healthwatch
Enfield

Listening to people's experiences of using NHS Continuing Healthcare

June 2020

Contents

Acknowledgements
Healthwatch Enfield would like to thank the people who shared their experiences of using NHS Continuing Healthcare with us.

Executive Summary

In 2017 the National Audit Office published a report about the findings of an investigation into NHS Continuing Healthcare (CHC) Funding. This investigation was initiated due to[1]:

> *'correspondence from over 100 members of the public raising concerns about the CHC process in England. The correspondents raised a range of concerns covering how well the assessments are carried out, whether CCGs are complying with the national framework and the equity of the decisions'.*

During 2019/2020, 28 individuals just in Enfield told us about their experiences of using NHS Continuing Healthcare. We should point out that there are over 600 recipients of CHC across Enfield and, therefore, the views of the 28 (7%) do not necessarily reflect those of all of the recipients across the service.

However, of those who did respond to our survey, individuals and their family members/carers raised a number of concerns around the assessment process and delivery of Continuing Healthcare that we believe warrant further independent investigation.

They described their experiences as 'difficult', 'stressful', 'long winded', 'humiliating' and 'upsetting'. Individuals told us they did not feel included in the process of assessing their care. They did not understand why a decision had been made, especially when reductions or withdrawal of payment occurs. It was clear that the role of the family member/carer, where service users could not speak for themselves, did not appear to be recognised or respected and they were not necessarily being involved. This is despite the operational policy recognising the need for advocacy.

In addition, in reviewing some of the paperwork being issued to recipients, these were long, confusing and unclear, re-enforcing the concern regarding a lack of effective communication.

Our key findings were that the assessment processes were unclear, that communication was poor and that individuals in receipt of CHC or their carers did not believe they were properly involved as set out in the CHC operational policy:

- 82% had a negative experience of the Continuing Healthcare assessment processes
- 68% did not receive any information to help prepare for their assessment and/or review
- 29% felt they/the person they care for was involved in making decisions during the assessment process

Our evidence suggests that any local changes made to improve the individual's experience of NHS Continuing Healthcare since the National Audit report was published are not leading to a better experience for all service users and that process and communication problems continue.

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[1] Investigation into NHS Continuing Healthcare funding summary, 2017, National Audit Office

We have been in regular communication with Enfield Clinical Commissioning Group (CCG) in relation to our findings. They have advised us that the current experiences of local people could be a consequence of the CCG now implementing and following robust systems to assess and award Continuing Healthcare funding.

However, there are concerns that Enfield CCG are currently working on a 'cost reduction' programme for Continuing Healthcare[2]. When we raised this concern, their response was "that there had been inconsistencies in the past and criteria and thresholds not always applied correctly. This has resulted in anomalies and hence the review of our processes to implement more robust systems"

Regardless of the reasons for the change in approach, our evidence base would suggest that individuals who responded to our survey feel very concerned and upset about the way in which the changes have been communicated and implemented.

As part of our role to amplify the voices of patients/service users and their families, we are asking Enfield CCG to:

- read and 'listen' to the experiences within this report of individuals and their families receiving Continuing Healthcare within Enfield
- conduct further work to listen to the current experiences of individuals and their families receiving Continuing Healthcare across Enfield
- use this evidence base to review processes and communication in order to improve the experience of individuals and their families applying for or receiving Continuing Healthcare

We are pleased that the CCG have recently undertaken to be part of a pilot NHSE programme which commenced on the 31st January 2020 to gain feedback from individuals about their experience of going through the application and assessment process for the first time. Enfield CCG have also been reviewing their processes to ensure greater consistency around:

- communication
- processes and
- thresholds

In addition, given that Continuing Healthcare is a complex process, at the time of writing this report, Enfield CCG have committed to explore ways to undertake further work to review the end to end processes across the system for existing recipients and how information is communicated to individuals and families. They have since also agreed to produce an action plan of improvement.

This will enable the CCG to understand what is and isn't working, and look to co-design solutions with all stakeholders, in order to improve communication with the individual and their family members/carers within Enfield.

