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# *Carers and Disabled Children Bill*

**Bill 13 of 1999-2000**

The Carers and Disabled Children Bill 13 is a Private Member's Bill introduced by Tom Pendry M.P. It is due for a Second Reading on Friday 4, February 2000. The Bill would introduce new provisions for carers, including direct payments in lieu of social services and would extend direct payments to disabled children aged 16 or 17.

The Bill Covers England and Wales.

No explanatory notes were available at the time of writing.

Jo Roll

SOCIAL POLICY SECTION

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## Summary of main points

The *Carers and Disabled Children Bill* would:

- create new duties for local social services authorities for carers aged 16 or over who are looking after adults
- make provision for vouchers to enable carers (both carers of adults and parent carers of a disabled child) to take a break
- extend the availability of *Direct Payments* in place of social services to carers (of adults and of children) and to disabled children aged 16 or 17

**Carers of adults:** Under existing legislation family and other informal carers who are looking after an adult can request an assessment of their caring needs but the assessment can only be undertaken in connection with the assessment of the person being cared for. Even where a carer's needs are assessed, services directly related to these needs cannot be provided to the carer. The Bill would:

- require local authorities, at the request of the carer and regardless of any connection with an assessment of the person being cared for, to assess carers aged 16 or over who are caring for an adult, in order to see if they are able to care, or continue to care, unaided
- require local authorities to then decide whether the carer had needs that could be satisfied by services from the local authority and whether to provide such services to the carer
- enable local authorities to charge for these services
- enable Regulations providing for local authorities to issue vouchers so that the person being cared for could buy services that would enable the carer to take a break at a time of their choosing
- enable local authorities to make *Direct Payments* to carers in place of services that they would otherwise have provided to the carer

**Parents of a disabled child:** Currently services for a disabled child can be provided to the family or any member of the family. They can be provided in cash but only in “exceptional circumstances”. The Bill makes no changes equivalent to the assessment and services provisions that it contains for carers of adults but it would make parallel provisions to:

- enable local authorities to make *Direct Payments* to a parent of a disabled child: and to
- provide for vouchers to enable a parent of a disabled child to take a break

**Disabled Children:** The Bill would:

- enable local authorities to make *Direct Payments* to disabled 16 or 17 year old children

**CONTENTS**

<b>I</b>	<b>Background</b>	<b>7</b>
	<b>A. Carers</b>	<b>7</b>
	1. Current legislation	7
	2. Carers needs still unmet	10
	3. The present Government's policy	12
	<b>B. Direct Payments</b>	<b>16</b>
	1. Current legislation	16
	2. The Present Government's Policy	20
	<b>C. Services for Disabled Children and their Families</b>	<b>22</b>
<b>II</b>	<b>The Bill</b>	<b>27</b>
<b>III</b>	<b>Responses to the Bill</b>	<b>29</b>

# I Background

The *Carers and Disabled Children Bill* brings together several overlapping strands of social services policy: services for carers looking after an adult, including young carers who might be looking after a disabled parent, *Direct Payments*, and services for disabled children and their families. All three strands interweave in relation to carers, who are the main focus of the Bill.

This paper therefore also focuses on carers. It starts by looking at services for carers of adults but in showing how these developed also covers developments relating to parent carers of children and mentions *Direct Payments*. The next section describes the development of *Direct Payments*. The final section briefly outlines the way that services for disabled children and their families fit into the picture. It mentions the pressure for increased provision for short-term breaks that has been prominent in relation to parent carers of children and of people with learning disabilities but also affects those caring for another adult.

## A. Carers

### 1. Current legislation

Explicit recognition in social services legislation of the needs of unpaid, informal carers, who are often family members, is relatively recent. Indeed, there has often been concern that the existence of a carer might simply serve to prevent the person being cared for from receiving any help at all.<sup>1</sup> Nevertheless, over the last 20 or so years, the role of carers has been increasingly recognised in policy statements, if not always in practice and not always with the same emphasis.

The legislation covering social services for adults and social services for children each has its own history but in both cases the issue of the needs of the carer as distinct from the needs of the person being cared for has gradually emerged alongside the concern that carers are not getting the services that they need.

In relation to people caring for adults, the Conservative Government's 1981 White Paper, *Growing Older*, referred briefly to day care, short stay accommodation in residential homes and hospitals, fostering with other families, and holidays provided both by local authorities and voluntary organisations, as ways of giving families a break from the strain of providing continuous care.<sup>2</sup>

The Griffiths Report on community care of 1988, which provided the foundation the major reforms of community care introduced by the *NHS and Community Care Act 1990*, said that

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<sup>1</sup> See, for example, Malcolm Wicks MP during the Committee Stage of his *Carers (Recognition and Services) Bill*, HC Deb 21 April 1995 c527

<sup>2</sup> Department of Health and Social Security, Scottish Office, Welsh Office, Northern Ireland office, *Growing Older*, Cmnd 8173, March 1981, p 38

its proposals took as their starting point that families, friends, neighbours and other local people provided most of the care for people in need. This would continue to be the primary means by which people would be enabled to live normal lives in community settings and the first task of publicly provided services was therefore to support and where possible strengthen networks of carers.<sup>3</sup> But the report was critical of arrangements at the time:

The information provided to carers about service availability and how they might be helped with their onerous responsibilities is limited. A failure to give proper levels of support to informal carers not only reduces their own quality of life and that of the relative or friend they care for, but is also potentially inefficient as it can lead to less personally appropriate care being offered. Positive action is therefore needed to encourage the delivery of more flexible support, which takes account of how best to support and maintain the role of the informal carer.<sup>4</sup>

The 1989 White Paper, *Caring for People*, listed six key objectives for community care reform, one of which was to ensure that service providers made practical support for carers a high priority.<sup>5</sup> Guidance on the *NHS and Community Care Act 1990*, but not the Act itself, said: “*The preferences of carers should be taken into account and their willingness to continue caring should not be assumed. Both service users and carers should therefore be consulted – separately, if either of them wishes – since their views may not coincide.*”<sup>6</sup>

The new focus on explicitly taking carers’ needs into account rather than implicitly accepting their existence also highlighted the lack of knowledge about who carers were. The Department of Health and Social Security (as it then was), in the light of policies which put an increasing emphasis on the role of the ‘community’ in providing care for disabled and older people, was keen to have more reliable information on the supply of informal care than was available from existing research.<sup>7</sup> Special surveys were commissioned as part of the official General Household Survey, in 1985, 1990 and 1995.

