

national transition support team

working together to improve transition
for disabled young people

NTST Briefing

Shaping the Future of Care Together – Adult Social Care Green Paper July 2009

Department: Health

Date of Publication: 14 July 2009

Consultation Deadline: 13 November

Geographical Scope: England

Link to full document download page:

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_102338

Introduction

This is a Department of Health green paper on the future of adult social care in England. It sets out the government's vision for the establishment of a National Care Service and attempts to tackle the issue of how the growing bill for social care is to be footed. This briefing is intended to give an overview of the strategy in relation to disabled young people's transition into adult life.

It is proposed that a new National Care Service should offer: Prevention Services; National Assessment; A joined-up; Information and advice; Personalised care and support; and Fair funding. Three funding options are considered – 'partnership', 'insurance' and 'comprehensive'.

The green paper appears, largely, to be written with social care for the elderly in mind. This makes it more difficult to understand what the proposed reforms would mean disabled young people.

There are several proposals that are relevant to disabled young people in transition. These are the use of national assessments, prevention services, more joined-up services and the national development of good practice through an independent body.

The discussion of funding includes suggestions about reform of disability benefits, with the explicit proposal of integration of Attendance Allowance into the social care system.

The consultation questions regard the broad approaches to social care suggested in the green paper and are listed at the end of this briefing.

The Council for Disabled Children and partners working as the national transition support team for the AHDC Transition Support Programme



The national transition support team is a programme of the Council for Disabled Children, which is hosted by the National Children's Bureau. Registered Charity No 258852. Registered in England and Wales No 952717. Registered office: 8 Wakley Street London EC1V 7QE. A Company Limited by Guarantee.

national transition support team

working together to improve transition
for disabled young people

Opportunities and Risks for Young Disabled People in Transition

This section provides an analysis of the key themes in the document that are particularly relevant to transition, with signposts to the relevant parts of the more detailed briefing below.

National Assessments

The green paper proposes the use of a national assessment system for determining social care entitlement that is applicable throughout England (see point 1.b.ii. below). This would help young people with disabilities be able to know what to expect from adult social care as those with similar needs in another part of the country will go through the same assessment and be able to share their experiences.

The assessment itself may be more attuned to the full range of needs experienced by young disabled people as it could draw on knowledge from all local authorities, who collectively have experience of catering for all of these needs.

Some young disabled people will rely on support from adult social care throughout their lives, so are perhaps more likely to want to move during the time they are receiving care. The portability of assessments between local authority areas may make life easier for these young people, as they will be subject to fewer assessments.

Prevention services

Prevention services are also a key area in the proposals for a National Care Service. This would include helping people in their home to establish their ability to live independently (see point 1.b.i. below). Although the green paper describes this support in the context of adults leaving hospital after a serious illness, this policy idea could be developed to meet the needs of disabled young people. Prevention services could help disabled young people overcome barriers to establish their independence for the first time.

Joined-up services

The government wants the proposed National Care Service to offer joined up services (see point 1.b.iii. below). As having to deal with multiple agencies to establish support is a problem for young people with disabilities in transition, suggestion of agencies working together is always welcome. However, joined-up working between children's and adults services, which is particularly important for young disabled, is not discussed in this document.

The Council for Disabled Children and partners working as the national transition support team for the AHDC Transition Support Programme



The national transition support team is a programme of the Council for Disabled Children, which is hosted by the National Children's Bureau. Registered Charity No 258852. Registered in England and Wales No 952717. Registered office: 8 Wakley Street London EC1V 7QE. A Company Limited by Guarantee.

national transition support team

working together to improve transition
for disabled young people

The Discussion of funding

The green paper proposes a broader entitlement to free social care for all regardless of wealth and income. The government specifically wants to avoid the situation where some people are forced to sell their homes to pay for care. There is an acknowledgement of the perception of unfairness in the system that makes people who have saved pay for their care and those who have not saved get it for free (see point 3 below)

It will be necessary to understand the impact if this on disabled young people to ensure that the reduction in support offered when moving from children's to adult services does not become greater for some disabled young people.

