VIEWS AND REVIEWS

ACUTE PERSPECTIVE

David Oliver: NHS continuing care confusion

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Every year the NHS Ombudsman receives hundreds of complaints about assessment, funding, and provision of free NHS continuing healthcare (CHC) for people with complex health needs or near the end of life.¹ The National Audit Office published a major report in 2017, partly in response to numerous complaints.² In 2018 the Public Accounts Committee published another, also looking at future threats to funding from targeted savings drives by clinical commissioning groups (CCGs).³

In June this year the BBC reported on the personal impact felt by already distressed people struggling to access such complex care, particularly in getting CCGs to agree funding.⁴ This followed reports of thousands of people dying while funding decisions were delayed.⁵

It's no coincidence that both the ombudsman's office⁶ and NHS England⁷ have public information on processes, entitlements, complaints, and appeals—or that so many charitable advocacy groups and law firms offer guidance and support for patients battling or navigating the system.⁸⁻¹⁰

Funding and provision of free CHC reflects a legacy of historical policy decisions to devolve responsibility for adult social care—such as personal homecare and long term residential care, based on eligibility criteria—to local government.¹¹ Means testing often leaves service users and their families bearing financial costs, and, despite entitlements for assessment and support enshrined in the Care Act 2014,¹² these people can be left to navigate the system without much support.^{13 14}

The problems with CHC are the less discussed B side to the serially broken record of social care. But they're not negligible. Around 160 000 CHC applications are made each year, and the NHS spends around £3bn a year (about 3% of its budget) on the successful ones.^{2 3}

Earlier in my career, different demographics meant that we had nowhere near today's numbers of people with very complex, unpredictable, or unstable needs requiring a mixture of highly skilled clinical and personal care. We also had more hospital beds, with less of an imperative to reduce very long stays and less focus on supporting end-of-life care outside hospital. By rights we should have expanded CHC funding and provision to match these changes, not cut and restricted them.

We've had several years of flat NHS funding, growing deficits and pressures on providers and service commissioners, and serial deep cuts to social care funding since 2010, leaving far fewer people with statutory support.^{15 16} In such a perfect storm, CHC funding has become a battleground between local government and its NHS partners, leaving the people who need these services caught in the crossfire.

There are detailed national eligibility criteria and assessment processes for CHC.¹⁷ It's a very high threshold to meet, even when assessment processes are applied consistently and objectively by trained assessors. Yet the National Audit Office² and the Public Accounts Committee³ reported major regional variation in how these criteria are applied, how long decisions take, and CCGs' ability to organise care first and argue about funding later. When CHC funding is denied, the serious financial consequences for patients and carers, and their inability to access support, cause anxiety and anger and can leave people stranded in hospital, until they die or negotiate a move to long term residential care.¹⁸

I'm sure that being an official continuing care assessor or panel chair is tough, given the emotionally charged and financially critical nature of the decisions. Stereotypes of uncaring bureaucrats motivated only by savings are probably unfair.

With formal complaints or news reports about individual cases, it's hard for professionals to challenge and correct apparent inaccuracies from their side. And every decision to fund one person's care has knock-on effects for someone else. These necessary decisions won't please the people who get turned down—even those who don't come close to meeting the official eligibility criteria.

We haven't got CHC right, and the situation may worsen if it isn't given at least the same attention as social care funding. As the latter has been repeatedly ducked and delayed, I'm not holding out much hope for the people affected.

Competing interests: See www.bmj.com/about-bmj/freelance-contributors.

Provenance and peer review: Commissioned; not externally peer reviewed.

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