Latest official estimates suggest that in 1995 there were 5.7 million carers but this figure covers some who spent a few hours a week ‘helping out’ and some who spent 50 hours or more a week devoted to caring. For example, 1.7 million people spent 20 hours or more a week caring and 855,000 spent 50 hours or more. Some myths were dispelled as it turned out that the proportion of men who were carers (11%), though below that of women (14%), was more substantial than many had thought. Men made up about 4 in 10 of the carers caring at least 20 hours a week and, given that the number of women in the population were higher

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<sup>3</sup> Sir Roy Griffiths, *Community Care: Agenda for Action: a report to the Secretary of State*, HMSO 1988, paragraph 3.2

<sup>4</sup> As above paragraph 4.3

<sup>5</sup> Departments of Health, Department of Social Security, Welsh Office, Scottish Office, *Caring for People, Community Care in the Next Decade and beyond*, Cm 849, November 1989, paragraph 1.11

<sup>6</sup> Department of Health, *Community Care in the next Decade and Beyond, Policy Guidance*, HMSO, 1990, paragraph 3.27 – 3.29

<sup>7</sup> Office for National Statistics, *Informal Carers: results of an independent study carried out on behalf of the Department of Health as part of the 1995 General Household Survey*, HMSO 1998 page V

than men, the proportion of men caring such long hours was not much different from that of women.<sup>8</sup>

Other surveys, such as the British Household Panel Survey, and small scale studies started to provide data revealing the diversity of situations facing carers and highlighting situations that had been ignored.<sup>9</sup> In particular, the nature and extent of children's involvement in caring, started to attract the attention of policy makers. In 1995 the Chief Inspector of Social Services at the Department of Health sent local authorities a letter saying that young carers had suffered from a lack of recognition and urged local authorities to provide integrated services that would recognise the needs of young carers. It pointed out that this could be done under existing legislation. For example, young carers "*with significant caring responsibilities*" should be seen as "*children in need*" under the *Children Act 1989* and therefore as children for whom local authorities were required to provide appropriate services.<sup>10</sup>

As far as legislation mentioning carers was concerned, Section 8 of the *Disabled Persons (Services, Consultation and Representation) Act 1986* included a requirement that when deciding on a disabled person's needs, the local authority must have regard to the ability of the carer to continue caring. The Act (section 4) also required local authorities to make a decision about which, if any, services to provide for the disabled person when either the disabled person or the carer requested it.

The 1986 Act could apply both to carers of adults and to parent carers of disabled children. A carer was defined as any person who provided care where "*the disabled person is living at home and receiving a substantial amount of care on a regular basis from another person (who is not a person employed to provide such care by any body in the exercise of its functions under any enactment*". (A disabled person was given the same meaning as in section 29 of the *National Assistance Act 1948* and Part III of the *Children Act 1989*, thus including both adults and children)

The *Carers (Recognition and Services) Act 1995* (often referred to as the *Carers Act*) started as a Private Member's Bill introduced by Malcolm Wicks, Labour MP, and was adopted by the Conservative Government. All carers young and old, caring for children, parents or other adults, were included in its definition, which covered the situation where, "*an individual ("the carer") provides or intends to provide a substantial amount of care on a regular basis for the relevant person.*" The definition was linked to situations where a local authority was carrying out an assessment for services to the cared for person under various other

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<sup>8</sup> General Household Survey 1985, *Informal Carers* by Hazel Green, Office of Population Censuses and Surveys, 1988; Office for National Statistics, *Informal Carers: results of an independent study carried out on behalf of the Department of Health as part of the 1995 General Household Survey*, HMSO 1998

<sup>9</sup> See, for example, "Informal Carers – A Moving Target," *Cash and Care*, Social Policy Research Unit, York University, 1999 for data based on the BHPS; and *Young Carers: An Evaluation of three RHA funded projects in Merseyside* by Ann Mahon and Joan Higgins, Health Services Management Unit, Manchester University, 1995 for details of some small scale studies looking at a particular groups of carers

<sup>10</sup> Social Services Inspectorate Letter, *Young Carers*, CI (95) 12, 28 April 1995

enactments. (As in the 1986 Act, people providing care under a contract of employment or as volunteers for a voluntary organisation were excluded from the definition of carer).

The *Carers Act* explicitly entitled carers of adults and parent children to ask for an assessment of their ability to care by requiring local authorities to carry out such an assessment on request. However, this was still linked to an assessment of the person being cared for. In particular, the Act did not enable a carer to request an assessment where the person being cared for had refused one. It also required local authorities to take the results of the assessment into account but again only in connection with their decision about services for the person being cared for. No new money was made available on the grounds that it was intended to give legislative force to what was already supposed to be good practice.<sup>11</sup>

Some carers have in theory been able to get help for themselves under other legislation, that is if their needs fall into one of the more general categories of people for whom help is available, for example, if they have need for community care services themselves or as in the example of young carers mentioned above. This was mentioned in the guidance on the *NHS and Community Care Act 1990*<sup>12</sup> and in the guidance on the *Carers Act 1995*.<sup>13</sup> The latter also referred to local authorities' powers to prevent illness under the *NHS Act 1977*<sup>14</sup>, which might be used to help a carer, and to services available under the *Children Act 1989*<sup>15</sup> for *children in need* that could be used for young carers or parents of disabled children.

## 2. Carers needs still unmet

In spite of such measures, reports about the lack of attention paid to the needs of carers and their lack of knowledge about the services available to them continued to appear. Some of them are mentioned below.

