

Shaping the Future of Care Together

Introduction

The National Family Carer Network (NFCN) is writing a response to the government's Green Paper, *Shaping the Future of Care Together*. We would like to hear your views on a range of issues that are relevant to family carers outlined below. Please do not feel you have to answer all the questions. We would also like to hear your views about anything else in the Green Paper that you are concerned about and that we have not covered.

Alternatively you may be writing your own responses. If you are able to share these with us, we would welcome that. We will need to hear from you by Thursday October 29 at the latest, as all responses have to be submitted by November 13 2009, and we need time to collate views. We will post the NFCN response on the website and will send a hard copy on request.

This briefing covers:

- The background to the Green Paper
- An overview
- NFCN's key questions for families that include an adult member with a learning disability

Background

We are all living longer and more people need social care as they get older. There are also more people of working age who need social care. Improvements in the NHS mean that people with complex disabilities and health conditions are living longer. A growing number of families are now part of a 'sandwich generation' where they may be supporting adult disabled relatives, elderly parents and sometimes grandchildren. Taxation from working adults is thought to be insufficient to cover future needs. The present system is also unfair. For example there is variation between different areas about what support people can get. Some older people have to sell their houses to fund their care. This consultation does not cover food/accommodation costs. It is only about social care

The government has already done a preliminary consultation and the ideas in *Shaping the Future of Care Together* are based on the responses to Care Support Independence. (You can read the NFCN response on the website <http://www.familycarers.org.uk/>)

The government says that it wants to set up a National Social Care system. A great part of *Shaping the Future of Care Together* is about meeting the needs of older people. However it does talk about the needs of disabled people of working age, but these are not fully explored. It is important that we make our views known so that we can ensure that the needs of adults with learning disabilities and their families are not overlooked. The Green Paper will be followed up by a White Paper next year- and that will form the basis of legislation.

If you want to read *Shaping the Future of Care Together*, you can find it http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_102338

There is also information about the Big Care debate that is going on. See <http://careandsupport.direct.gov.uk/>

Brief overview of the Green Paper

The vision for the future (Section 3 p 47)

- Preventive services: You will receive the right support to help you stay independent and well for as long as possible and to stop your care and support needs getting worse;
- National Assessment: Wherever you are in England, you will have the right to have your care and support needs assessed in the same way, and the same proportion of your care and support paid for wherever you live;
- A joined up service: All the services that you need will work together smoothly particularly during assessment;
- Information and advice: You can understand and find your way through the care and support system easily;
- Personalised care and support: The services you use will be based on your personal circumstances and need;
- Fair Funding: Your money will be spent wisely and everyone who qualifies for care and support will get some help meeting the cost of care and support needs.

Making vision a reality (Section 4 p 65)

The Green Paper has identified three key changes that are needed:

- More joined up working between health, housing and social care services and between care and benefits services
- A wider range of care and support services
- A better quality, more innovative service, based on best evidence about what works.

Funding social care (Section 6 p 95 onwards)

With respect to funding options, the Green Paper rules out payment of all social care through taxation or expecting the individual to wholly fund their own care.

It focuses mainly on people over 65 and suggests three ways to fund their care:

Partnership - People would be supported by the government for around a quarter to a third of the cost of their care and support, or more if they have a low income. This would mean that most younger people who needed it would probably get their care free (i.e. funded through general taxation) as they would have comparatively low incomes.

Insurance - As well as providing a quarter to a third of the cost of support, the government would make it easier for people to take out insurance for the remaining costs. People born with care and support needs would not be able to get insurance and would need to be supported as under the partnership scheme.

Comprehensive - Everyone gets care free when they need it in old age in return for paying a set amount or a set proportion of their assets into a state insurance scheme at

65, if they can afford it, whether or not they need care and support. The government would look into having a free care system for people of working age, alongside this paid for mainly out of general taxation.

(Under the insurance and comprehensive models, payments could be deferred and be paid after death from the individual's estate.)

