



**Information for Learning Disability Partnership Boards
about
The National Framework for NHS Continuing Healthcare
and NHS-funded Nursing Care**



The National Health Service,



social services,



and money.

Easy read summary

The government has said that local areas have to get better at deciding whether the National Health Service (NHS) or social services will pay for someone's care and support.



So, there is a set of papers – a **National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care**. It has things in it to help people make good decisions. Your local area has had to use it to make decisions since **October 1st 2007**.

The new papers (the Framework) say that:

- The NHS and social services must find out exactly what support someone needs with their health before deciding who will pay. There is a new form to help them to do it.
- NHS and social services staff must work together to find out what care and support someone needs. They have to agree what support a person needs with their health and tell the Primary Care Trust.
- If the person *mostly* needs help because of their health problems, the health service must pay the *whole* bill for their care and support.



- If the NHS is paying the full bill, they will arrange the support and decide how it will be provided. They have to listen to what people and their carers say about how they would like to get the support, but they do not have to do it that way.

...and we'll
decide how to
support you



- If someone only needs a small amount of support because of their health, the NHS will pay for it, but social services has to pay for most of the support the person needs.

- People and their carers must be told the decision about whether the NHS will pay for any of their care and support. People can ask for the decision to be reviewed.



- If the NHS pays the full bill, it will affect the person's direct payments, and might affect their benefits too.

- The NHS and social services must pay for the care and support that the law says each of them should put into place for people, and not try to get the other one to pay.



- If the NHS stops having to pay for someone's care and support, it must not take services away until social services agree to take over. And, if social services stop having to pay, they must not take services away until the NHS takes over.



Partnership Boards can help by asking who will do what, who needs training, and how this can be done without adding lots of extra work for people. The Board can help to make sure things work well in the local area.

More information, in plain English

What is the National Framework?



The National Framework is being introduced by the Government to try to put an end to situations like Ann's below.

Ann was admitted to a health service assessment unit because her behaviour had become so challenging that she and her elderly parents were getting hurt. After 5 months her psychiatrist felt that she was ready to go home as her behaviour was more manageable. She would continue to need daily medication, weekly art therapy, psychology and psychiatry support. But, her parents said that they just could not cope: she needed somewhere else to live. The social worker quickly found her a flat and a specialist community support provider. The provider employed staff skilled in work with people presenting challenging behaviours, some of whom were qualified nurses. The support would cost £3,800 per week. The social services department felt that the health service should pay for the support because Ann has continuing healthcare needs. The Primary Care Trust felt that social services should pay because Ann's needs are mainly about help with daily living. Four months later Ann was still at the assessment unit and the health and social services departments were still arguing about who should pay for her support after she moved.



It is about **how to decide** whether the National Health Service (NHS) or social services will fund someone's care and support when they appear to have continuing healthcare as well as social care needs. It covers care and support for anyone aged 18 and over, not just people with learning disabilities, and the whole of England has to use it.

It is about if and when the NHS will pay **in full** for someone's care and support, and it is also about if and when they will pay for health and nursing care as **part** of someone's overall support plan.

The Framework was introduced on **October 1st 2007**. Primary Care Trusts, Strategic Health Authorities and Local Authority Social Services have had to use the Framework to make decisions from that date.



What does it contain?



The Framework has information and tools to help local areas make decisions that are within the law and based on an accurate picture of people's needs. It tells you what the Government says *has* to be done, and gives guidance on how to do it. It contains –

- national policy
- directions¹
- the legal position
- the steps that need to be taken: the process
- and three documents to help people make decisions (there's more about these later).

So, what support should social services fund and what should the NHS fund?



This is the tricky question! It is all about what the NHS and social services have to provide by law, but that's a bit blurred around the edges. It is blurred because it is about meeting a very wide variety of people's needs, in a wide variety of situations.



Let's have another look at Ann's situation.

Ann presents very challenging behaviour that appears to have improved with daily medication, weekly art therapy, and some psychology and psychiatry support. She is in a health service unit, supported by healthcare staff, but moving on to a flat with 24 hour support from a specialist community support provider. The provider employs staff skilled in working with people presenting challenging behaviours, some of whom are qualified nurses.

Ann will need support to look after herself and her home, and to lead an ordinary life, and she needs some help with her personal care. She also needs support to manage her medication and a lot of support to manage her behaviour, including at night.

¹ Directions under the NHS Act 2006 and LASS Act 1970

There are three main questions.



They need to be asked in this order:

1. **Does Ann need ‘continuing care’?** This is care over a lengthy period of time in order to meet her physical or mental health needs. The Framework contains a checklist to help work out whether someone has continuing healthcare needs. Social services and the NHS both fund long term/continuing care, so if the answer is yes another question needs to be asked...
2. **Does Ann have a ‘primary health need’?** This is where the quality and quantity of care she needs is *more than the local authority is responsible for*. The Framework contains a decision-support tool that helps work this out. If it is judged that she *does* have a primary health need, the NHS must **fully fund** her care and support, whatever type of accommodation she is living in or wherever the support is needed. If, on the other hand, she doesn’t have a primary health need, there is still another question to be asked...
3. **Does Ann need *some* healthcare or nursing support as part of her overall care package?** The NHS can pay for care from a registered nurse as a small part of her full community care support package. It can also pay for other health care support agreed as part of the care plan, such as specialist counselling or art therapy².