Reform of Disability Benefits

There is some discussion of reform involving disability benefits. Comments in the discussion imply a proposal to replace Attendance Allowance with provision through more personalised care in the social care system. This would not affect young disabled people directly as Attendance Allowance is only available to those aged over 65.

Although it is only Attendance Allowance that is specifically named as a benefit that could be integrated into social care, it is not clear from the wording of the discussion if this is the only reform of disability benefits under consideration. (see point 4 below) This has caused some concern amongst recipients of disability living allowance, who thought their benefits may be at risk. However, if the current political climate, the ambitions of other parts of this green paper and apparent reasons for the specific proposed change are taken into account, the risk of benefits reforms that impact directly on disabled young people can be considered minimal. Since the controversy broke out, Care Minister Phil Hope has said that he has no intention of abolishing DLA.¹

National development of good practice in Social Care

The green paper proposes that there should be an independent body responsible for assessing the effectiveness and value for money offered by different approaches in social care for people in different circumstances. The strengthening of evidence bases could benefit young disabled people going through transition as it may enable quicker identification of appropriate social care and more certainty about what kind of care can be expected as an adult. Professionals working with disabled young people may welcome more information about how the work of this proposed independent body will fit with the person-centred planning agenda. (see point 2 below)

¹ <http://www.disabilitynow.org.uk/latest-news2/conference-exclusive-hope-kills-dla-threat-1>

The Council for Disabled Children and partners working as the national transition support team for the AHDC Transition Support Programme



national transition support team

working together to improve transition
for disabled young people

Overview of Key Proposals and Key Quotes

This Section will include relevant comments and proposals or action points from the document. Similar issues are revisited in several sections of the green paper so page references have been provided for individual quotes.

1. A National Care Service

- a. This would coordinate funding and assessment of needs, with local authorities and individuals retaining their current powers to decide how needs are met.
- b. The National Care Service would allow people to receive the following six things:

i. Prevention services

1. This would involve, for example, help in re-adjusting to home life for 6 weeks after leaving hospital
2. “Re-ablement is about helping people to get back some of the skills and confidence they may have lost through poor health, a disability or going into hospital or residential care. Short-term programmes of re-ablement can help some people to relearn and practise personal care tasks such as washing and dressing, so that they can live independently at home for much longer. We think that people who are leaving hospital and need care and support for the first time should have the right to the re-ablement help they will benefit from at home, for example for six weeks. This extra support will help people get back to their normal lives. And, depending on funding decisions, we could extend this right to more people.” (p51)

ii. National assessment

1. “Wherever you are in England, you will have the right to have your care and support needs assessed in the same way...You will be able to take your needs assessment with you wherever you go, so wherever you are in England the assessment of your needs will be the same” (p53)
2. The right to the same proportion of costs to be paid ‘does not guarantee that people with the same assessment in different parts of the country will be able to choose exactly the same services. (p53)

The Council for Disabled Children and partners working as the national transition support team for the AHDC Transition Support Programme



The national transition support team is a programme of the Council for Disabled Children, which is hosted by the National Children's Bureau. Registered Charity No 258852. Registered in England and Wales No 952717. Registered office: 8 Wakley Street London EC1V 7QE. A Company Limited by Guarantee.

national transition support team

working together to improve transition
for disabled young people

iii. A joined-up service

1. “You will only need to have one assessment of your needs to gain access to a whole range of care and support services” (p55)
2. “We want to create an assessment process that considers people’s individual needs, means and eligibility for all forms of support in a more joined-up way. This will build on the developing arrangements for the Common Assessment Framework for adults, to minimise multiple questioning of the same people for the same information.”(p55)
3. “Local authorities will continue to be responsible for ensuring that reassessment takes place on an ongoing basis (for example, when someone’s needs change or at regular review points set out in the agreed care and support plan)” (p55)

iv. Information and advice

1. “you will find it easy to get information about who can help you,” (p55)
2. This will include the provision of advocacy through Putting People First where appropriate (p56)
3. The information to be offered would include:
 - a. Financial guidance and information to help them prepare for the future.
 - b. Information on how to stay independent and well.
 - c. Support for carers.
 - d. Information on how to access care and support and about quality of services.
 - e. Guidance on what people are entitled to.
 - f. Support to fill in application forms.
 - g. Information and support for people approaching the transition between children’s and adults’ services, and their carers.
 - h. Information and advice on the services that are available (both traditional care services and non-traditional services such as telecare and handyman services) and how to choose between them.
 - i. Signposting to, and help with, applying for benefits and other forms of support.” (p56)

