



Continuing Healthcare

Service user and carer experiences of applying for
NHS Continuing Healthcare funding

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Executive Summary

Healthwatch Lambeth conducted interviews with eight people between May and August 2022 to find out more about their experiences of applying for Continuing Healthcare (CHC)/Funded Nursing Care.

Key Findings

Quality of information and advice

All respondents reported not knowing anything about CHC before the health event that required them to seek additional care funding. They said they would have welcomed more information prior to applying.

Making an application

Our findings demonstrate the vital role professionals play in supporting service users to navigate the funding process.

Most service users learnt about CHC funding for the first time through health and care professionals, who were responsible for completing a checklist which determines whether a service user qualifies for a full assessment.

Not all respondents were able to speak clearly about the checklist, saying they did not remember it, or that this stage may have been completed without their knowledge.

Respondents talked about their personal challenges of living with illness and disability. In the wake of life altering medical events, some had had huge changes in their caring responsibilities, requiring significant life and lifestyle changes; they described feeling overwhelmed with health and social care systems. The involvement of a professional they felt they could trust helped them feel more confident in the process and was key to the quality of their experience.

Respondents who spoke about more negative experiences said the involvement of a single professional was not enough in all situations.

For service users and/or their carers to be able to navigate the process, a good, well-established relationship to the professional and high-quality communication between all agencies is necessary.

Communication

Respondents expressed frustration at the difficulties in communication surrounding the CHC process, the lack of clarity on entitlements and procedures, and ongoing confusion about what CHC was even when the application process was underway.

From the point of referral, receiving clear explanations of CHC, what the assessment would involve, and frequent updates on the progress of the application, were all factors for those who spoke about feeling informed, involved, and having their choices and wishes respected during the process.

Staff sickness, absences and high turnover impacted communications. Respondents said they would like more to be done, if the professional dealing with their case was unavailable, to ensure they continued to receive regular updates.

This issue was further complicated as there was a lack of clarity about who was meant to be contacting applicants, and there was no clear point of contact for CHC queries and updates.

Not being able to contact or communicate with professionals or teams more directly involved with CHC compounded issues around poor responsiveness from professionals elsewhere in the health and care system.

Experiences on the day of assessment

The quality of assessments and confidence in the process was closely related to several factors. These included whether respondents had received guidance notes prior to the assessment and an opportunity to ask questions; whether respondents felt clear about what was happening or would happen after the assessment; whether they felt listened to and whether they perceived professionals involved were familiar with their needs.

Timeline and delays

Waiting for a decision on the funding from the panel can be very stressful for service users and carers, and any delays prolong uncertainty.

While many respondents had positive comments about the speed at which their assessments were arranged, their experiences on waiting for a decision from the panel was varied. Some respondents who experienced long waits described feelings of stress and uncertainty particularly around continuity of service provider, accessing a service provider they deemed more suitable and not knowing about what costs they would need to cover to ensure suitable and/or preferred treatment.

Provision of care

Many respondents were interviewed when they had only just had the funding confirmed. Some were clear about arrangements going forwards, but others still faced uncertainty over what care the service user would receive and what the CHC funding would cover.

Many respondents appreciated the high quality of care they or their loved one was receiving and recognised CHC funding made this possible.

The impact of reviews and reassessments

The timing of the interviews (in terms of the respondent's journey through the process) meant most were unable to comment on experiences of attending reviews.

However, the data we were able to gather showed frustration with seeing different professionals each year, creating uncertainty around whether they would continue to receive funding.

The possibility of funding being reduced or removed at reassessment creates a high level of stress for service users, who may be put at risk as a result, with many unable to afford equivalent care packages.

Recommendations

Communication with service users and carers should be improved throughout the process. Some people reported positive experiences of communication, but this was not consistent across all interactions with professionals or at different stages of the journey.

Improved public-facing independent information should be produced explaining what CHC is, how people can access it, and the process for applying. This was something all respondents said they would have found very useful.