It is clear that Ann does need long term/continuing care, but not that she has a *primary* health need. In her new home she will receive some support from registered nurses, but does she really need that?

Funding decisions have to be based on a clear picture of a person’s *needs*, not the support that is being provided. In Ann’s case, more information is required about what she needs help with.

² Other examples are assessment by doctors and nurses, district nursing, rehabilitation services, respite health care, specialist community health care support such as physiotherapy, psychology, dietetics, palliative care ...and more.

How will decisions about funding be made?



The Framework is about a *person-centred* and *fair* way of assessing people's healthcare needs and making decisions. Your area will have to take 3 steps:

Step 1

Use the *NHS Continuing Healthcare Checklist* to identify people whose care and support the NHS *may* fully fund. If someone's needs fit, they move on to step 2. Even if they don't, the NHS may still pay for some of their support if it is agreed as part of their care plan.



Step 2

Use the *Decision-Support Tool* to get an overall picture of a person's healthcare and support needs and to recommend to the PCT whether support should be funded or not. It must be a multidisciplinary assessment and recommendation, and professional judgement has to be used. Risk assessments have to be attached.



Step 3

The PCT makes the funding decision, but the recommendation should be followed in 'all but exceptional cases'. Finance officers should not be part of the decision-making. The decision has to be put in writing to the person (and their carers or representative where appropriate).

What if a person's needs change?

Being diagnosed with a long-term health condition or disability does *not* mean that a person's care and support will automatically be funded by the NHS. It depends on their needs, and the steps above would have to be followed.



If people have already been through the steps above, or the NHS is paying for a part of their care package, there is a funding **review process**. The first review is no more than three months from the original funding assessment, even if health funding was not given, and then at least every year.

What if people don't agree with the decision or with the care and support the NHS arranges?



People can apply for the funding decision to be reviewed. The PCT must let everyone know when and how they can do it. But, if the NHS is paying, they will decide what care and support is appropriate to meet the person's needs – people cannot ask for the care and support to be reviewed, only the decision about who will pay for it.

As a first step the review of the funding decision can be carried out locally, but if the person is not satisfied with the result it must go to an Independent Review Panel organised by the Strategic Health Authority.

If the PCT and social services just can't agree who will pay, the support that's needed must be provided anyway. They must say how it will be funded until they reach an agreement. Local areas will need a way of handling such situations.

What should people expect?

- To be treated fairly and not be treated differently from any other adult.
- To be asked for their consent to be assessed for health funding.
- To have their wishes about how they get support listened to.
- Not to get health funding as a Direct Payment or as part of an Individual Budget. It is not allowed. People also cannot get Independent Living Fund monies or the Disability Living Allowance care component if they are *fully* funded by the NHS.
- Not to have to wait for the support they need because the NHS and social services can't agree who will pay.
- To get the decision about health funding, and the reasons, in writing.



- For a decision on health funding to be taken quickly if they are very ill and rapidly getting worse. There is a *Fast Track Pathway Tool* to help with this.
- To be informed that they can ask for the decision on NHS funding to be reviewed, and about how to do it.
- Not to be affected by any of this if they already get NHS funding because they moved out of a long-stay hospital or accommodation run by the health service.



What will help it to work?

The Partnership Board may find it helpful to talk about the following questions:



Who will co-ordinate people's continuing healthcare assessments? Will it be existing staff, or will assessors be employed? What about for people with learning disabilities being discharged from a general hospital?

How will information from existing multidisciplinary assessments be used so that time is saved and work already done is not repeated?

Who will require training, and how will they get it?

How will your area make sure that 'professional judgement' is not leading to unfairness? How will it be checked?

How good are the risk assessments that are carried out? They are an important part of the continuing healthcare assessment. Do people need training or guidance?

How will your area make sure that people know about the review process for funding decisions, and that they will have confidence in it?

How will your local area do all this in ways that fit with Valuing People?

How will the process be governed locally? The PCT has to lead the work. What will your PCT put into place, and what will *your* role be?

Other Frequently Asked Questions



I've heard that social services can fund people living in nursing homes, but surely that's healthcare. Am I right?

It all rests on the judgement about whether someone has a *primary* health need. If they do, the NHS pays for everything. If they don't, then social services is responsible, but the NHS may pay for some specialist health or nursing support if it is needed.

What happens if a person has had control of their support through a direct payment, and then the NHS takes over paying for their support?

Their direct payment would end. Your local health and social services should talk about this kind of situation now, and agree what they will do so that people keep as much control as possible.

How long will a decision about NHS funding take

The Framework says that it should take no more than two weeks to carry out steps 1 to 3 and tell people the decision. If healthcare and support is already being provided, it can take longer.



When someone is getting good healthcare and support their health needs are not so obvious. How does that affect things?

Steps 1 and 2 should be based on the person's needs as if they weren't getting the support.

What can we do to make sure people with learning disabilities get support in the way they want it?

It may be useful for the Partnership Board to discuss this. Why not ask the PCT and social services to agree some shared principles and ways of working with local advocacy organisations?

What happens if someone says I don't want NHS funding because I'll lose benefit?

If people don't give their consent, the assessment for health funding can't go ahead. But social services may say that they won't fund the support, because the NHS should.