In 1997, the Carers National Association (CNA) published a report on the first year of the operation of the *Carers Act* (which came into effect on 1 April 1996) which said that just under half of the carers that the CNA had surveyed had been told about their rights when the (user) was assessed for services and only 18% had asked for an assessment.<sup>16</sup>

In 1998, the Department of Health's Social Services Inspectorate published a critical report on local authority support for carers. This began:

The quality and type of support that carers receive remain a matter of chance. Support depends far more on where carers live and who they are in contact with in social services than on what they need. Some carers are offered very sensitive practical and

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<sup>11</sup> See, for example, John Bowis, then Minister at the Department of Health, HC Deb 1 March 1996 c758-9W

<sup>12</sup> Department of Health, *Community Care in the next Decade and Beyond, Policy Guidance*, HMSO, 1990, paragraph 3.29

<sup>13</sup> Department of Health, Social Services Inspectorate, *Carers (Recognition and Services) Act 1995 Practice Guide*, 1996, paragraph 11.2

<sup>14</sup> Schedule 8 paragraph 2

<sup>15</sup> Section 17

<sup>16</sup> Carers National Association, *Still battling? The Carers Act one year on*, June 1997

emotional support. But others receive no information about what might be available and they are not assessed. This is despite the responsibilities placed on local authorities by the Carers (Recognition and Services ) Act 1995.<sup>17</sup>

The report found differences in support between user groups, for example, that support for carers of older people usually appeared better developed than support for other user groups. In the case of ethnic minorities, although there were examples of good practice, in some instances support for carers did not respond to their needs. The report also said that assessments and reviews for carers were not routinely part of social services practice and most carers were unclear about their entitlement, as were many staff.

The SSI report did find that the implementation of the *Carers Act* had brought greater focus on carers' needs, but mostly "on paper". If carers' issues were to regain the priority for action in local authority social services departments that they had at the time the *Carers Act* was implemented, managers need to take an active role supervising front-line staff. The report itself set out key areas of action for local authority social services departments and said that a *renewed stimulus for carers' issues* was necessary.<sup>18</sup>

The report of a survey of young carers undertaken in 1997 and published in 1998 concluded that the needs of many young carers were still unknown and unmet. Only 11 per cent of young carers in the survey had been assessed for services, and only 5 per cent under the *Carers Act*. The report said that the position of young carers as a group appeared to have changed slightly for the better since 1995 but there was considerable scope for improvement.<sup>19</sup>

A report of the research on young carers in the journal *Community Care* quote a spokesperson for the Association of Directors of Social Services as saying that the research showed that social services departments had tried to embrace the spirit of the Act but that it had proved difficult because they were given no extra resources to do so.<sup>20</sup>

In 1999 the Carers National Association published another report identifying shortcomings in the support available to carers, which made a number of recommendations, including:

- Health and social care support should not be withheld on the grounds that a family carer is available.
- Those in full-time caring relationships should be offered a re-assessment of their needs every six months.

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<sup>17</sup> Department of Health, Social Services Inspectorate, *A Matter of Chance for Carers? Inspection of local authority support for carers*, November 1998, paragraph 1.1

<sup>18</sup> As above, and chapter 1

<sup>19</sup> *Young Carers in the United Kingdom, A Profile*, C Dearden and S Becker, reported in *Community Care* 7-13 May 1998 pages 16-17

<sup>20</sup> "Survey shows young carers still miss out on rights to need assessments", *Community Care* 7-13 May 1998 pages 4-5

- Social services departments and health authorities should establish mechanisms and procedures to identify and assess groups of carers and their relatives with special needs, such as minority ethnic carers, rural carers, and low-income carers.
- Social services departments should develop an extensive network of short-term break schemes, including sitting services, and encourage the development of these services in the voluntary and private sectors.
- Legislation should be introduced to enable carers to receive services and support in their own right.
- Legislation should be introduced to establish a nationwide Carers Payment Scheme whereby carers are given money to choose and buy their own support services.
- All social services departments should expand direct payments schemes to all disabled people.
- There should be one-stop-shops or single points of entry, so that carers and their families can access health and social care services, housing services, housing services, transport and benefits through one access point.<sup>21</sup>

### 3. The present Government's policy

The Labour Party's General Election Manifesto heralded the present Government's interest in carers by saying that it recognised "*the immense amount of care provision undertaken by family members, neighbours and friends*".<sup>22</sup> About a year after the Government came to power, Tony Blair, the Prime Minister, announced plans for developing a national strategy for carers to enable their concerns to be built into Government policy.<sup>23</sup> A report setting out the strategy was published in February 1999.<sup>24</sup>

The Minister responsible for developing the strategy was Paul Boateng, Minister at the Department of Health when he took responsibility for the strategy, and Minister at the Home Office when he made the statement to Parliament on the report in February 1999. The Prime Minister's announcement said that the strategy was to be developed with "an independent reference group of organisations, including the Carers' National Association, the Association of Directors of Social Services, Royal Colleges, Confederation of British Industries, National

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<sup>21</sup> *We're in this together*, Carers National Association, 1999

<sup>22</sup> Labour Party, *New Labour: Because Britain Deserves Better*, page 27

<sup>23</sup> Prime Minister announces national strategy for carers, Prime Minister's Office Press Release, 10 June 1998

<sup>24</sup> *Caring about Carers: a National Strategy for Carers*, HM Government, February 1999. Two associated reports were also published, the *Report of the Consultative Conference on a National Strategy for Carers* and a guidebook on the provision of short-term breaks, *A Real Break*.

Health Services and others.” The Minister with responsibility for co-ordinating the implementation of the strategy is currently John Hutton, Minister at the Department of Health.

Although the strategy does not appear to define the term “carer”, it is concerned with informal, unpaid carers, who are often family members. The report says that the term covers a diverse group of people, including, for example, a pensioner caring for his wife with Alzheimer’s, a young parent of a severely disabled child, a middle-aged wife of someone who has suffered a head injury in a road accident, or a child of 14 whose single parent has mental health problems. It does not cover paid carers such as those working in residential care homes or in people’s own homes although these and other services are discussed in the report where they are considered relevant.