Service users should receive comprehensive information of the details of their entitlement, what the CHC funding package will cover and how they can challenge decisions.

Service users should have a clear point of contact, so they know who to speak to about any concerns or questions they have, including after funding has been agreed.

All professionals should have an understanding of the eligibility criteria for CHC, and familiarity with the decision tools used. There should be training and support provided for where there are gaps. These tools should not be used mechanically, but with professional

judgement and input from those with the best understanding of the service user's needs.

When attending multidisciplinary meetings, **care providers should be prepared, knowledgeable and confident about what information they need to contribute** for a high-quality CHC decision to be made by the panel.

The panel should adhere to the 28-day decision timeline. They should also communicate regularly with service users waiting for long periods with realistic updates on the progress of their application, to limit the negative impact of delays.

All services and providers party to CHC-funded care packages should ensure service users who need additional support to navigate the process receive it. All service users should be informed of how they can access independent advice.

The existing National Framework for CHC sets out guidance on eligibility, timescales, best practice for conducting assessments, and the provision of personalised care. **We recommend Lambeth use the National Framework as a baseline when undertaking their review of CHC and ensure all aspects are implemented.**

Background

What is Continuing Health Care (CHC)?

'Continuing Healthcare' refers to NHS funding for adults with long-term health and care needs that are intense, complex or unpredictable, known as a 'primary health need.'

The package fully covers residential and care costs. Unlike local authority funding, it is not means tested.

To determine eligibility for this funding, applicants have their needs assessed by a team of professionals. A recommendation is then made to the Integrated Care Board (previously the CCG).

The national picture

Nationally the system varies in complexity between local authorities, as reported by independent organisations and services providing advice and support to families navigating the process.

Being assessed as eligible for Continuing Healthcare funding is vital for many individuals with complex health needs, who require long-term support from health and social care services.

The number of people in England with multiple long-term conditions requiring social care has risen. Also, those aged over 85 are more likely to have one or more respiratory, neurological and mental health conditions, as well as dementia, hypertension, diabetes and stroke. The population of over 85s is projected to double by 2035.¹

Social care, unlike the NHS, is not free at the point of use, and it is reserved for those with the highest needs and lowest assets, as assessed by the local authority. Many people, and their carers and families, have to – at least partially – fund social care themselves.

Of the 1.9 million new requests for social care in 2019/20, only 43% received funding from local authorities, and there has been an overall reduction in the number of people receiving care despite increasing need.²

The existence of CHC, an NHS-funded package of care including residential accommodation, available to those able to demonstrate health need arising from ‘accident, disability or illness,’ is a lifeline to many.

Continuing Healthcare is administered by Integrated Care Systems, formerly known as Clinical Commissioning Groups. Sitting at the intersection between healthcare and social care, the structure and organisation of CHC is complex, opaque and people who lack appropriate advice and guidance regarding access to the funding risk missing out on the service they need, with serious health and financial consequences.

What others have said about CHC

Though there is limited widespread knowledge of CHC, groups such as the Continuing Healthcare Alliance, co-ordinated by Parkinsons UK, bring together 20 charities and organisations to highlight service user experiences of CHC and advocate for improvements to its way of working.

Their 2016 report highlighted issues such as low awareness of CHC, with 60% of those surveyed having no knowledge of it until very late in their journey through the health and care system, with many finding out by chance rather than receiving some form of signposting from a professional.

More than half felt that they had not had enough information or advocacy while applying to CHC, and 78% of professional respondents believed the system was difficult or very difficult for patients to navigate.³

The 2020 Ombudsman report *Getting it Right the First Time* emphasised the sensitivity of the decisions being made during NHS Continuing Healthcare assessments and reviews, and the vital importance of robust processes.

A review of 336 complaints made between April 2018–July 2020 revealed CCGs had made avoidable mistakes with significant impact for service users, carers and families, including being forced to fund care inappropriately and/or live with extended stress and uncertainty, with damaging implications for health outcomes.⁴

In determining why mistakes were made, investigation nationwide has flagged up issues such as poor communication, lack of staff training, poor or inconsistent implementation of guidance such as the 2007 National Framework, and failure to plan for care and support appropriately.