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[2] North Central London, Joint Commissioning Committee Papers, January 2020, p125, C5 on point JCC28

Introduction

'NHS Continuing Healthcare (CHC) is a package of care for adults aged 18 or over which is arranged and funded solely by the NHS. In order to receive NHS CHC funding, individuals have to be assessed by Clinical Commissioning Groups (CCGs) according to a legally prescribed decision making process to determine whether the individual has a 'primary health need''[3]. Currently, over 109,181 individuals are in receipt of Continuing Healthcare across the country[4].

Healthwatch Enfield is an independent consumer champion for health and social care. Following feedback from a few local residents about difficulties and concerns accessing and using Continuing Healthcare in Enfield, we wanted to hear more from local people about their experiences.

Despite the challenges of obtaining feedback from many service users themselves due to cognitive and physical impairments, during 2019 we heard from 28 local residents and/or their family members/carers who shared their experiences of using Continuing Healthcare in Enfield.

Methodology

Views and opinions were sought from local residents in the form of a survey promoted via our social media and face to face engagement with local residents. Enfield Disability Action also distributed the survey to their members on our behalf. The survey was used to assess people's views on:

- their overall experience
- their level of involvement and understanding of the process
- the accuracy and timeliness of the assessment and payments
- whether they felt they felt adequately supported throughout the process

Of the 28 people we heard from, 3 people responded as individuals, 9 people told us they were carers of someone who receives Continuing Healthcare and 13 said they were a family member in receipt of the service. The remaining three people did not tell us which capacity they were responding in.

28 respondents reflect the views of around 7% of 600 service users. Whilst those who responded were particularly concerned, we cannot verify that this is a view across the majority of service users or their carers/relatives.

One of our team also reviewed some of the CHC letters issued by Enfield CCG to understand how these supported the process. We also met with two consecutive Heads of Continuing Care to share our interim findings and seek clarification around the processes.

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[3] NHS Continuing Healthcare, NHS England

[4] CHC Statistical Release, Q2 2019/20, NHS England

Key themes raised

The tables below set out a summarised overview of the feedback we received categorised into four key themes along with a snapshot of supporting analysis and quotes. The section titled 'Summary of what service users and their families/carers told us' in each table represents the views and opinions of individuals who responded to us.

Detailed feedback analysis and verbatim quotes can be found in appendix 1.

Overall experience

Summary of what service users and their families/carers told us

- The assessment process is 'difficult', 'stressful', 'long winded', 'humiliating' and 'upsetting'. The bedside manner of nurses (assessors) was described as "rude/aggressive"
- There appears to be a lack of transparency and consistency around record keeping and the process itself
    - different forms & methods used by different nurses
    - information that should already be well documented is asked for repeatedly
    - awards previously given are challenged without individuals being clear as to why
    - communication between service providers adult social care & CCG is poor
    - decisions appear to be at discretion of assessor on the day
- People felt that the assessment process objectives are focused on "getting them off the books" and "reassessment of domains" rather than a supportive assessment or revision of care plans.
- Moving from Social Service to Continuing Healthcare seemed problematic

Involvement and understanding

Summary of what service users and their families/carers told us

- Services users felt they were not involved in decisions about their care
- Individuals do not appear to understand why a decision has been made, especially when reductions or withdrawal of payment occurs
- The role of the family member/carer, where service users cannot speak for themselves, is not recognised, respected or mandatorily involved
- There is a lack of clarification around accountabilities. E.g. who is responsible for gathering supporting evidence?
- They do not feel there is enough information to support them through the process

Timeliness and accuracy

Summary of what service users and their families/carers told us

- There are long wait times (3-9 Months) for initial review.
- Budgets and payments are sometimes incorrect and the process to challenge and correct them is complex.
- The quality of the data and findings presented in the assessment appear to be inaccurate.
- There is a lack of confidence in the capability and objectiveness of the assessor:
    - adequate research is not undertaken
    - there is a lack of prior knowledge of their case history
    - When changes/awards are made they take too long to be applied.
    - There is no notice given when payments are withdrawn or reduced.
    - Reviews are not conducted annually.