The Council for Disabled Children and partners working as the national transition support team for the AHDC Transition Support Programme



national transition support team

working together to improve transition
for disabled young people

v. Personalised care and support

1. “As part of your care and support plan, you will have much greater choice over how and where you receive support, and the possibility of controlling your own budget wherever appropriate” – also in introductory comments “People who need services are often the experts in their own care, and the system for the future must respect this”] “People should also be able to choose how much of their care and support is provided by a carer, and carers should be able to choose how much care and support they wish to provide.” (p58)
2. “Under the new care and support system, once people are assessed they will get a personal budget rather than being told what services they should receive. They will have as much support as they want in using this resource.”(p60)

vi. Fair funding.

1. “everyone who qualifies for care and support from the state will get some help meeting the cost of care and support needs”. (p100)
2. The separation of disability benefits and social care can lead to ‘inconsistent and unfair outcomes’ – older people have two assessment processes to go through. (p102)

The Council for Disabled Children and partners working as the national transition support team for the AHDC Transition Support Programme



The national transition support team is a programme of the Council for Disabled Children, which is hosted by the National Children's Bureau. Registered Charity No 258852. Registered in England and Wales No 952717. Registered office: 8 Wakley Street London EC1V 7QE. A Company Limited by Guarantee.

national transition support team

working together to improve transition
for disabled young people

2. National development of good practice in care services

- a. “We will also consider the benefits of having an independent body to provide clear advice and evidence on what works best for those needing care and support, and what gives best value for the resources invested. This could include trialling new ways of predicting who is most likely to need high levels of care and support in the near future and helping them before their need arises or their condition worsens.” (p51)
- b. “The independent body could be a new organisation, or we could give the remit to an existing organisation (for example, SCIE). It would look at which interventions work and what gives best value for resources in care and support, for particular people in particular circumstances.” (p79)

The Council for Disabled Children and partners working as the national transition support team for the AHDC Transition Support Programme



The national transition support team is a programme of the Council for Disabled Children, which is hosted by the National Children's Bureau. Registered Charity No 258852. Registered in England and Wales No 952717. Registered office: 8 Wakley Street London EC1V 7QE. A Company Limited by Guarantee.

national transition support team

working together to improve transition
for disabled young people

3. Funding options

- a. The following options are proposed:
 - i. **Partnership** – Everyone who needs social care gets a proportion of basic care costs paid for by the state. The proportion would depend on income and assets of the individuals supported.
 - ii. **Insurance** – People to pay into an insurance scheme, state or privately run, a set some and have all basic social care services provided free of charge
 - iii. **Comprehensive** – People over retirement age to pay one-off sum or rate according to their income and assets to guarantee free social care, including accommodation when they needed it.
- b. Individuals paying for themselves and funding care through taxation of whole working population are ruled out as solutions
- c. The government wants to avoid situation of people selling house to pay for care to be avoided. It still professes, however, to be committed to providing free care for those with most need and least means (pp17-19)
- d. “We also need to think about how we can make sure that everyone’s needs can be met without penalising people who have worked hard and saved all their lives.” (p100)
- e. “the system should... be universal – so that whatever system is in place , everyone who is eligible for care and support will be entitled to help with paying for the care that they need.” (p100)
- f. Other issues discussed regarding funding include:
 - i. Whether age at which needs are developed should affect the way people are treated: “People [who were involved in the 2008 engagement process] found it difficult to decide whether people developing care and support needs at different points in their lives should be treated differently. They were split on whether there should be a different approach to younger disabled people because they are usually unable to prepare to meet the costs of their care and support in the same way as people can prepare for their old age. Overall, people’s main concern was that the system should be fair and that everyone should have an equal opportunity to achieve the same outcomes. If this were achieved, it did not matter to them so much whether this was through a single system for everyone.” (p14)
 - ii. The fairness of offering more support to those who develop their needs at younger age (p92) (following on from above)
 - iii. Whether local or national government should decide how much money is to be allocated to particular needs. (pp21-22)
 - iv. Reform of benefits (see section below)