The unique nature of the NHS Continuing Healthcare as a funding package rather than a coherent service, and the role of the CCG in administering it, may contribute to a lack of co-ordination between agencies party to the funding, and too much complexity in the application process, leading to incorrect or inappropriate decisions.

The Lambeth context

In Lambeth, the continuing healthcare service is delivered by three organisations, Guy's and St Thomas' (GSTT) Adult Continuing Healthcare Team, Lambeth Council Placement Support Team, and the South East London Continuing Healthcare Team.

An internal thematic review of complaints received by GSTT indicated service user experiences of poor communication, delays, admin and processing errors, lack of helpfulness amongst staff, and overall lack of clarity about eligibility and care arrangements.

While complaints may not be representative of most service users experience, and some complaints were related to care providers or other agencies not directly related to CHC, they potentially highlight an issue with the complexity of the existing process which may be particularly challenging for unpaid carers to navigate.

These issues are reflected in the feedback gathered independently by Healthwatch Lambeth from 2017-2019, and in a national review of complaints brought to the Parliamentary and Health Service Ombudsman published in 2020.

The establishment of the Lambeth CHC leadership group was designed to address some of the issues service users were facing locally.

A decision was taken to focus on the lack of joint working and collaboration across the three different teams involved with Adult Continuing Healthcare, and to consider a move towards integrating them into a single service.

Discussions about an integrated CHC service have been taking place since Feb 21 among Lambeth Council and then-CCG commissioners and Guy's and St Thomas' Integrated Care Transformation Programme.

Healthwatch Lambeth was asked to speak to service users and their families about what matters most to them, to find out what was working well, and what was not working about the system. The development of the new integrated service would address these priorities and issues.

Project scope

Healthwatch Lambeth was approached by the Lambeth CHC leadership group to talk to people who had been through the process of applying for a CHC funding package.

The main aims of the project were to:

- Understand the perspectives of service users and their carers regarding their experiences of interacting with CHC.
- Highlight areas for improvement as well as examples of best practice.
- Use insight into what matters to service users to shape recommendations for the integrated service.

Methodology

Service leads contacted individuals who had received an assessment or review within a certain timeframe to explain the project and obtain their consent to share their details with Healthwatch Lambeth.

Healthwatch Lambeth carried out in-depth qualitative interviews of eight people between May-August 2022 to find out about their experiences of applying for Continuing Healthcare.

One respondent was receiving care themselves, and seven were unpaid carers/family members. Most had engaged with professionals, who had initiated the referrals on their behalf.

Demographic information in most cases was provided by unpaid carers/family members for the service users, who were not self-identifying due to capacity issues. 50% of service users were male and 50% female. The age range was 45-93. 25% were White, 50% were Black Caribbean and 12% were Black African. All were living with long-term disabilities.

Respondents were asked about how they learned about CHC and their experiences of the different stages of applying. They were asked about referrals and assessments and panel decisions, including the impact of waiting and delays. They were asked for specific feedback on the communication they received from professionals, and how any questions or concerns were dealt with.

Strengths and limitations

The strengths of the project were:

- Our ability to work closely with the Lambeth CHC leadership group and to enlist their support in recruiting respondents.
- The interviews were conducted in a manner that was suitable for the respondents, in terms of timing, accessibility and flexibility.
- They were in-depth and designed with scope for respondents to speak at length about what was important to them.

Our limitations were:

- While many service users being considered for CHC will not have capacity, this group represented most of our sample size. Though we gathered feedback from family members and carers, further engagement with service users who have capacity and/or the ability to communicate their priorities would provide valuable insight.
- More investigation is needed of those who have capacity, or who may be navigating the process with less professional support, to understand whether they are getting their needs met. People from this group were not well represented in our sample.
- We had a relatively small sample of individuals we were able to talk to. Our target group consisted of busy unpaid carers balancing multiple responsibilities and pressures which presented a difficulty and delay with recruitment.
- The specific nature of the project meant we were unable to take on the task of recruitment ourselves in the broader community and we required assistance from service leads.
- Not all respondents had received a decision about CHC at the time of interview so were not able to give a complete picture of their journey.