Support

Summary of what service users and their families/carers told us

- Service users did not receive any information prior to the assessment to help them prepare, set or manage expectations.
- Service users are not supported to gather information required, e.g. contact details and processes involved.
- People don’t understand how to:
    - use the budget setting tool
    - apply the budget
    - challenge inaccuracies (especially financial)
- There is no point of contact and people are not informed when their assessor is changed or how to reach them.
- Requests for information is difficult emails are ignored

Summary of key findings

82%

had a **negative experience** of the CHC **assessment process**

62%

were not told that they, or a family member **could be present** during the CHC assessment and review meetings, and that they **could have an advocate** if they wanted to

68%

did **not receive any information** to help **prepare** for their CHC assessment and/or review

91%

were not given information about the **financial implications** of being funded under CHC and **potential impact on benefits** they receive

29%

felt they/the person they care for was **involved** in **making decisions** during the assessment process

36%

felt they had been **involved** in conversations about **care plans and support needs**

26%

had a care plan that **clearly shows their budget** and **how it will meet their needs**, after being awarded CHC funding

16%

were **present** when the **decision was made** about their funding and **understood the** reasons why the decision was made

27%

had **reviews** at least once a **year**

35%

know **who to contact** if they have any **problems** with their CHC budget

Conclusion

Feedback from the individuals we spoke to and who engaged with us suggests that their experience of the Continuing Healthcare system during 2019, in particular, was poor. We heard that individuals and their families felt that the Continuing Healthcare processes and assessments are upsetting and aggressive, that support is inadequate and communication poor. Whilst we cannot confirm whether this view is reflective of recipients and their families/carers across the service, those who responded were particularly concerned.

Individuals do not believe they/their family members are fully involved in the assessment process and discussion about their care and nor are they given sufficient information in a format to enable them to understand what is happening. From the evidence base we have collected, it seems clear that the role of the family member/carer, where service users cannot speak for themselves, is not consistently recognised or respected in accordance with the CCG's CHC operational policy.

Service users and family members gave examples of inaccuracies and delays in payments; uncertainty around how to apply budgets; unclear accountabilities and possible inconsistencies in the execution and documentation of assessment findings.

In addition, in reviewing some of the paperwork being issued to recipients, these were long, confusing and unclear, re-enforcing the concern regarding a lack of effective communication.

Following the National Audit Office investigation into Continuing Healthcare in 2017[5], our current evidence base suggests that the any local changes made to improve the individual's experience of NHS Continuing Healthcare since the National Audit report was published are not leading to a better experience for all service users and that process and communication problems continue.

In addition, there are concerns that Enfield CCG's need to reduce costs[6] is a driver for the change in process which is impacting on local peoples' experiences of Continuing Healthcare in Enfield.

As part of our role to amplify the voices of patients/service users and their families, we are asking Enfield CCG to:

- read and 'listen' to the experiences within this report of individuals and their families receiving Continuing Healthcare within Enfield
- conduct further work to listen to the current experiences of individuals and their families receiving Continuing Healthcare across Enfield

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[5] Investigation into NHS Continuing Healthcare funding, Full report, 2017, National Audit Office

[6] North Central London, Joint Commissioning Committee Papers, January 2020, p125, C5 on point JCC28

- use this evidence base to improve processes and communication and, therefore, improve the experience of individuals and their families applying for or receiving Continuing Healthcare

Appendix 1 -detailed feedback analysis and verbatim quotes

. The survey was used to assess people's views on:

- their overall experience
- their level of involvement and understanding of the process
- the accuracy and timeliness of the assessment and payments
- whether they felt they felt adequately supported throughout the process

Note: all "quotes" included below have been copied verbatim. We have not corrected grammar or typing errors or edited the acronyms/terminology used.

Overall experience of using Continuing Healthcare

Overall, individuals summarised their experiences of the CHC process as 'appalling' and 'poor'. Users reinforced that they experience limited communication and do not know who to contact to discuss their difficulties. We also heard about a lack of consistency amongst the process and a lack of understanding about how decisions are made subjectively. Individuals told us about late payments and changes to their care plans that they were not aware of.

'CHC is the most appalling process. There is wide inconsistency amongst the nurse assessors. A few months apart different nurses have very different opinions on the domain levels.

