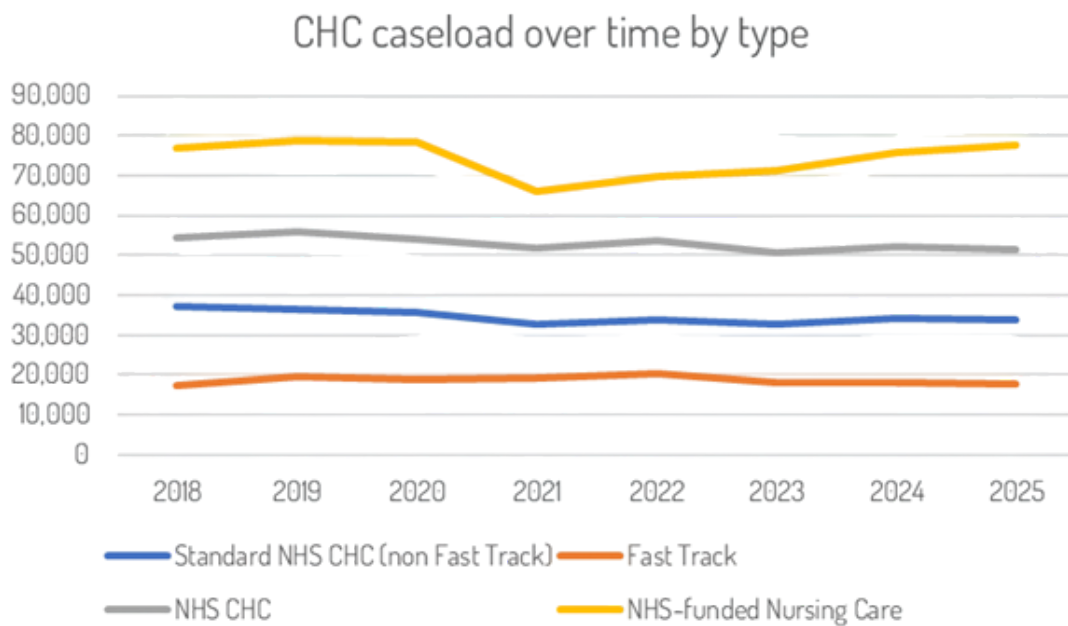


Figure 1: Graph showing how CHC caseload has changed over time based on snapshots taken on 31 March every year 2018-2025. Caseload broken down into types of CHC funding



This is despite an increase in the number of older people and people with chronic conditions. The number of people aged over 65 increased by 6% in same period. If we consider the expected increase due to an ageing population, **this suggests that there is a gap of 5516** people not receiving CHC funding compared to 7 years ago.

For cash-strapped councils, this shift has significant consequences. Based on average care costs of £950 a week, that is a cost shunt of £5.2mn a week or close to £270mn a year from the NHS to councils and to people who self-fund. This averages at £1.8mn per higher tier local authority per year. Given that people with CHC funding often have the most complex needs and therefore the most expensive support, this is likely an underestimate.

Our analysis does not suggest the ICBs are wrongly rejecting cases; assessing the 'right' rate of CHC is tricky. Indeed, one factor has likely been the introduction of Discharge to Assess, in which the percentage of people who have their Standard CHC assessments in hospital has fallen from 18% to 0%.



These might mean assessments are undertaken when someone is closer to baseline after recovering at home, so is more accurate. It might also mean that fewer people are being assessed because there is less pressure to clear a hospital bed, so people are missing out.

The reduction in the rate is despite increasing NHS spend on CHC (Standard and Fast Track) which rose from £4.3 2015/16 to budget of £6.5bn in 23/24 'likely reflecting factors such as the increased cost of care and increased complexity of needs for those eligible.'

So, if CHC rates are down, is it because the process is getting fairer?



Question 2:

Is CHC fair?

It only takes a brief glance at CHC data to see the massive variation in rates across the country. Numerous reports have highlighted that the rate of CHC in the highest rate area is 3.5 times the lowest. In a fair system, people would receive CHC funding who are qualified for it regardless of where they live. As a result, areas with higher levels of need would have higher rates.