Our findings

Quality of information and advice

All respondents said they did not know anything about CHC prior to the event that caused them to seek additional care funding. They all said they would have liked more information prior to applying.

A lack of public awareness about CHC, leading to confusion about whether people are eligible, and have been considered, for funding is reflected in national findings.

'A lot of it I've found it very confusing.'

'It seems like a bit of a closed shop. What I've got so far is quite vague.'

'It's still a little bit blurry where this funding comes from, even while it's been explained to me.'

Most respondents had been told about CHC funding by a social worker after a specific event (e.g. hospital stay) where it was evident care needs had risen and existing care arrangements were no longer tenable.

One respondent learned about CHC after seeking independent advice after moving to Lambeth from another borough, and after being reassessed for a significantly lower level of funding by the local authority.

'I can't think that I would know anything about it if I wasn't provided with it and a third-party organisation hadn't been involved.'

Most respondents were not closely involved in the application for funding and spoke about the decision to apply being taken by a professional such as a social worker or hospital team.

As family members of the person needing care, they were given updates about what stage they were at in the process. However, they did not feel informed of the details of the CHC process itself, including eligibility criteria.

Some people recalled being told the application may or may not be successful, but little else. They gained more understanding at later stages of the process.

Though many spoke positively about professionals taking the initiative to apply for the funding and support them as a family in this way, others described feeling disempowered.

They were unclear what information they had received and had no understanding about CHC and what to expect from the process.

They felt they would have been better prepared for assessment, and had more of their questions answered, if they'd received more and better information at an earlier stage.

'I went in a bit half-blind. I'm beginning to understand this better.'

'I didn't understand what the process was. I just thought it was a good thing. There's so much going on, just another thing to tick off the box. I didn't realise how important it was.'

This lack of information respondents had about CHC led to their limited involvement in a process driven by professionals.

Some people said they did not have more questions, nor did they try to find out more until later in the process, after the assessment had been arranged. They described being preoccupied with finding a suitable home for a relative, concerns relating to travel distance from supportive family

and care arrangements, especially when the CHC application was at an early stage and did not require their input.

Recipients of CHC are managing multiple long-term health conditions and/or disabilities requiring high levels of care, and frequently lack capacity. Our respondents were for the most part unpaid carers who were juggling their involvement with multiple professionals and services.

Any information and advice about the CHC funding package, where it was available, may have been lost amongst a multiplicity of meetings, care discussions and correspondence, taking up their time and energy. It also may not have been adequate for people shouldering caring responsibilities, who could not carry out extensive research and had limited access to independent advice or support.

Making an application

The role of professionals

Our findings regarding information and advice demonstrate the vital role professionals play for service users as they navigate the funding package.

In addition to being the way many service users learn about CHC for the first time, health and care professionals are responsible for completing a checklist to determine whether a service user qualifies for a full assessment.

Not everyone was able to speak with clarity about the checklist, as they did not recall it at interview, or this stage may have been completed without their knowledge.

'We had nothing to do with it, it was (the hospital team) who did whatever liaising (they) had to do with whoever, be it social services or CHC...we did not have to get involved in that.'

Many respondents spoke about the importance of their relationship with the social workers and hospital teams to their experience of the CHC assessment.

They said they appreciated the pro-activeness of the services around them, starting the process for a life-supporting funding package at a time of high need and vulnerability. They spoke about professionals' efficiency, the effort in keeping them informed and updated, and their responsiveness to questions and concerns.

'We had a meeting with (the social worker) before we had the main meeting...she explained things thoroughly, any questions we had she answered.'