In contrast to some previous approaches to the needs of carers, the strategy covers a range of policies that are the responsibility of different government departments as well as of local authorities and the NHS. It emphasises support for carers who are in, or would like to be in, paid jobs as well as for those who are unable to take a paid job. The report was announced on 8 February in a Press Notice issued by the Prime Minister’s Office, a Written Answer by the Prime Minister<sup>25</sup> and a statement by Paul Boateng to the House of Commons.<sup>26</sup> Putting these together, the main elements of the strategy appear to be:

- A new census question to increase information about carers
- A carer’s pension, intended to give those of pensionable age an extra £50 a week by the year 2050
- A new ring-fenced grant of £140 million over three years to help certain carers take a break (in addition to the special grants to help elderly and disabled adults live independently)
- Legislation to extend local authorities’ powers so that they can address carers needs directly
- A Council Tax reduction for disabled people and their carers who live in accommodation valued at Band A which contains an extra room that they need because of the disability or because of the need for floor space to allow wheel chair circulation
- Consideration of the scope for extending New Deal to help carers return to work
- More carer friendly employment, with the government taking the lead, including the right for carers to take time off to deal with a family emergency
- Support for young carers, including help at school
- Special help for disabled children, with technology to help carers with housing and with transport
- Support for neighbourhood services including care centres
- A new focus on local authority, health and other services taking carers’ needs fully into account, including joint health and local authority plans for support to carers.

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<sup>25</sup> HC Deb 8 February 1999 c36-7W

<sup>26</sup> HC Deb 8 February 1999 c21-33

The provisions on carers in the Bill currently before Parliament are thus part of a wider strategy, some of which is already being implemented. Examples in the social services field include the approval, in March 1999 of the Special Grant for Carers and the publication of the Charter for Long Term Care in December 1999. The *Special Grant Report* described the conditions for local authorities to receive the first year's money of the grant, which they have to use to help carers take a break. In line with existing legislation, the money is available for community care services so is available in the form of services to the (adult) person being cared for.<sup>27</sup> The Charter for Long Term Care, is expressly designed for people aged 18 or over who have difficulties associated with old age, long-term illness or disability; and “*carers who support people in these circumstances*”.<sup>28</sup>

The section in the *National Strategy for Carers*<sup>29</sup> Report on services for carers is particularly relevant to the current Bill and is therefore reproduced below although other sections, such as the next section on helping carers to take a break, are also relevant .

11. Local authorities and others can do a great deal within existing community care legislation to increase flexibility and choice for carers. But there are also legislative obstacles preventing authorities from making provision which would be of great benefit to carers directly, or from putting packages of measures together – including those designed to allow carers to take a break – which would be both more cost-effective and in line with carers' wishes and needs.

12. The way current legislation is cast prevents carers receiving help in their own right. It undervalues their role and needs, and their ability to have a proper say in the kind of provision which best suits them.

13. For example, where a person who needs care has been offered but has refused a community care assessment, it is currently not possible for a local authority to assess the care r 's needs, even if that is what the carer themselves wanted, and to make life easier for the care r, and also for the person being cared for, by giving help directly to them. Local authorities in these circumstances are prevented from providing equipment for the home, such as a mobile phone, which could ease the carer 's burden and reduce the risk of injury. Or when putting a package together which would allow a carer to take a break from caring for a while, a local authority cannot include, in a package, help intended directly for the care r, such as paying for a taxi, even though the alternative – such as providing several hours of a sitting service – could well be both more expensive and less p referable for the person being cared for.

14. Individual carers could have greater flexibility and choice if they were able to receive direct payments or credit scheme arrangements to enable them – with the consent of the person needing care – to arrange for services to be given to them in a

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<sup>27</sup> Department of Health, *Special Grant Report (No 44)* HC 303 of 1998/99, March 1999

<sup>28</sup> Department of Health and Department of Environment, Transport and the Regions, *Better Care, Higher Standards: a charter for long term care*, December 1999

<sup>29</sup> See foot note 24

way that was useful and at a time and a form that was appropriate. For example, a credit scheme could operate on the basis of providing time-based credit which could be exchanged during the year for sitting services or other short - t e r m break support at a time appropriate to the carer.

15. These changes require legislation. In looking at legislation, we need to retain the balance between both respecting the views and meeting the needs of the person being cared for, and giving greater control to carers over services they need to carry out their caring more effectively and to maintain their own health, emotional wellbeing and independence.

16. While bearing this in mind, the Government will legislate when Parliamentary time allows to ensure that authorities are able to address carers' wishes and needs more directly.

The social services aspects of the National Strategy for Carers seems to have all party support even if there are criticisms of some aspects of the Government's policy. The main criticism in relation to social services seems to be inadequate funding. Responding to Paul Boateng's statement on 8 February 1999, Philip Hammond, for the Conservatives, said:

The Opposition welcome any additional support for carers--the great silent army that, quite literally, props up our social care system. We believe that the family is the best mechanism for delivering support to the elderly, the disabled and the frail wherever that is a practical reality.

To support those family carers who give of their time so selflessly is not only a moral obligation on society but the most basic form of economic common sense. Care in the family, where that is possible, is often the best solution for a vulnerable person and for society as a whole. However, we recognise that those benefits have too often been at the expense of the carers. We welcome the tone of the hon. Gentleman's statement, but as so often, there is a gap between the rhetoric and the reality. Much of the statement is a recycling of announcements that have already been made, and still more of it consists of an announcement of further consultation....

The hon. Gentleman has recycled earlier announcements of £750 million for promoting independence and £375 million for vulnerable children. The rhetoric from the Dispatch Box about the improved co-operation between health and social services, the legal duties of partnerships, and the demolition of Berlin walls sounds impressive, but health authorities and social services departments, certainly in London and the south-east, are experiencing squeezed budgets--the hon. Gentleman's rhetoric will ring hollow there. With the best will in the world, the grand vision cannot be realised in areas where the resources available are under concerted attack by the Government.

