

**Personal Care At Home:  
Consultation on proposals for regulations and guidance:  
A response from the National Family Carers Network (NFCN).**

**Introduction:**

1(i) The National Network of Family Carers [NFCN] welcomes the opportunity to contribute to the consultation on the proposals for regulations and guidance on free personal care at home..

1(ii) NFCN is a national network of organisations of and for family carers of adults with a learning disability. By linking groups and organisations, the network gives a national focus to a wide range of policy issues concerning family carers of adults with a learning disability. Our key objective is to work together to promote better life chances for families that include an adult with a learning disability.

Therefore, the present consultation is of particular interest and concern, given the demographic, social and policy developments around provision and support for people with a learning disability.

**General points:**

NFCN welcomes the opportunity for some people with very high support needs to receive free help but this must not be at the expense of other services. Ongoing preventative work is essential and also there must not be a reduction in support to other vulnerable people with very high support needs such as those with challenging behaviour.

Many family carers are very concerned that the personalisation agenda will lead to them having to give more support to their relative. This must not be an unintended consequence from this initiative.

The capacity of local authorities to respond to and support those who are currently eligible to receive services is fragile in many areas of the country. They will need to have much more capacity to respond to this new demand for assessment. There are many families who have never sought help from local authorities who may well come forward when the help is offered free of charge. We know there are many hidden carers in the community.

We would wish to see a whole family approach to the assessment of need and the family carer should not be seen as part of the 'provision' available, unless they have agreed to provide a certain amount of care and support. Their rights under carers' legislation must be respected and explained to them. This should form part of the regulation.

An appropriately trained and motivated work force must be created if these measures are going to keep people safe in their own homes. The staff who currently work in registered homes may not be able or willing to be lone workers.

We think it will be very important that the public are made aware that these rules will apply to all adults with the highest social care needs and not just those in older people's services. Training on the regulation will be needed by all local authority staff who deal with adults not just those in older people services.

The provision of appropriate information is very important if all those entitled to benefit are to know what they can expect.

We note that these regulations are intended to be temporary until a national care service is established, as this is likely to take some time and require further consultation.

There is no mention of continuing care criteria and funding from the NHS.

**Our questions: How will people know which of these 2 routes (Community Care and Continuing Health Care) to go down for an assessment? Will they have a choice?**

**The executive summary:**

The summary mentions people who need prompting to carry out the personal care tasks but this group (which is large) then drop out of the proposals.

**Our question: Are people who need prompting to do these tasks to be excluded ?**

**Part1: What the policy is trying to achieve:**

1.NFCN thinks that for some people a period of rehabilitation may help them to regain some independence but for many young people with profound and multiple learning and physical disabilities they will already have had a lot of work done to help them reach their potential. They need a smooth transition from children's to adult services with the proper assessments done in a timely fashion and budgets put in place so no funding gaps arise.

The capacity of local authorities to set up and deliver these rehabilitation services will need increasing from the present position.

**Our question: Are there enough qualified staff in the work force to do this work and how might those who are qualified but no longer working in the sector be encouraged back?**

2. It is stated that where intensive support is refused, the person will not be entitled to free personal care. There will need to be 'best interest' consideration under the Mental Capacity Act. This needs adding to the regulation. If a person refuses because they are mentally unwell at the time, will they be able to subsequently change their mind? (If they have had a traumatic and life altering event they may not be ready to accept their situation within 6 weeks of discharge from hospital.)

**Part 2:**

7: This part needs to be made much clearer. It reads that where a family carer is involved the cared-for person will not be eligible for free care.

Whilst family carers are often happy to provide some support to their learning disabled relative, especially if they still live with them, they must not be taken for granted as part of the provision package. They have rights of their own and these must not be over ridden. Family carers need better recognition and support and facing the family with charges because they are prepared to give support to their relative is a disgrace. They may withdraw their support in these circumstances and then much more paid support will need to be provided.

**Our question: If the family carer is not prepared to provide 'personal care' but will give other help such as shopping and food preparation, what is the situation then?**

9. Many families of adults with a learning disability would wish their relative to have the opportunity to live in their own home but the necessary supported living accommodation is not available. This guidance appears to be aimed solely at people who have got their own home rather than those living in their parents or siblings homes.

**Our question: Are you intending to exclude people with a learning disability who do not live in their own accommodation but in a friend or relatives home?**

The standardised assessment tool must recognise that there are young adults who will fall into this criteria and not just older people in declining health. These people want to be included in the community and have meaningful, active lives.

The guidance needs to include a service provided by a third party, funded by a personal budget, not just those directly provided.

**Section 2.3:** If services are to be person centred and individualised then you cannot set fixed amounts of money. They have to be on a personal basis. An indicative level may have to be very wide.

**Section 2.4: Aspects of the implementation for councils.**

**Our questions:**

**Will it be mandatory for councils to use the standard assessment tool with all client groups?**

**Will you trial the tool with some young people in transition from children to adult services? Although few have to pay for services, it needs to recognise those who have had significant 'negligence' compensation.**

**Part 3:** We do not wish to comment.

**Response to your 6 questions:**

**Question 1:** We agree with the most of the substance of the proposal but the success or failure of it will be in the ability of local authorities to physically and financially respond to the requests of assessment and support.

**We do not agree that where a family carer is involved the cared-for person will not get free care.**

In our view, this is discriminatory and may not comply with the Equalities Bill.

If the family carer is not prepared to provide 'personal care' but will give other help such as shopping and food preparation, what is the situation then?

**Question 2:** There is no detail in the proposed regulation about what is meant by 'at home'. Will they have support for going to GP appointments, family visits, etc?  
Not everyone who comes within the 'critical' band is house bound.

There is not enough clarity about the role of family carers (unpaid !) and how, if they provide help, their relative will be excluded from this scheme.

**Question 3:** The regulation needs to include that local authorities work 'within the spirit of' the Bill.

**Question 4:** There is not any guidance on the people who need prompting to carry out the tasks. What will their position be?

**Question 5:** There are equality issues for family carers in this document. If their relative is not eligible for free care because they are prepared and willing to help take care of the person this cannot be fair. People who get funding from this route rather than NHS continuing care criteria will have the right to a direct payment . There may be other rights they will enjoy which is a good thing.

**Question 6:** Impact assessment. We do not wish to comment. \_Caroline Farnes, Director