'It was straightforward with the hospital. We were notified of everything.'

'It just makes so much difference when you've got a professional that knows what's going on and they take the time and trouble to prep you.'

These responses highlight the value placed on skilled qualified professionals by service users. Many service users associated the process of the CHC application with a specific professional who they saw as steering the process on their behalf and advocating for the person needing care and their family.

However, some we interviewed described having limited contact with the professionals involved, or had received updates on the progress of their CHC application they didn't understand or that wasn't explained to them appropriately.

It was clear service users felt professionals were instrumental to their ability, or lack of it, to navigate the CHC application process.

We would expect professionals to have greater knowledge and familiarity with a funding package, especially when respondents had little to no understanding of it prior to being told about it.

People commented on their personal challenges of living with illness and disability, the confusion and overwhelming feeling they experienced with health and social care systems in general, and their changing caring responsibilities in the wake of life-altering medical events, requiring significant change to their lives and lifestyles.

The involvement of a professional they felt they could trust and who gave them confidence in the process was key to the quality of their experience.

But respondents did speak about more negative experiences which showed that involvement from a single professional is not always adequate.

For service users and/or their carers to navigate the process, a good, well-established relationship to the professional and high-quality communication between all agencies is necessary.

Communication

Our respondents had mixed experiences of the communication they received from professionals and agencies throughout the process.

From the point of referral, receiving clear explanations of CHC, what the assessment would involve, and then frequent updates on the progress of the application, were all important to people feeling informed, involved and having their choices and wishes respected. Many respondents spoke of professionals by name and described having a good rapport with them.

One respondent's relative was in a nursing home, which made the application for CHC funding difficult. He had difficulties contacting the allocated social worker about other matters and, though the home informed him of the date and time for the assessment and asked him to come in, he lacked understanding about the meaning and purpose of the assessment until the day. Such significant communication gaps between agencies, professionals and service users and/or carers impact on the quality of the information shared during assessments and could have consequences for the quality of decisions.

'It was only until the assessment that I knew more...the questions were sent to me the same morning of the meeting. And the assessor said that she felt I should have had the questions earlier...It was only going through the questions in the assessment that gave me the idea of what they were talking about.'

Others who felt they had been well-communicated with initially, often by a specific social worker, found that once the funding had been agreed, the social worker was no longer involved.

Respondents waiting to hear about new arrangements for their relatives, and who had relied on communication from the specific professional who had supported them, found themselves waiting for updates, unsure of what the next stage was. Respondents were frequently unclear who was supposed to be contacting them and how they could find out.

'(The social worker) was very, very good, she was the one who was visiting my mum through COVID. But once my mum left hospital that social worker wasn't looking after her anymore.'

'The social worker rang me and said it's not her department anymore. (CHC) have taken over. And they should be the one contacting me...And I haven't had much support since. I think we've had one call from them. I'm a bit disappointed there.'

Issues such as staff sickness, absences and high turnover also affected the communication received in several cases. Respondents said they would have liked for more to be done if the professional dealing with the case was unavailable, to ensure they continued to be updated. This issue was further confused by a lack of clarity on whether they had a worker allocated to them.

'I go around the houses. There isn't one specific person that I know of that is her social worker. I need one person I can talk to.'

'It's really stressful for some families...when they've got really poorly relatives, you have to keep ringing around and get frustrated.'

A lack of clarity about who they were meant to be contacting, or whether a clear point of contact existed for CHC, was also frequently mentioned as a source of frustration and confusion for respondents.

Being unable to communicate with professionals or teams more directly involved with CHC compounded issues with poor responsiveness from professionals elsewhere in the health and care system.

There was also variation in the quality of communication respondents received from the different agencies party to CHC, risking information being lost.

One respondent learned of the decision several months after the funding had been agreed because the relevant email had not been forwarded to her at the time.

Another, speaking about a previous unsuccessful application, had waited six months for an assessment on that occasion.