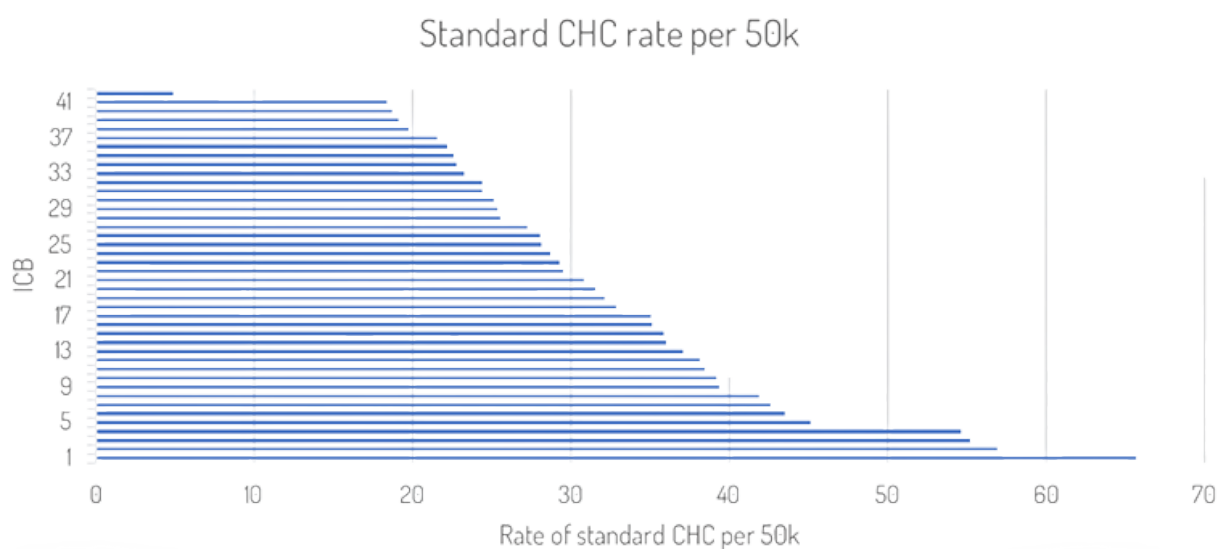


Figure 2: Graph showing Standard CHC rates per 50k as per 31 March 2025, sorted by ICB

To assess whether CHC rates correlate to population need, we built the CHC index. We identified and mapped the population factors that should drive CHC and then compared this with actual rates.

We started by considering what factors we should use. Ultimately, CHC funding is given to people with significant health needs. The NHS measures rates of chronic conditions at GP and ICB level. We selected the 6 conditions which are most common causes of CHC – dementia, diabetes, heart failure, COPD, chronic kidney disease and osteoporosis. We ranked each ICB against each of these factors and combined them to create a predicted Standard CHC ranking. We then compared this prediction to the actual ranking.

What we found was a very weak correlation of 0.10. In other words, the areas with the highest levels of chronic illness were only slightly more likely to have a high rate of Standard CHC funding compared to a low need area. The three ICBs with the highest Standard CHC rate have respectively, an average level of chronic illness, a very low level of chronic illness and a high level of chronic illness.

We were surprised the correlation was so weak so we looked at some other factors to see if they were stronger. We considered at the percentage of the population aged over 65 and Index of Multiple Deprivation rankings as ages and deprivation are drivers of with chronic ill health. The correlation between population 65+ and our expected CHC ranking based on health data was high (0.87), as you would expect.

However, the correlation with Standard CHC rates were similarly weak (0.09). For the Index of Multiple Deprivation, it was slightly negative (-0.05), meaning areas of high deprivation had marginally lower rates of Standard CHC.

	Rank of Standard CHC rate per 50k	Expected rank of Standard CHC based on chronic illness prevalence	Rank of population 65+
Expected rank based on chronic illness prevalence	0.10		
Rank of population 65+	0.09	0.87	
Rank of index of multiple deprivation	-0.05	0.15	-0.13

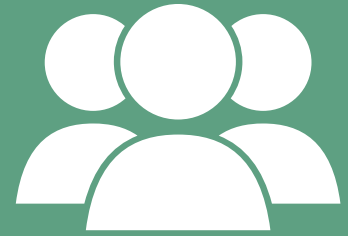
Figure 3: In the table, 1 is a perfect positive correlation and -1 a perfect negative correlation. 0 indicates the data does not correlate at all. As the table shows, while the expected CHC rank correlates to age and deprivation, the actual CHC rate only very weakly correlates to any likely determining factor.

This suggests that the instinct that CHC rates are unfair is correct. If rates are not driven by underlying population need, local practice must be causing the difference.



Figure 4: CHC Index comparing Standard CHC rates per 50k with expected rates.

Question 3: What is the impact of this on people and practitioners?



The squeeze in access to CHC and the inconsistency in practice has a negative impact on practitioners across the system.