The ring-fenced special grant for respite care is welcome. The chance of a break from their responsibilities is probably the need most often cited by carers, but in many areas, social services departments and health authorities are already cutting back on the support that they are able to give to the voluntary sector. So long as budgets are under such pressure, how can the Minister ensure that the ring-fenced grant does not

merely substitute for existing funding, often via voluntary organisations that currently provide respite care?<sup>30</sup>

Paul Burstow for the Liberal Democrats, said:

We very much share the view that carers play a vital role which, for too long, has been given inadequate and insufficient attention. Much good practice in the national strategy needs to become the norm. Gathering it together in this one place and highlighting the gaps is a very welcome initiative, which we on the Liberal Democrat Benches certainly support.

We must consider not just the fact that carers save the nation £3 billion, but that they bring an extra quality of life to the loved ones whom they look after and support. Does the Minister therefore accept that the strategy's success hinges on the many thousands of people who are carers but remain uncounted and unsupported? How will the strategy address those hidden carers, about whom the agencies do not yet know? As many as eight out of 10 carers have not yet been assessed by social services departments. How will the Government ensure that such assessment proceeds apace, given that, on Treasury figures, social services departments will be £100 million short in their core budgets in the coming year? How can support and assessment go forward on that basis? I would be interested to hear the Minister say how.<sup>31</sup>

A similar response seems to have come from the Association of Directors of Social Services and many of the relevant charities, according to an article in the journal *Community Care*, the week after the strategy was published. Another concern, voiced by Mencap, was that the proposals fell short of providing a legal entitlement to respite care.<sup>32</sup>

## **B. Direct Payments**

Like the explicit recognition of carers, Direct Payments are a relatively new development in social services legislation. They start with the *Community Care (Direct Payments) Act 1996*. This section outlines the Act and its history.

### **1. Current legislation**

The *Community Care (Direct Payments) Act 1996* came into force on 1 April 1997 in relation to certain *community care services* for certain adults. It enables local authorities to make payments to individuals where they would otherwise have provided services. The individuals then use the payments to buy themselves services equivalent to the ones that the local authority would have provided (but not for buying local authority services).

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<sup>30</sup> HC Deb 8 February 1999 c24-5

<sup>31</sup> HC Deb 8 February 1999c26

<sup>32</sup> "National strategy needs more money to succeed", *Community Care* 11-17 February 1999 page 2-3

Local authorities do not have to provide these payments and individuals do not have to receive help in this form if they would rather have a service arranged by the local authority. The Act provides that where they do make a payment, local authorities may require repayment if the money has been misused.

Individuals may not buy services from close family members or people who would be living in the same household anyway. This was the result of the stated policy intention that Direct Payments should not be used to replace existing support networks within families and communities or to create pressure for informal care to be put on a formal contractual basis.<sup>33</sup> The excluded categories are set out in Regulations, which also set out who may or may not receive a Direct Payment and exclude people aged 65 or over from receiving Direct Payments. People with learning disabilities are included as long as it appears to the local authority that they are capable of managing their affairs.<sup>34</sup>

Direct Payments can only be made in relation to certain community care services and therefore apply to adults they do not apply to carers. Community care services are defined in Section 46 of the *NHS and Community Care Act 1990*. The sorts of services that are covered by the *Direct Payments Act* include, for example, assistance in the home, short-term residential care, attendance at a day centre, but not long-term residential care (which is also a community care service but is excluded by Regulations<sup>35</sup>).

The starting point for getting a Direct Payment is a local authority's assessment of a person's community care needs. If it appears to the local authority that someone needs services - whether it be someone to provide personal assistance, an adaptation, special equipment, or any other service which the authority might provide - it has a duty under the *NHS and Community Care Act 1990*<sup>36</sup> to assess his or her needs.

Following an assessment, local authorities have powers and duties to provide community care services but before the Act, in England and Wales they were expressly forbidden by several statutes from providing cash for the same purposes. (They could provide cash for the benefit of children under separate legislation but even then it was mostly to be provided in exceptional circumstances.)

Where local authorities provide such services, they are able to make a charge for them. The legislation that empowers local authorities to charge for such services is Section 17 of the *Health and Social Services and Social Security Adjudications Act 1983*. This says, among other things, that an authority providing a relevant service may "*recover such charge (if any) for it as they consider reasonable*" and that if a person "*satisfies the authority providing the service that his means are insufficient for it to be reasonably practicable for him to pay for the service the*

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<sup>33</sup> HL Deb 15 January 1996 c410-411

<sup>34</sup> The *Community Care (Direct Payments) Regulations SI 1997/734*

<sup>35</sup> As above

<sup>36</sup> Section 47 and related legislation

*amount which he would otherwise be obliged to pay for it, the local authority shall not require him to pay more for it than it appears to them that it is reasonably practicable for him to pay."*<sup>37</sup>

The *Direct Payments Act* makes parallel provision for local authorities to make a Direct Payment at a rate below their estimate of the cost reasonable of securing the service unless the payee satisfies the local authority that his means are insufficient for it to be reasonably practicable for him to make up the difference.

The principle behind Direct Payments was to help disabled people control their own lives. The Act had cross party support and was supported by many disability groups. In particular, the Disablement Income Group and the British Council of Organisations of Disabled People (which consisted of 50 organisations representing disabled people) had both been campaigning for direct payments for some years. The principle is also supported by the local authority associations and the Association of Directors of Social Services.

In spite of wide support for the principle, there were concerns about the implementation of Direct Payments.<sup>38</sup> The question of who would be eligible to receive direct payments was particularly controversial, in particular the Government's decision that Regulations should exclude people over 65 - at least initially. The question of support services was also an issue. Other issues included the question whether local authorities should be required, rather than permitted, to provide direct payments where there was the demand; the proposed exclusion of family members as employees; whether personal assistant and/or care agencies should be regulated; and the adequacy of resources.