Key questions for NFCN members

The Green paper focuses on the shape of social care and on how it might be funded, although the picture is sketchy at times. We have identified some key questions to which we think it is important that we provide a response, from the perspective of families that include an adult with a learning disability. They are in three areas:

1. The shape of social care
2. Funding social care
3. Implications for family carers

1. The shape of social care

1a) How can we help to define social care so that it promotes independence and widening opportunities?

Disabled people have expressed some concern that in promoting a care model there is a risk that the government may be undermining the citizenship role that disabled people and their supporters have fought for, for so long. There may also be fears on the part of family carers that their relative's independence may be undermined if they are unduly dependent on their families and do not have support to be as autonomous as possible as adults. Of course we have concerns that social care should not be interpreted too narrowly and should include support for the activities and opportunities that enable people with learning disabilities to lead full lives.

Social care is the provision of services that offer personal care and support to disabled and other vulnerable people to help them achieve independence and to contribute to their communities. It could be personal care such as washing and dressing if these are needed, support in everyday life such as shopping or support for opportunities to engage in their communities, for example to participate in daytime activities outside the home. (Foundation for People with Learning Disabilities: *Prepared for the Future?* 2009)

We would like further definition of what is meant by basic care and support. Please let us know what you think social care should look like. Please give us good examples and examples where people are not getting the care they need.

1b) What do we want to say about prevention, identified as one of the principles underpinning social care?

The paper seems to use prevention to mean universal services, services that promote wellbeing, specific prevention services such as preventing falls, and also positive management of long term conditions.

We think preventive services are of great importance to people with learning disabilities in ensuring that they do not experience additional problems. This is particularly the case

for some people with learning disabilities who under Fair Access to Care may currently be excluded from support services. A small amount of support can prevent the development of additional problems. For example, if people have no access to work or activities it is no surprise if they become depressed. Therefore we think good support can prevent additional difficulties. What do you think?

How would you like prevention to be defined?

1c) Do you favour a national assessment system or local eligibility criteria?

The unfairness and discrepancies in the current system have been among the factors behind the drive towards a National Care Service. You may have experienced the downside of local eligibility criteria, both because of exclusions from services or variations in the levels of need that will be met when people move between authorities. A portable national assessment could help to overcome this. Local authorities would still be involved for example in assessment. A national system would need to be responsive to local circumstances - life being more expensive in some parts of the country. If personalisation is to be fundamental, there also has to be flexibility. A national assessment system could undermine choice and flexibility.

Please tell us about your experiences. Do you prefer a national or locally based system? Do you think a national assessment is of use without a national entitlement?

2. Funding social care

2a) Do you think that funding should be controlled nationally or locally or have elements of both?

Linked to the discussion on assessment, there is a huge debate about national versus local control of funding for social care, with the argument split roughly between those who want maximum allocation to individual (via a national entitlement) and those who say that removing funding and flexibility from local authorities will damage their ability to develop services in response to individual need in an innovative way and to provide preventive services.

Again please let us know what you think about a national system or a locally based system.

2b) Do you think there should be a review of strands of funding to make a simpler system?

There is a discussion on p 103 on non means tested benefits like the Attendance Allowance for disabled people over 65s and whether such benefits should be merged into a simpler system of social care support. We have concerns lest in the future DLA could also disappear as it enables many people to lead fuller lives. It is hard to see how replacing it with one stream of social care support could give the same flexibility. Many older family carers are also very worried about any proposal to merge the Attendance Allowance with other funding streams as both DLA and AA have national eligibility criteria and in many cases represent the only financial support that families receive. We would like to know what you think about this and the future funding of social care.

2c) Do you think sufficient money is allocated to social care for people with learning disabilities?