'The quality of the nurse assessor reports is generally poor and the manner of some nurses is very unprofessional e.g. on numerous occasions not following the correct procedures and trying to bypass the family by arranging meetings without inviting us, interrogation as if we are liars, not valuing our views, treating us with disrespect by making derogatory comments e.g. a nurse even mocked and laughed at us during the DST'

'Within the CCG there is confusion about processes. Nurses seem free to conduct reviews in a way that they choose and using different review paperwork. Totally inconsistent. Also, what was agreed at a review may be added to /altered after the review. Review paperwork has to be chased up'

'Calling for a DST without a review is an example of the poor practices at the CCG'

'Some reviews have been interrogation like - almost felt we were being call liars yet it was the CCG that awarded the funding and not us because we were not present at the MDT. It just seems that the system is totally inconsistent. In our case, the family member was awarded CHC but we were told by a manager ' we will get X off the funding at the 3 month review.' Such treatment is threatening. I have absolutely no faith in this system. My dealings with the NHS for myself and family members has always been good or better and on occasions outstanding but dealing with NHS CHC seems to lie outside all the ethics and professionalism of the NHS I have experienced in my life. My family member is just a budget that the CCG wants to get off

its books. I am very worried about what the CCG CHC nurses may decide about my family member. So worried they will move them or change carers. We have no say'

'Not a good experience. No one to contact. Inefficient and totally unsatisfactory support from the nurses'

'The CCG does not have an up to date local policy. The one online is dated 2016. The process on the website looks good but in reality, these pledges and time scales are not followed. The quality and training of the nurse assessors needs to be looked at. Financial managers are pushing health professionals to make decisions in the interests of the CCG budget rather than patient need. Some nurses appear to have lost sight of their professional duties'

'The CCG appears to find it impossible to make its PHB payments by the contracted date. MSM manages the PHB payments on behalf of the CCG, and they have been unable to make the monthly payments by the contracted date on 7 occasions, due to lack of payment from the CCG, during the past 18 months. On 4 occasions the payments have been more than 10 days late, and the worst case was more than 2 weeks late. I have been obliged to make formal complaints on 2 occasions, both resulting in extensive reassurances, but last month's payment was late again! I understand that all Enfield's PHB users have been affected by the CCG's payment delays'

'Since being on CHC thought my life was going to get better, but has gotten worse, live the life that I want to live, be able to do my own thing. CCG has made my life worse, and made one question my life worth living on the net'
'The assessor was rude/aggressive, raised her voice and ignored evidence'

'The CCG treats people badly. They do not follow the rules and have no local up to date policy. The policy is dated 2016!'

'The whole process needs to be thoroughly investigated because there is widespread malpractice. Staff need to be consistent. Paperwork needs to be completed and supplied without delays'

'If I don't get the package I won't know how to manage. My son needs to be turned over every four hours and he also has fits. He is in a wheelchair and can't communicate. It is just me and my husband looking after him. I am 68 and have arthritis and health issues myself and my husband has had bypass surgery. This whole thing is so confusing and upsetting.'

'they need to involve the family more'

'nothing positive at all'

'Not elderly friendly. Unless I intervene my parents would not know what was going on'

Experience of the assessment process

When referred for a full CHC assessment, individuals told us that they waited between 3 – 9 months for an assessment, with the average duration being 6 months. Some individuals told us that they couldn't remember how long they waited, but it was a 'long time' and was 'months rather than weeks'. A few people told us that they had their assessment 'quickly' and that they 'did not wait long'.

Three people told us that the assessment process was 'ok' and one person reported that it was 'relatively straight forward the first time'. One person mentioned they thought the assessment process was 'fair'.

The remaining 23 individuals reported that they found the assessment process 'difficult', 'stressful', 'long winded', 'extremely frustrating', 'humiliating' and 'upsetting'. Individuals reported a lack of communication with little/no involvement of family members, causing stress and upset for some.

'The screening tool for my family member was completed without my knowledge by a social worker. The London Health Needs Assessment was completed with little consultation with the family. The DST was a very difficult and upsetting meeting'.

'The assessment process is very difficult but the NHS Nurses were unprofessional and incompetent. The expected the family to collate almost everything. They were too lazy to read information or contact the GP. Our GP confirmed that the CHC Nurses had never requested medical records before or after the assessment. The emphasis was totally on us to 'make the case' yet the medical, consultant and social care records were really detailed. The only purpose of the assessment appears to be to prevent very ill people getting the support they need'.