The Conservative Government had hesitated for some years before deciding to introduce Direct Payments. At the time of the passage of the *NHS & Community Care Act 1990* through Parliament, Andrew Rowe, a Conservative backbencher, attempted to bring in a new clause to legalise direct payments for care or personal assistance services. He failed to obtain the unequivocal support of either Government or Opposition.<sup>39</sup> Two years later he introduced a Ten Minute Rule Bill on the same issue but failed to secure a Second Reading.<sup>40</sup>

In 1993 Lord McColl introduced a bill with a similar purpose in the House of Lords which passed all its stages in the Lords but made no progress in the House of Commons.<sup>41</sup> On Third Reading, Lady Cumberlege announced "*with considerable regret*" that the Government could not support the Bill but did not seek to oppose it.<sup>42</sup>

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<sup>37</sup> Charges for residential care are covered by separate legislation and the rules are more rigidly specified in the legislation.

<sup>38</sup> See *The Community Care (Direct Payments) Bill [HL]* Bill 64 of 1995/96, Library Research Paper 96/29 for more details about the background to the Bill and its passage through Parliament.

<sup>39</sup> SC E 22 February 1990 cc1223-1232

<sup>40</sup> *The Disabled Persons (Services) Bill*, HC Bill 44 of 1992/93.

<sup>41</sup> *The Disabled Persons (Services) (No.2) Bill [HL]* of 1992/93: Second Reading: 21 April 1993; Committee: 11 May 1993; Third Reading: 24 May 1993

<sup>42</sup> HL Deb 24 May 1993 c81

At about the same time as Lord McColl's Bill was being debated in the House of Lords, the Health Select Committee in the House of Commons was conducting an enquiry into the new arrangements for community care under the *NHS and Community Care Act 1990* which had been introduced in April 1993. The Committee's report concluded that although it might be necessary to wait until the community care reforms had settled down, its members believed that the principle of giving *some* users the financial resources to purchase their own services merited investigation.<sup>43</sup>

The Government's response to the Health Committee was given in September 1993. In this it continued to express doubts about the introduction of Direct Payments to individuals in lieu of services and referred to the fact that the new community care arrangements had only just been put in place but concluded that the Government was committed to continuing to examine the issue of direct payments and it would give further careful consideration to the Committee's suggestions.

The change of view was announced on 24 November 1994. Virginia Bottomley, then Secretary of State for Health, said that eligibility would be restricted to a small group and the intended power would be permissive. A later Written Answer made clear that no additional resources would be provided.<sup>44</sup> Virginia Bottomley's announcement said the following:

I intend to take, in conjunction with my right hon. Friends the Secretaries of State for Scotland and for Wales, a new power to enable social services authorities and social work departments to make direct cash payments to disabled people in lieu of community care services. Direct payments are a logical extension of the citizen's charter. They will give disabled people greater independence and choice and involve them and their carers more fully in their own care.

This development will give disabled people greater independence and control over their lives. It fully complements the other important measure which my hon. Friend the Minister for Disabled People is announcing. But, as a new departure, direct payments carry some risks. So in the short term we intend to limit those able to receive such payments to a relatively small group, probably those disabled people who are able and willing to manage their care. The intended power will also be permissive - authorities themselves will need to decide whether to take advantage of it, based on their judgement of whether it will help them make better use of their resources. Direct payments will be an alternative to community care services, where authorities assess a need for them. There will be no overlap with social security benefits.

There are many complex issues to be resolved. We will be working with the key interests to make sure the details are right. It would be unwise to introduce legislation

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<sup>43</sup> *Community Care: The Way Forward*, Health Committee, HC482 -1 of 1992/93 pp xv-vi

<sup>44</sup> HC Deb 7 February 1995 c131W

before we are satisfied that we have done so. We hope to move a Bill as soon as practicable.<sup>45</sup>

Since the *Direct Payments Act* came into force, there has been pressure from various organisations to extend it, both in terms of coverage and in terms of support and information to enable those who are already covered to make use of the scheme possibility. About a year after the Act came into effect, Paul Boateng, then Minister at the Department of Health, berated local authorities for dragging their feet in implementing the scheme. He was reported in the journal *Community Care* to have said that only 31 councils had introduced Direct Payments schemes.<sup>46</sup>

The reported response from the Association of Directors of Social Services was that most authorities were setting up the appropriate advice and support systems before implementing their schemes.<sup>47</sup> A later article, in January 1999, reported the Association as saying that one obstacle had been the lack of pump-priming money to establish a support infrastructure. Ian Davey, chairperson of the Association's disability committee was quoted as saying that experience from other countries showed that direct payments were cost-neutral or even cheaper than traditional means of providing services. But there were start-up costs to establishing a scheme.<sup>48</sup> The National Centre for Independent Living has said that many disabled people are daunted by the prospect of recruiting workers and of accounting for money even though they would value the independence provided by Direct Payments if they had enough support.<sup>49</sup>

Some concerns relate to particular groups. For example, there have been reports about the problems that people with learning disabilities have encountered when attempting to obtain Direct Payments.<sup>50</sup> Voluntary organisations, such as the Anchor Trust and Age Concern, have called for the extension of Direct Payments to people aged 65 or over. Age Concern has also made several other recommendations including: that it should be mandatory for local authorities to offer Direct Payments and that the Government should consider extending the scheme so that relatives could be employed.<sup>51</sup> Carers, too, have called for their own Direct Payments (see previous section).