Detailed discussion about funding so far has focused mainly on care for older people. The Green Paper states that it is envisaged that most people who are disabled from birth or become disabled during their working life would continue to have their care and support funded by the state because they are likely to be on low incomes and to have limited assets. Would you like to see this care and support more clearly defined? Care is expensive and even in a time of financial stringency, more resources may be needed. To shuffle budgets around is unlikely to be enough. Many people with learning disabilities also have associated health problems. To what extent should health and social care budgets be better aligned not only to meet any specific health needs but also to ensure the health and well-being of people with learning disabilities and their family carers? Please give us examples of recent cuts or changes in the way in which services are delivered and let us know what you think about how funding care needs can best be met.

3. Implications for family carers

The main discussion focuses on the funding of social care for older people. However we believe there would need to be a discussion about the expectations placed on family carers of adults with a learning disability and also whether the needs of family carers are sufficiently taken into account. Currently social care is provided by state funding and support, voluntary organisations and by family members and friends, but the balance between these is nowhere defined.

We know that so often families want to be involved and enjoy and value their role, but they do not want to be over stretched with consequent repercussions on their health and economic circumstances.

3a) What should be the personal and financial responsibilities of families of adults with a learning disability?

This is not explicitly addressed in the Green Paper. It has some references to family carers and recognises that they are going to continue be involved in care. It suggests that a new system based on the vision in section 3 would give a better deal for carers.

Many families are 'topping up' care and support for their adult family members with a learning disability. Residential care is usually totally covered cost-wise, bar personal expenditure, but personalised services in the community are not necessarily so covered. What should happen about charging policies (again not really touched on) and the responsibilities (and rights) of families? For example, how should the personal and financial contributions of family carers be reflected and valued within personal budgets? Some other countries have very specific legislation and guidance on what families are expected to contribute in certain circumstances and indeed what family carers have a right to expect. Would we want to go down this route (it can disadvantage as well as advantage families)? Disabled people will shortly have the 'right to control' over their lives as part of the Welfare Bill but family carers will have no such rights.

We are asking for your views on how you think that a reasonable level of caring suited to a family carer's circumstances can be organised. Do you think there should be some kind of agreement between family carers and the state about expectations about the amount of care/ financial support, as there is in some countries?

3b) Should there be family assessments?

Should a National Assessment System explicitly take into account the implications of any changes on the lives of family carers of adults with learning disabilities whose role is often lifelong? It is estimated that 64% live in the family home. Even when a person with a learning disability moves from the family home, family carers usually remain involved in their lives and may continue to give practical support. Many European countries have family-focused assessments. These incorporate self-assessment and self-directed care but permit negotiation and discussion between family members without in any way negating the wishes and feelings of the person or persons needing care and support. How would this impact on people with learning disabilities themselves?

Do you think family assessments would be a good idea?

3c) How can good succession planning be ensured?

We also know that for many families there is the nagging fear of what is going to happen in the future, when they are less able to care. How do you think succession planning can best be organised to meet the family member's needs? Some parents wish to bequeath their family home to their son or daughter with learning disabilities so that they could continue to live there. How can this be made easier?

Many families are worried that if non-disabled people are encouraged to pay into insurance schemes or offer a 'lump sum' at age 65, or from their estate, to fund care and support in the future, then those people without assets (e.g. people with learning disabilities) might have less choice and a lower level of support if they had to rely on national taxation to meet their needs. Should families be able to 'buy' into insurance or other schemes on behalf of their relative with a learning disability (e.g. from the family estate following the death of a parent)? How can we guarantee that those people *without* assets receive a comparable standard of care to those whose families *can* provide for the future? For example, should the Government under-write their inclusion in any national insurance schemes?

Please could you send us examples of good practice in succession planning, tell us about difficulties and give us ideas for improvements.

Concluding remarks

Please send your comments by email to info@familycarers.org.uk or by post to **NFCN, c/o Hft, 5/6 Brook Office Park, Folly Brook Road, Emersons Green, Bristol, BS16 7FL.**

Once we have your comments and papers we will collate views – and sometimes express a range of views – in our response to the government. We will work hard to ensure that the views of families that include an adult member with a learning disability are well represented in this debate.