Practitioners recognise practice could be improved. When we asked social workers to rate the quality of CHC Checklists their council produced, they gave us everything from 1-10 with an average of 6. This matches what nurse assessors have said about a lack of consistency in the Checklists they receive and our own review of anonymised Checklists within a single council, which shows unclear outcomes and decision making. National data backs this up – across Sub-ICBs, the percentage of NHS Continuing Healthcare assessments that result in eligibility range from 5% to 58.3%.

This quality issue exacerbates relationship challenges.

90%

of ASC respondents agreed that 'Disputes between partners are a significant burden on the system'.

In one case study, CHC funding was stopped following a review that social care were not invited to. After appealing the decision, FNC funding was put in. Both nurse assessors and social workers told us they would like to work together better but poor-quality applications, communication and decision making can cause frustration all around.

Social workers told us they think that ICBs apply criteria inconsistently and have become stricter in their interpretation of criteria. They feel Checklists are rejected when they should not be and are time-consuming to complete. They also think the process ends up being unfair. Nurse assessors feel this as well and are frustrated at the Checklists they receive. It absorbs time for everyone when documents are bounced back and forth.

📌 This matters in an industry in which **58% of social workers think workloads are unmanageable, 97% think vulnerable people would be safer if caseloads were lighter, and 65% say their mental health is suffering because of their work.** Nurses report similar wellbeing and caseload challenges.

All of this leads to a bad experience of CHC for some vulnerable people, at the particularly distressing moments of escalating ill health. Although some people find the process easy, numerous studies have highlighted negative experiences. An Age UK report in 2024 found that:



People don't know they are eligible and often hear from charities, or engage with medical professionals, such as GPs who don't understand the process.



When a family member does not meet the criteria, families do not understand what and are even told that it is because funding was rationed.



Families are falling through the gaps, left providing nursing care because social care support is unable to manage needs, but are still being rejected for CHC.



Many reported negative experiences of the process that was 'appalling and gruelling'. Some said they gave up because it was too painful.



CHC funding was withdrawn when a person's needs only got worse. The fear of support being withdrawn was very stressful for families.

Question 5: How can we make CHC better?



Overall, the evidence suggests that Standard CHC funding is harder to get and unfair nationally, with a negative impact on professionals as well as people receiving support and their families. How do we make the system work better?

Changes in national policy may be required for a full reset of the system. However, local areas can still make changes to make the experience of CHC fairer and better. We co-created **CHC Plus** with councils to help address the core problems in the system. Introducing **CHC Plus** alongside practice improvement can lead to benefits for local authorities, ICBs, and the people and families they support.

What is CHC Plus?



CHC Plus is a tool that uses AI to produce a high-quality, consistent draft of a CHC Checklist. The social worker uploads the documents they usually use to write a Checklist.

The AI tool then generates summaries of needs in each domain. The worker reviews and improved the summaries and rates the needs. They then download the completed Checklist ready for the usual QA process. CHC Plus can be embedded in your practice and service development to enhance the opportunities identified.

We recommend:

Record and use data better to measure performance, inform decision making and reset relationships 📊

Local authorities often keep very little data on CHC. When we have asked, we are often told they don't know how many people receive CHC funding in their area, how many Checklists are completed, how many are positive or negative and how many get accepted. Some of this data is held at ICB level but if the local authority is not coterminous, it is hard to get a full picture.

Keeping better records and looking at national averages allows local authorities to assess whether your local rate is likely high or low. This can be compared with local health data which public health teams do keep at a local authority level. We recommend CHC managers also improve tracking internally. How many Checklists are completed? How many are positive? How many require rework, internally or externally? Are there consistent problems you need to consider like quality of evidence? This evidence is essential in knowing how to target training and support, assessing effectiveness and challenging ICB colleagues if things are changing.

CHC Plus can support this. Data tracking in the tool means you can monitor how many checklists are completed – both positive and negative, how long it takes and how good the quality is. When we implement **CHC Plus**, we work with the area to baseline existing CHC performance and practice.

This provides the ongoing evidence to monitor how effective your CHC applications are, allowing you to note how practice is improving or to evidence if standards at the ICB change. Having real data provides a stronger basis for resetting relationships than anecdotal evidence and perceptions of change.

Produce better Checklists



Understanding what stops social workers producing high-quality Checklists is crucial to making them better. ASC staff identified time constraints as the biggest barrier. Managers told us that they think sometimes Checklists are not completed when they should be because social workers don't have time or prioritise different tasks. Social workers also struggle to get the right evidence and engagement from families and care homes.