## 2. The Present Government's Policy

The present Government announced a review of Direct Payments on 24 April 1998. The scope and timetable of the review were set out in a letter to local authorities:

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<sup>45</sup> HC Deb 24 November 1994 c333W

<sup>46</sup> "Boateng attacks councils' failure on direct payments, *Community Care*, 28 May – 3 June 1998

<sup>47</sup> As above

<sup>48</sup> "The Costs of Control," *Community Care*, 21-27 January 1999

<sup>49</sup> "Exercising the right freedom of choice," by Frances Hasler of the National Centre for Independent Living, *Professional Social Work*, June 1999

<sup>50</sup> See, for example, Joseph Rowntree Foundation Findings, *People with learning difficulties and their access to direct payments schemes*, June 1999 – Ref 649

<sup>51</sup> *Direct Payments Review, Age Concern's Response*, Age Concern Briefings Ref: 2398, July 1998

6. The Government has decided to review the implementation of the direct payments legislation. The review begins on 24 April 1998, and its outcome should be available by the end of the year. The review will provide the Government with information to allow it consider whether there should be any changes to the legislation, for example, to extend the eligibility criteria for direct payments to allow people aged 65 and over to receive them.

7. If local authorities, disability groups, voluntary organisations, direct payment recipients, and any other interested parties wish to contribute to the review you should send your comments to me at the address below by Friday 31 July. Comments are particularly invited on your practical experience of the implementation of direct payments or any studies or research you have carried out.<sup>52</sup>

The Social Services White Paper published in November 1998 announced that the Government would be removing the age limit so as to make people aged 65 or over eligible for Direct Payments. The White Paper also gave an indication of the Government's general approach to Direct Payments:

2.14 One way to give people greater control over their lives is to give them the money and let them make their own decisions about how their care is delivered. This was made possible for physically disabled people and people with learning disabilities aged under 65, through legislation which came into force last year. Local authorities are now able to offer cash to such people whom they had assessed as eligible for home care, day care or occasional short stays in residential or nursing homes. At the start of this year, around 1,000 people were participating in schemes, in 31 authorities. More authorities are bringing in schemes this year.

2.15 Direct payments are giving service users new freedom and independence in running their own lives and we want more people to benefit from them. We have decided, therefore, to remove the age limit and to make people aged 65 and over eligible for direct payments.

2.16 We will also be seeking to ensure that more authorities are offering this opportunity to service users in their areas. We will be conducting a further survey to see where direct payments schemes are being offered, and to find out from those councils who have no plans for a scheme where the obstacles lie. If the case is strong enough, we will consider making it mandatory for all authorities to operate schemes, to ensure equity of opportunity across the whole country.

2.17 Other changes to direct payments are being considered as part of a review of the scheme to learn lessons from its first year of operation. The review is also looking at how direct payments support independent living by working in conjunction with the other help available, including the Independent Living Fund, a social security fund which provides benefit support on the basis of a social services assessment to very

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<sup>52</sup> Department of Health, *Community Care (Direct Payments) Act 1996: A Guide to Receiving Direct Payments and eview of Direct Payments*, LASSL (98) 7, 24 April 1998

severely disabled people to help them to live independently in the community. When the review is completed early next year, we will consult local authorities and other interested groups on our plans for strengthening and extending the scheme.<sup>53</sup>

In October 1999, the Government published new draft guidance on the Act in response to the review, which referred to the extension of the scheme to people aged 65 or over and included a copy of the draft Regulations for achieving this. It also covered various other changes that did not need to be made by primary legislation. Although the document was limited to changes that did not require primary legislation, the covering note announced the Government's intention to introduce other changes that would require legislation:

As part of the review of direct payments, Ministers have concluded that direct payments should also be extended to disabled children aged 16 & 17 and to adults caring for disabled children. These proposals will require primary legislation and so will need to await a suitable legislative opportunity before they can be implemented. In addition Ministers have concluded that any future legislation which gives local authorities powers to provide services to carers should also include the power to make direct payments in lieu of those services.<sup>54</sup>

### **C. Services for Disabled Children and their Families**

The *Children Act 1989* Part III makes provision for local authority services for children and their families. In particular Section 17 of the Act requires local authorities:

- (a) to safeguard and promote the welfare of children within their area who are in need and
- (b) so far as is consistent with that duty, to promote the upbringing of such children by their families, by providing a range and level of services appropriate to those children's needs.

Section 17 defines a child "in need" as including a disabled child and defines a child as being disabled:

if he is blind, deaf or dumb or suffers from mental disorder of any kind or is substantially and permanently handicapped by illness, injury or congenital deformity or such other disability as may be prescribed.

Among the other provisions of Section 17, is provision that services for the benefit of a child "in need" can be provided to any member of the child's family:

Any service provided by an authority in the exercise of functions conferred on them by this section may be provided for the family of a particular child in need or for any

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<sup>53</sup> Department of Health, *Modernising Social Services* Cm 4169, November 1998

<sup>54</sup> Department of Health, *Community Care (Direct Payments) Act 1996*, October 1999

member of his family, if it is provided with a view to safeguarding or promoting the child's welfare.

The Section also says that the services provided by a local authority may include giving assistance in kind or, "in exceptional circumstances", in cash.

This legislation could enable a wide range of services for disabled children and their families. Some evidence of the needs of such families is available from recent research, including studies for the Government. One of the points to arise from the most recent publications is short-term breaks (in the past more often referred to as 'respite care') appear to be popular but that there seems to be a shortage of supply.

The Joseph Rowntree Foundation has been funding a programme of research concerning disabled children and their families. In November 1999, it published a summary of the main findings from the first five years of the programme and identified a number of policy implications. Among these were that:

**Human rights**

- The human rights of disabled children (for example, their right to be consulted) are often not recognised in practice, particularly in the case of those who have high levels of support needs.

**Co-ordinated support**

- There is little evidence of inter-agency working and few examples of co-ordinated approaches to family support.
- Parents and carers of disabled children often have to deal with many different professionals and would appreciate a co-ordinated approach with one person acting as a 'keyworker'.

**Flexible support**

- Families with disabled children need and appreciate access to support which is flexible in terms of timing and type of help provided.

**Information**

- The availability of information, and the way in which it is given, is often crucial to the well-being of parents and carers.

**Housing provision**

- Having a disabled child can mean that a family has particular housing requirements. Whether these housing needs are met or not can make a major difference to the quality of children's and parents' lives. It can also influence what other support is required.