'The process was unpleasant and overly lengthy (in my opinion). It was extremely negative, with nurse assessors not following the correct procedures. It was made even more frustrating as the assessing nurse appeared to know very little about my son, and had made little attempt to get to know him in any way. As a parent, I did not feel that my opinion was considered important, even though I am his COP Welfare Deputy and employ his care team via D.P.s. During the first CHC assessment in 2014, the decision of the MDT was overridden by a Panel, who reduced significant domain levels, to avoid CHC entitlement. The Panel then agreed 50-50 funding. This was later upgraded to full CHC funding during the re-assessment completed in 2016'.

'Very difficult and no one to help'

'Very stressful - every budget was not correct and messed it up the whole process'.
'Long winded. Not friendly very formal and impersonal'

'I have no words to describe the whole process of this assessment. It was short of more like harassment or bullying into a decision that the assessor already had taken. She was not interested to hear anything from the people present'

'Upsetting'

'Lots of meetings and paperwork'

'Difficult. I requested the presence of all the parties involved in my daughter's care at the meeting'

'long and I did not agree with the outcome'

'Stressful trying to ensure all my daughters complex needs, behaviours etc were included'

Just over 1 in every 3 individuals (38%) told us that they were told that they, or a family member could be present during the CHC assessment and review meetings, and that they could have an advocate if they wanted to.

The same proportion of individuals told us that they received information that they understood to help prepare for the process. Over 2 in every 3 individuals (68%) reported that they did not receive any information to help prepare for their CHC assessment and/or review. Individuals reported that they had to do research themselves and that requests for information were not responded to. One individual told us that they understood what was happening during the assessment process, but they received no information about what was going to happen afterwards.

'I had to read up everything myself on behalf of my family member'

'Originally the nurse assessor was excellent. We met and discussed everything. Recently no information just sarcastic emails saying nothing could be done until the dispute hearing had happened. A three month wait from the DST until dispute (24th June) so still waiting since April 1st'

'CCG CHC Nurses do not respond to requests for information, family carers are almost treated with contempt - how dare we ask question or request paperwork'

'Some information was provided, but I had to do most of the research for myself'

'Given the money and left to deal with it myself. Found situation stressful I was promised things that were non-realistic'

'I was called to be present at the assessment and when I asked if there was anything to help me any literature they said no, just be present at the meeting if I wanted to'

'I sourced the information from the internet'

'Extremely frustrating and dismentoring. there has never been a moment of clarity about the immediate moment of the future'

'I received information for the process however it was never explained what the process after would be'.

'No documentation was given or verbal communication'

'I have only received dates of review meetings to attend but never asked to prepare anything to take with me

Two people (9%) reported that they were given information about the financial implications of being funded under CHC and potential impact on benefits they receive.

Patient/carer involvement

7 individuals (29%) reported that they felt they/the person they care for was involved in making decisions during the assessment process. Some people told us that the person they care for was not involved making decisions during the assessment process because the person they care for lack the cognitive capacity for involvement, but others explained that they felt that they were not involved as a carer/family member of the person in receipt of CHC who may not have the capacity to be involved themselves.

'Due to cognition unable to participate or understand'

'Originally yes. Presently no. No communication, services removed or just not paid so they have stopped providing'

'Had to do all our own research and a professional consult an advice service'

'My son lacks the mental capacity to be involved, which is why I am his COP Deputy. I did not feel that my role in representing his interests was recognised or respected. I had to insist on this being recorded, but it did not appear to make much difference to the way the process was managed'

'This is a yes and no as he has mental health problems so cannot make all decisions himself'

'they were not able to'

'Communication was very bad and no classification, called up for advice or information were not able to give the night support'

'They often lack capacity'

'My daughter has severe autism and has a learning difficulty. She cannot be present at such meetings as she would not understand what was going on and would be extremely distressed'

'My son has severe learning difficulties and that is not possible as he doesn't understand'

'Due to my daughters complex needs she wasn't present at any of the assessments or reviews. She does not have mental capacity to understand'

'My daughter lacks the mental capacity to understand at all'

'The assessor was making her own decisions. Did not take into account what mum and other professionals said'

Just over 1 in every 3 individuals (36%) told us that they felt they had been involved in conversations about their care plan and support needs. Some individuals told us that they never received health care support plans and/or that they had little information/communication about what was in place.