'I think they need to come out with proper realistic timescales...even a holding letter, saying the panel are still reviewing we apologise, anything. But once it's left and left...you don't know if you're sitting at the bottom of a pile somewhere.'

Respondents who had received panel decisions at the time of interview described decision letters and emails that were brief, with little detail regarding practical arrangements, no indication of how long they could expect to wait for more information, and no clear contact provided.

Some respondents found it difficult to communicate with care providers who were unclear themselves about the process of the CHC funding application, and who would tell respondents they too were struggling to get updates.

Experiences on the day

Once a service user is eligible for the next stage in their application, an assessment is arranged. This is conducted by a group of different professionals joining together in a multidisciplinary team meeting (MDT). The assessment should involve the service user and/or their carer, and health and social care professionals familiar with the individual and their needs.

Preparation

How prepared respondents felt for the assessment was closely related to the quality of communication they received, and the strength of the relationship with the professional who was supporting them with the application.

Experiences were mixed, with some respondents having received guidance notes and an opportunity to ask questions beforehand, whilst others had very little notice.

Issues with remote assessments

The impact of COVID-19 restrictions was mentioned as a source of frustration, as assessments had to take place remotely.

A few spoke of their perception that this reflected a lack of interest in ensuring the assessment was done properly and felt this created an additional barrier to the nurse assessor gaining a true understanding of the service user's needs.

'You can't really assess someone over the phone, you can't see them physically. I thought it was a bit shoddy.'

'It's important that everyone is around the table facing each other. It's crucial for the nurse assessor to see the patient. It makes talking about the assessment easier.'

One respondent spoke about an online assessment that had not gone well due to difficulties with conveying information about her mother's health remotely. When the assessment was rescheduled, it was arranged in person, and she was deliberate in how she approached it.

'Before we started the meeting, I took the nurse assessor and the social worker up to mum's room and introduced her. I took mum's covers off so they could see her hands and her feet. They could see the room they put her in, they could see the hoist, they could see the disabled chair. So, they had a better understanding of her needs before we went into the meeting.'

Being heard – the quality of assessments

Many respondents had positive comments about the quality of the assessment itself, feeling they were clear about what was happening and they felt listened to.

'The questions they asked were quite good and relevant.'

'(The nurse assessor) was very professional, he kind of held things together.'

'I was welcome to voice any concerns (in the meeting). It was really easy to follow and (the social worker) explained why she had put forward whether it would be a high or a medium or a low. It was really quite interesting. I didn't realise it would be so in depth.'

Others had concerns about whether all the agencies involved in the meeting had come prepared, speaking of residential care staff who

attended without up-to-date notes about the service user's needs, or being disappointed if managers sent deputies rather than attending in person. When information was not received from care providers or dealt with in a timely way, this affected one respondent's confidence in the outcome.

'Once I was told that (the assessor) didn't receive an assessment form from the home, I thought, (my mum) won't get it.'

Respondents also spoke about how challenging it was for them to convey the details of their personal situation, when discussing medical conditions not widely known about or attempting to explain the details of fluctuating health day-to-day. Some respondents felt unable or unsure of how to ask for support with this, aware of the vulnerability of their position with assessors seen as gatekeepers to vital funding.

'You could easily be in danger of not getting the funding for your health situation if you were to present your case in the wrong way. You have to become personally expert in the form the CHC assessment takes, which is quite difficult.'

'It came across more like (the nurse assessor) was scared to put something in front of the panel. She was scared of it getting chucked out because it would reflect badly on her and like she hadn't done her job properly. It almost felt like her role was to mark everything down, regardless of the fact of mum's circumstances.'

Clarity and confidence

There was a mixed picture when respondents were asked if they were clear about what would happen following the assessment.

All respondents understood they would have to wait, but some felt confused about what they were waiting for, and they were not clear about which professionals or agencies were involved in making the decision.

Those who had concerns about the way the assessment was carried out felt less confident about the outcome and more confused about the process.