CHC Plus drives improved quality. **CHC Plus** produces a good quality checklist every time. Trained on good practice and tested extensively by social workers on real cases, it pulls through the relevant information using the correct tone and language. This improves consistency. With **CHC Plus**, it is much quicker to create a Checklist. That means the key barrier to good quality Checklists – time – meaning social workers are more likely to produce one.

There is an appetite to complete Checklists better.

77%

thought more training would improve quality and we know that across the country many CHC managers are working hard with the ICB counterparts to deliver and embed this training.

Introducing **CHC Plus** is a great way to upskill your teams. Using AI can lead to concerns about deskilling. However, because workers will need to review summaries and rate domains, they will be exposed to good practice. The training to use the tool can be combined with training on CHC. And the conversations around implementation support building awareness of why CHC matters. By saving time in completing Checklists and removing barriers due to lack of confidence and skill, **CHC Plus** creates space to have better conversations about CHC. **CHC Plus** comes with a support package to help you build your practice.

Work with nurse assessors to understand what they are looking for



In our research, we have found examples of excellent relationships between ICB nurse assessors and local authority CHC managers which have led to improved practice.

As nurse assessors accept or reject Checklists, their feedback around what they want to see is vital. In our research, nurse assessors told us they valued high-quality Checklists more than local authority colleagues appreciated. Specifically, they told us they wanted to see the below:



They need to see concrete evidence of care needs aligned the framework but they often received strengths-based summaries of a person. This is how social workers are trained to write and it can be uncomfortable for social workers to write in this negative way.



Sometimes local authorities think Checklists are a formality, providing minimal information, whereas it is a critical foundation to inform the full assessment. This means that local authorities could support a successful full assessment more by producing a well-written Checklist with the appropriate information.



Domains are often overscored with insufficient evidence provided which means the Checklist has to be rejected and rework may be required.



It is not always clear where the evidence comes from making it hard to trace back when picking up the full assessment process.



So what can adult social care workers completing Checklists take away from this to make sure they write better Checklists that get accepted first time?

- > Clearly describe how a person's symptoms impact on the care they receive.
- > Provide factual information and indicate where it came from.
- > Clearly describe the support currently in place and how effective it is.
- > Once you have scored a domain, read through the description to confirm you have provided enough evidence to explain your rating.
- > Think of your descriptions as setting up a full assessment and providing a springboard for it.

Overall, talking to nurse assessors highlights the way that improving the way CHC Checklists are written could reduce rejections and rework, saving time for everyone working in the system and reducing frustration on both sides.

This would ultimately be better for people being assessed as they might get funding sooner and in a simpler way. We recommend nurse assessors and CHC managers review this list together to see how it matches your experience, assess your current practice and identify areas of improvement.





CHC Plus can help to kick-start that conversation. Because **CHC Plus** saves time in producing Checklists, Checklists produced are more detailed and set up the full assessment better.

Whereas a worker might not have the time to provide a detailed summary, with the help of **CHC Plus** a fuller picture of need with clear sourcing is shared with the ICB to inform their assessment.

Nurse assessors can also get involved in the trial period, testing the outputs from **CHC Plus** and giving feedback on what they want to see. This feedback can be immediately incorporated into the tool. This is a great opportunity for ICB teams to shape the Checklists they receive, Checklists that won't require time consuming rework on all sides. It also provides a chance to reset relationships if they are difficult and to collaborate better.

To find out more about CHC Plus or to explore our insights and data, please contact



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- Age UK – Continuing to Care: NHS Continuing Healthcare Report (p.15)
- UK Parliament – Ministerial Clearance Table (PQ19413)
- NHS England – CHC/FNC Quarterly Data (Q4 2017/18–2024/25),
Section 1.1
- Age UK – Continuing to Care: NHS Continuing Healthcare Report (p.8)
- Age UK – Paying for Residential Care
- Age UK – Continuing to Care: NHS Continuing Healthcare Report (p.9)
- Nuffield Trust – Falling Through the Gaps: A Closer Look at NHS
Continuing Healthcare
- National CHC Data – CHC and FNC Quarterly Data (Q4 2024/25), Tab 1.1
Snapshot
- NHS Digital – Quality and Outcomes Framework (2023/24):
Prevalence, Achievement and Personalised Care Adjustments at ICB
Level
- The Guardian – “Almost nine out of 10 nurses in England work when
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- Age UK – Continuing to Care: NHS Continuing Healthcare Report (p.11)
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