People told us about a lack of continuity in the assessors working within CHC and that they have to keep providing information again to new people. We heard about some people's difficulties from switching from adult social care funding to CHC health funding.

'No support plan ever drawn up by health. Continued with the social care support plans and the package shifted to health'

'Yes, unfortunately the nurse and commissioners leave so often that there is no continuity and you end up having to re tell each new commissioner and nurse assessor everything. Very frustrating'

'Nurses don't care about need. Only the budget is a concern to them. Even more so trying to remove CHC at each review (unsuccessfully) on scurrilous grounds which sever to show a lack of concern or empathy. For example, at each subsequent review the nurses said the original assessment was wrong and could not understand how CHC was awarded. The fact is that CHC was awarded on strong evidence and the family had no part in the decision yet we feel we are being blamed for their decisions'

'My son's package was well established and recorded under ASC. I ensured that this would be maintained when he transferred to CHC funding'

'Through meeting and asking me about my son condition they advised me what they can do for me'
'No discussions'

'When the person concerned lacked capacity'

'Assessor was brutal, rude and had her own opinions about the person'

'At CCG reviews - only my daughters progress/current situation has been discussed. I do not recall her care plan being mentioned'

'Many conversations with the company providing her care, with the staff at her day centre and with social workers responsible'

Getting and using Continuing Healthcare funding

Just over 1 in every 4 people (26%) told us that a care plan was produced that clearly shows their budget and how it will meet their needs, after being awarded CHC funding. However, it was unclear from the information we received, as to whether this meant that 76% did not have a Plan or there was no clear budget allocation or that they disagreed with it. Further work would need to be conducted to clarify this.

Individuals told us about difficulties getting their care plans changed when needs change over time, and some people told us that their care plans do not refer to their budgets and only includes a list of their needs.

'Over the years the need has changed. ECCG are poor with administration and have lapsed on doing reviews and updating care plans. Lots of things done verbally with two previous commissioners that have been agreed provided but not written down. All removed by present commissioner'

'MSB were contracted by the CHC to produce a Care Plan for my son. I ensured that it included accurate financial information. The budget was increased a year ago, but I have been unable to obtain an up to date Care Plan, as I understand that the CCG has ceased its contract with MSB. I am currently continuing to ask the CHC for an updated Care Plan'

'Told by support money(broker) the money can be used for equipment, etc did not get what was promised'
'Care plans are always updated. They do not refer to budgets through. Only care'

'It was in the past, that is how I know how much I should be getting but since it switched to CCG I have not had information to explain what is going on. I have been chasing this up for months and they never answer the phones or get back to me. I finally had an appointment booked this morning with the commissioner but she phoned to cancel. She now says it will be tomorrow. We will see.'

'I have not had sight of a care plan since the CHC funding was instituted'

'I have never received any documents stating CHC funding for my daughter or budget or how spent to meet her needs. I was only informed she would receive 100% CHC funding'

'Never received a care plan'

16% of people told us that they were present when the decision was made as to whether or not they should be granted CHC funding and that they understood the reasons why this decision was made.

Individuals told us that although they were not allowed to attend the meetings where decisions were made, it would be helpful to do so. They said that it took 'some time' after the decision for them to be made aware of the outcome and the explanation was not always clear. We were told about instances where funding decisions were 'suddenly' changed and that individuals 'did not know why'

'Nurse Assessors did not allow to me attend MDT as an observer. At that time, I understand this 'rule' was applied inconsistently. Decision communicated by social worker'

'Not part of the decision making process so family do not attend'

'Family are not allowed to attend the MDT.'

'paperwork sent out some time after decision'

'The whole process was a shambles she already made up her mind. Did not care at all about the client.'

'I didn't know I was allowed to be present when the decision was made!'

'All I know is that my respite care has suddenly stopped and I don't know why.'

'Decision was not communicated until 3-4 weeks. Just had review- went to panel last month. Still not had feedback'

Individuals told us about difficulties they experience setting up their CHC budget, including a lack of support from Enfield CCG, limited information and poor communication.