Others had clear explanations from social workers or care providers they were waiting for a panel decision, and they had been warned a positive outcome was not guaranteed from the earliest stages. They felt confident that, whilst they could not be certain of having the outcome they were hoping for, the nurse assessor had all the necessary and relevant information.

'I felt listened to, I felt part of the process. I came away feeling quite positive.'

Timeline and delays

Waiting for assessment

Issues around timelines and delays were closely related to the communication issues raised by respondents, and experiences were mixed.

Some respondents spoke positively about how quickly the assessment was arranged, saying they were pleasantly surprised they had not had to wait too long.

Some found it difficult to comment on the time spent waiting as a distinct stage in the process. Possible reasons for this include the relatively short wait, and because relatives had care providers liaising on their behalf and were not privy to all the details of the application.

'Even allowing for covid, it wasn't massively long. I wasn't sitting thinking 'when is this going to happen?''

'The hospital was very quick with it, very quick. I didn't have to wait long at all.'

'I thought it would be a bit longer because they did say it might take a bit longer. I was quite surprised by how quickly it came through.'

Waiting for a decision

Waiting for a decision on funding from the panel can be very stressful for service users and carers, and delays prolong uncertainty.

In the past, a lack of NHS guidance on timelines for the CHC process led to unacceptable delays nationwide. The more recent National Framework states nobody should be waiting more than 28 days between the information being received by the panel and the decision being made.⁵

While many respondents had positive comments about the speed at which their assessments were arranged, their experiences varied when they reached the stage of waiting for a decision from the panel.

Some respondents reported waiting only a few weeks, but others said it had taken several months before they had an outcome of the assessment, and some had not received a decision at the time of the interview.

Another respondent whose family member was in a rehabilitation centre out of borough while the application was made waited several months for a decision but said this did not cause them concern as they were confident their family member's needs were being met.

'...As far as we were concerned, Mum was in the right place, getting the care she needed. The only worry would have been if we had gotten a letter or something saying they were moving her. Then all hell would have broken loose.'

Reasons for the stress and uncertainty experienced by respondents included not knowing whether their relative would be able to stay with a particular care provider they were happy with, whether they would be able to access a different care provider the respondent felt was more suitable, and the insecurity of not knowing which costs they may have to try and

cover to ensure suitable and/or preferred care and treatment, affecting their ability to make financial decisions about the future.

'You worry you will be left without the care that is life supporting. Having any kind of question mark hanging over whether you will be funded or not is horrible.'

'If we had to pay for full funding, how were we going to do that? There was all sorts of things going in my head, I was asking but I didn't get any answers.'

Provision of care

When somebody is awarded CHC funding, the Integrated Care Board is required to commission a package of care. This should be done using information about all the individual's health and social care needs and taking all possible steps to ensure their preferences are met.

No respondents recalled being spoken to about personal budgets or care packages, although in our small sample these options may not have been relevant.

Many respondents were interviewed at a stage when they had only just had the funding confirmed, which presented a mixed picture of their experiences of care provision. Some were clear about arrangements going forwards, whilst others were still facing uncertainty over what kind of care the service user would receive and what the CHC funding would cover.

One respondent, although very happy with the quality of care their relative was receiving, was given confusing and contradictory information from the home relating to finances post-panel decision, suggesting the provider themselves was unclear about CHC funding.

'They said I'll be hearing from Lambeth social services finance because she's been in there a year now so she will need to start

paying the full amount for her care...questions I've asked in the past haven't been answered.'

One respondent spoke about a relative whose condition had deteriorated and described feeling anxiety and distress at knowing he was not being cared for safely because the current care provider was unable to meet his needs. Despite knowing the funding was agreed, at the time of interview she had not heard anything about what the practical arrangements would be.

'I just want to know what's going on, basically. Even the home's getting a bit frustrated because they're having incidents with my dad...he became violent, and the police were called. We've been in limbo. It's very stressful.'

Other respondents had positive experiences of well-organised and efficient care transfers, having their choices as a family listened to and respected, and being satisfied with the quality of care their relative received.