The Council for Disabled Children and partners working as the national transition support team for the AHDC Transition Support Programme



national transition support team

working together to improve transition
for disabled young people

4. Possible reform of disability benefits (pp102 – 104)

- a. “Attendance Allowance is the main disability benefit for older people. It is available to anyone who has a care need that develops at or after the age of 65. Attendance Allowance operates in parallel with the social care system for those aged 65 and over. Attendance Allowance is not a benefit paid to replace lost income: it is intended for broadly the same purposes as social care – to contribute to the extra disability-related costs of those individuals who need assistance to live independently. Like social care, Attendance Allowance is subject to increasing funding pressures. But Attendance Allowance is not means-tested, so people get it regardless of how well-off they are. Many disabled older people will receive support from other parts of the benefits system, including through Disability Living Allowance, instead of Attendance Allowance.”
- b. “We know that disability benefits such as Attendance Allowance are highly valued by the people who receive them, and that they give people control over how they spend their money to meet their care and support needs. However, we also recognise that there are inconsistencies of approach between disability benefits and social care within the current system. This is because the social care and disability benefits systems have developed in isolation from each other and these two largest portions of government care and support expenditure are being allocated on different bases. This can lead to inconsistent and unfair outcomes.”
- c. “Having two different funding streams also means that older people have to apply separately for the two sources of support and undergo different needs assessment processes which may put people off applying for support. This can result in some people not receiving all of the support they are entitled to.”
- d. “If we decide that integrating some disability benefits, such as Attendance Allowance, into a simplified system is the right approach, we would want to ensure that the future social care system retains and builds on the main advantages of the current disability benefits system. We know that disability benefits are popular because they provide a universal entitlement which does not depend on where a person lives, they provide a cash budget which can be spent on the services someone wants, and people often use them to support lower-level needs in ways that help them to stay independent and well for longer rather than developing high levels of need. These three aspects – a universal system that is consistent across the country, flexible methods of payment through personal budgets and investment in prevention – will all be important components of the new system. Chapter 3 laid out what we will do to support these.”

The Council for Disabled Children and partners working as the national transition support team for the AHDC Transition Support Programme



national transition support team

working together to improve transition
for disabled young people

Consultation Questions

1. We want to build a National Care Service that is fair, simple and affordable. We think that in this new system there are six things that you should be able to expect:
 - prevention services
 - national assessment
 - a joined-up service
 - information and advice
 - personalised care and support
 - fair funding.
 - a) Is there anything missing from this approach?
 - b) How should this work?

2. We think that, in order to make the National Care Service work, we will need services that are joined up, give you choice around what kind of care and support you get, and are high quality.
 - a) Do you agree?
 - b) What would this look like in practice?
 - c) What are the barriers to making this happen?

The Council for Disabled Children and partners working as the national transition support team for the AHDC Transition Support Programme



The national transition support team is a programme of the Council for Disabled Children, which is hosted by the National Children's Bureau. Registered Charity No 258852. Registered in England and Wales No 952717. Registered office: 8 Wakley Street London EC1V 7QE. A Company Limited by Guarantee.

national transition support team

working together to improve transition
for disabled young people

3. The Government is suggesting three ways in which the National Care Service could be funded in the future:
- Partnership – People will 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.
 - Insurance – As well as providing a quarter to a third of the cost of people’s care and support, the Government would also make it easier for people to take out insurance to cover their remaining costs.
 - Comprehensive – Everyone gets care free when they need it in return for paying a contribution into a state insurance scheme, if they can afford it, whether or not they need care and support.
- a) Which of these options do you prefer, and why?
- b) Should local government say how much money people get depending on the situation in their area, or should national government decide?

Keith Clements – Policy Officer – NTST

19/08/09

The Council for Disabled Children and partners working as the national transition support team for the AHDC Transition Support Programme



The national transition support team is a programme of the Council for Disabled Children, which is hosted by the National Children's Bureau. Registered Charity No 258852. Registered in England and Wales No 952717. Registered office: 8 Wakley Street London EC1V 7QE. A Company Limited by Guarantee.