'Impossible to communities with CCG CHC. Felt totally lost with no point of support from the CCG'
'Originally fine as nurse assessor was good. Have no budget or services at the moment as all withdrawn only basic carers'

'I made very sure that I was well acquainted with the CHC budget-setting tool (PACE, I believe), and that I was involved when it was used. There were a few 'false starts' when the budget produced was insufficient, but I worked with the nurse assessor to ensure that it did eventually come up with a very accurate figure. It was extremely fortunate that I did have a good deal of experience with this type of software, having been very much involved with the ASC Complex RAS, when it was first implemented. I don't think that most people would have been in a position to do what I did to ensure the correct budget. The process was quite quick, once the budget setting tool came up with an appropriate figure'

'Difficult'

'Did not receive any information on what can be done with care money, as was told previously, physio privately/equipment. Which has not been the case. No equipment needed has been provided'

'Several Months. communication was poor'

'No one to contact. Money late'

Almost 1 in every 4 individuals we spoke to (23%) have a support broker that helps them manage their CHC. Some of these individuals told us about a poor experience whereby mistakes were made, and budgets were calculated incorrectly by the support broker. However, one person told us about a positive experience of their support broker.

'Rubbish! no communication whatsoever mistakes on initial report'

'Calculated all budget incorrectly- issues with agency'

'Their services cannot be faulted. They support their client and the family'

'I just send all my paperwork off to them every month like I was told to do. That is all I know'

Almost 3 in every 4 individuals we spoke to (73%) told us that they received support from Enfield Council Social Services before moving to CHC (or vice versa). Some people told us about a positive experience of moving the support from Enfield Council to Enfield CCG. These individuals reported that their care plans/support received has not changed and that the process was 'simple'.

'Enfield social services are very helpful'

'Nothing changed'

'Went smoothly and things carried on as before. No changes in care and no new support plan'

'It was simple'

'No problem moving from one service to another'

'The process was, from my perspective, seamless as Enfield Social Services were, and still are, involved. Provision has continued to be the same as that provided before the CHC decision'

However, some individuals told us about a poor experience of switching and explained that they experienced a lack of communication, a reduction in services and a lack of support to solve any problems.

'No changes in package but none ever spoke to us about the package. Only interested in trying to prove static improvements at the annual reviews. Over and over again put through assessments'

'Originally ok. Now horrendous'

'No reduction in service and no change in providers. The biggest change is that you fall into a void - no longer SS available for support and no one to support at the CCG. Our only contact with the CCG is for reviews and these are usually focussed on seeing if the nurses can find a reduction in need so that they no longer have to fund'

'NO change in support but it has been threatened'

'I was adamant that I did not wish to have any change to my son's very excellent existing service. I was successful in securing this. We did have problems with the financial arrangements during the transfer, as ASC and the CCG did not appear to communicate with each other! At one point I received a demand for re-payment of a very large amount money to ASC, for a month's D.P., which was totally wrong, and resulted in my having to take this to a senior finance manager to sort out. It was not a pleasant experience'

'Respite was reduced without any reason or explanation'

'Some problems with PB payments and who to contact if you have a problem'

'I was told I can have any agency and I save money, was forced to leave current agency as it was too expensive, forced to get cheaper agency and careers are not able to support properly'

'I thought the hand over was ok as the social worker told me it was in our best interest to move over to the new system. For the first year it seemed to be fine, everything stayed the same, then this year, my care company told me they had not been getting paid for the care they provide so they may have to stop coming. Also this year my respite care has stopped too but I don't know why'

Continuing Healthcare reviews

Over 1 in every 4 people we spoke to (27%) told us that their reviews have taken place at least once a year and some individuals told us that their CHC funding has been stopped or changed overtime.

Individuals told us about problematic experiences of 'reviews' whereby they felt they lacked support in adapting care plans according to changing needs over time. We heard about difficulties contacting the appropriate staff to make changes to care plans, in addition to services being reduced without warning nor explanation. Individuals told us about a lack of consistency when conducting reviews, in addition to little knowledge on how reviews are objectively conducted and decisions made.