In our small sample, the data indicated smooth care arrangements were likely to take place when the relative had been assessed in a hospital environment, and their discharge to a permanent home was contingent on the panel decision going in their favour.

Some respondents already had their relative in a care arrangement that suited them, and the panel decision confirmed the existing arrangement would continue. They didn't receive many details on practical information regarding care arrangements at this stage but indicated this was not a high priority for them.

'I'm not questioning how it works...it's not like she owns her property or anything like that. We got her in the place we wanted her to go, and we've been happy ever since. We are grateful as a family.'

When things go wrong

While we did not speak to any respondents who had been through an appeals process, one respondent shared a single experience which highlighted the complexity of the CHC process from a service user perspective.

They had been alerted to an issue surrounding the funding arrangement for their care provider from the local authority, suggesting that care provider would no longer be working with Lambeth. Changing to an approved care provider, at the early stages of the COVID-19 pandemic, was something they were desperate to avoid, but were unsure of how to get their voice heard.

Though the respondent was eventually able to stay with their preferred care provider, they described the difficulty of finding an appropriate person to speak to about the issue, and a lack of clear procedure for more complex complaints. The impact of extended waiting and uncertainty was highly stressful and compounded by having to speak to multiple professionals who themselves were not confident of advising people on how to resolve serious issues or appeal formal decisions.

'I got to the point of looking to see if I could contact the health ombudsman which seemed like a crazy route to have to go down...It all got very difficult...I was almost liaising between the care company and GSTT. And I discovered I shouldn't have been party to any of these negotiations, which I fully agreed with...it was quite a strange experience.'

The respondent expressed uncertainty about how common their experience was, and it was unclear whether a formal decision had ever been made in their case.

While we were unable to draw a comparison in our sample, the national research in 2016 from the Continuing Healthcare Alliance found significant variation in how CCGs conducted the appeals process in the absence of clear guidance in the National Framework specific to CHC funding.³

They also found many cases in which people, exhausted and distressed by the complexity of the system, had declined to appeal a decision or chose to resolve their appeals by accepting less than the full amount they were entitled to.³

The impact of reviews and reassessments

The timing of the interviews in terms of the respondent's journey through the process meant the majority were unable to comment on experiences of attending reviews.

However, the data we were able to gather indicated frustration with seeing different professionals each year, adding uncertainty around whether they would continue to be funded.

'In the annual review you end up almost starting from the beginning. They read your file but don't know anything else. You're jumping through the hoops, putting in the lengthy medical explanations. I haven't ever really had any changes (to my condition) over the whole time I've been getting CHC. I never say anything new and only worry that someone will see my case in a different light.'

Similar experiences were reflected in the findings of the Continuing Healthcare Alliance report, which questioned the value of repeated reassessments for those at end of life, living with a progressive condition such as dementia, or who were living in an advanced stage of their condition with limited prospect of change.³

The possibility of funding being reduced or removed at reassessment creates a high level of stress for service users who may be put at risk as a result, with many being unable to afford equivalent care packages.

Conclusion

Everyone who finds themselves in the position of applying for CHC funding is likely to be living with a high level of need and vulnerability. The process, and the outcome, has a significant impact on the person, and those close to them.

Healthwatch Lambeth found areas where people are facing major issues while interacting with the CHC teams which are reflected in our recommendations.

We also heard feedback about skilled, compassionate professionals and examples of good practice, and hope the service works closely across teams to ensure this happens consistently across the borough.

Next steps

In January 2023 the decision was taken by the Integrated Health and Social Care Board that the plan for NHS continuing healthcare integration would not go ahead.

It remains important the three teams find a new way of working in partnership to improve the experiences of service users and prevent unacceptable delays and avoidable communication issues from disrupting the care and treatment of vulnerable people in the borough.

Healthwatch Lambeth looks forward to collaborating further with the Continuing Healthcare steering group to explore how best to implement the recommendations outlined in this report.

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