'No. No help. No contact. Alone. SS provided a point of contact and support when needed. All the CCG CHC team were interested in is moving my family member off CHC. I would describe the system as abusive'

'Only had one review in 2016 since initial eligibility which is now why they have taken this to a brand new DST in 2019. They have no paperwork - administrative failures - previous commissioners have nothing on file'

'NO updated care plans. In fact, the care plan is not even discussed. The review is about re assessment of the domains'

'The review is based on proving that CHC should not have been awarded in the first place'

'We just updated the care plan. See if any changes had occurred in the year. No discussion on respite on the care plan'

'No opportunity to change service. No opportunity to increase budget or update care plan'

'For the first two years the nurse assessment was excellent and very helpful. The last assessment was not clearly communicated with the objective to underline my case'

'Nothing, money reduced. Given a less budget then what was on. Not given full budget. No one at CCG was helpful, feel that I was ignored. Management was very rude'

'The CCG has not provided a copy of the review report. I have no idea what was written. All I know is that there will be a DST and that is the reason why the CCG says it cannot release the review report. Previous reviews were provided on request after much chasing. Making up the rules, I think as was told I'd get a copy and now they've changed their minds'

'Reviews are about reassessing eligibility. CCG does not follow any consistent process. They change the paperwork and approach depending on the client'

'We are now in dispute of eligibility - Primary health needs have increased since 2013 not got better! It's all about saving money!'

'Despite all the threats and attempts to remove, the CCG CHC Nurses cannot find legitimate reasons to stop or cut the budget due to genuine needs. However, in doing so they have cause us uncertainty and distress. The Nurses hold power over what will happen to the patient and the family have little or no say. Social care was better and there was compassion and genuine respect for the family carers. In social care, although very stretched, we were treated with dignity but CHC is not a caring process and I dread the next review'

'Reduced respite days'

'I have now been deemed ineligible for CHC although my needs have not diminished, I have more care needs and they considered that my care needs were too well managed and not taken into account'

'Currently getting through full assessment, they think condition has improved when it was getting worse'
'First year yes because nothing changed. Second year I don't understand why money has stopped being paid. I was happy with the care package we had before. I cannot manage this way'

'My experience of the reviews has been that the CHC representative[s] can be somewhat confrontational. There seemed to be an unwillingness to accept the views of the other professionals involved in my daughter's care. All of whom had a long standing appreciation of my daughter's disability and the care that she requires. Indeed, following the original review, some of the domain scores were marked down from those agreed upon in the meeting, by the CHC. The representatives from CHC had no personal knowledge of my daughter and have never met her'

'CHC review in June this year has caused immense stress and worry. Firstly, they wanted my daughter to be left alone in her flat for 10 hours at night and 5 hours during the day (with someone popping to check on her every 30 mins!!) She has 24/7 1:1 care and has 2:1 during day so she can go out in the community. They have now decided she can have 1:1. But NO 2:1 which means due to her complex needs it would be impossible. Also CCG are completely disregarding the immense risks involved and choose to completely ignore us as her parents and the care provider. They never even met my daughter until after making the 1:1 decision. They say her needs have changed! Her needs have NOT changed -they are being well managed and therefore this impacts on how she is behaving'

'Not enough clear information. No reviews.'

'Changed But no review'

Just over 1 in every 3 individuals (35%) told us that they know who to contact if they have any problems with their CHC budget. Individuals told us that the support they receive is poor and told us that they do not have a point of contact.

'Zero support'

'There is no point of contact. The service is only about assessment and trying to remove the funding and not support or advice'

'ZERO support. Ignore phone calls and letters'

'I am not informed if my 'named' nurse assessor changes. I find it extremely difficult to obtain a response, if I have an issue - although, following a complaint about this, I have been told that improvements have been put into place. This remains to be seen!'

'The care manger keeps changing. They don't reply to e-mails, you have to keep re sending for them to contact you'

'The system is not fit for purpose in Enfield. feel really worried about care and no one to help'
'The CCG have not been helpful, no response to emails calls ignored. I find they have an attitude towards people with a disability, no understanding or helpful towards them, they are in the wrong job'

'Often call are not answered or returned – it's very frustrating - I have to keep chasing it up'

'I do but there have been many changes in personnel. Historically communication has not always been prompt, but latterly it has improved a bit.'

'Not helpful at all. They emailed a letter where my daughter either signs her permission OR I have power of attorney. NEITHER are appropriate! My daughter cannot speak, read or write and she lacks mental capacity! They didn't even give this as an option on their online form!'

'I don't know who to contact at all'

This report can be made available in alternative formats, such as easy read or large print, and may be available in alternative languages, upon request.

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