**Short breaks**

- Family-based short breaks ('shared care') have proved popular with both parents and children; waiting lists have increased over the last few years.
- Some families prefer residential-based short break services, particularly if their children have nursing care needs. Some disabled adolescents like spending time away from home in a communal setting with their peers.

**Economic and social policy**

- Central government's economic and social policy initiatives generally treat the families of disabled children as peripheral or invisible.

- Tackling the social and economic inequality faced by disabled children and their families requires resources; policy initiatives to date have not allowed for this.<sup>55</sup>

The Government's *Quality Protects* programme for children includes targets for helping disabled children and attempts to map their needs. A recent analysis for the Department of Health of local authority responses to this programme, with special reference to disabled children, based on 88 Management Action Plans (MAPs) of local authorities also referred to the shortage of available provision for short-term breaks:

73 authorities made specific reference to areas of unmet need, many noting demand for certain services such as respite care greatly exceeding supply. The majority of authorities did not routinely record unmet needs, with concerns being expressed about recording unmet needs which the authority could not address. Particular areas of concern included the need to target scarce resources towards the most severely disabled children. Two plans recognised the importance of creating greater inclusion within existing mainstream services to 'free up' more specialist services for the children with more complex needs. However, only 13 MAPs made explicit links to mainstream leisure, day care or after school provision: the majority focusing upon traditional respite care services for family support.

Mencap has been campaigning for several years for disabled people and carers to have a legal right to short-term breaks both for adults and children. For example, Lord Rix, chairman of Mencap, introduced the *Disabled Persons and Carers (Short-term Breaks) Bill* in the House of Lords in 1996<sup>56</sup> and a similar Bill was introduced by Huw Edwards in the Commons in 1998.<sup>57</sup> But neither of these was successful.

In 1998, Lady Pitkeathley, previously head of the Carers National Association, asked the present government whether they had any plan to introduce a right to short-term respite care breaks for disabled people and carers. Lady Jay, then Minister at the Department of Health replied:

My Lords, the Government are not planning to bring in legislation to introduce such a right, We nonetheless recognise the great importance attached to respite care for carers and those for whom they care and we are committed to ensuring that local authorities also recognise this.<sup>58</sup>

The National Strategy for Carers Report referred to in Part I of this paper discussed short-term breaks. This paper reproduced the section from the Report on services for carers in Part

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<sup>55</sup> *Supporting Disabled Children and their Families*, Joseph Rowntree Foundation, Foundations, Ref N79, November 1999

<sup>56</sup> *Disabled Persons (Short-term Breaks) Bill* [HL], Second Reading, 17 April 1996 c751-782

<sup>57</sup> *Disabled Persons (Short-term Breaks) Bill*, HC Second Reading, Deb 18 March 1998 c1305-1310

<sup>58</sup> HL Deb 30 March 1998 c8

I above. This mentioned breaks but there was also a section specifically on services for carers, which is reproduced below.

17. Supporting the independence of carers means allowing them to have some time on their own, or for themselves. This means time to pursue their own interests, see their own friends, take care of their own needs or just catch up with jobs around the house. A break from caring is invaluable in reducing the psychological and emotional stress faced by many carers. Access to support services and breaks can also help carers to continue providing the support they give to a sick, disabled or elderly person.

18. Some local authorities provide a wide range of services to give carers a break. But in many areas there is no choice. All too often, the only service available to allow the carer a break in their area is a place for the person being cared for in a residential care or nursing home.

This may not provide what either the carer or the person needing care wants. A number of local authorities also provide day centres to give a break to the care r. But there can be difficulties, particularly where the t r a n s p o r t to the day centre is unreliable or does not arrive at a fixed time to allow the carer to plan his or her day and carry out other activities. A range of services is more likely to meet the diverse needs of care r s .

19. The most common form of break for carers is support from friends or relatives, which is used by 2.3 per cent of all carers <sup>29</sup>. Only 1.3 per cent of carers used time in a nursing or residential home for the person for whom they were caring to enable their last break. Among carers who spend at least 20 hours a week caring – nearly half of them had been caring for more than five years – 49 per cent had not had a break since they began to care. Six out of 10 carers, who lived with the person they cared for, felt unable to leave that person unattended for as little as 2 hours. Of those, 14 per cent had, in the past, made use of a sitting service.

20. Some carers do not use services to allow them to take a break – for a number of reasons, including: • a lack of information about the availability of services and how to access them; • little choice about the timing or type of service; • the quality of services is not always good and can deter carers and the person for whom they are caring.

21. But when services are provided they are usually found to be helpful. One of the most comprehensive studies of services providing a break for carers was *Better for the Break* <sup>30</sup> which considered services for carers of elderly people with Alzheimer's Disease or related disorders.

The study found that:

- ninety per cent of the carers in the study who used day care said that it had made their lives better, and 80 per cent thought it benefited the elderly person.
- a third of those who had used relief care at least once felt the elderly person benefited, and 80 per cent of them said relief care had made their own life better. The

most frequently reported benefit was increased patience and feeling more able to carry on; • sixty per cent of those who had used a sitting service said the visits helped the person they cared for. Nearly all the carers said the service had improved things.

22. We are publishing, alongside this report, a separate document called *A Real Break*, which provides useful details about schemes to allow carers a break which meet their particular needs and circumstances as well as those of the people they care for.

23. For many people, local authorities will have the lead responsibility for arranging and funding services to allow carers to take a break from caring. The NHS also has a crucial role, especially when specialist medical or nursing help is required for the person needing care in order to allow the carer to have a break. Planning and provision of services to give carers a break must involve both the local authority and the health authority. They should agree on who will be eligible for services, and describe their proposals in Joint Investment Plans. Carers and organisations which represent them should be consulted on those plans.

24. The Government has already announced the allocation of £750 million over the next three years to promote independence through prevention of illness, disability or disease, and through rehabilitation, and carers and the people they care for will benefit from this. On top of that we are making available a new special grant – ring-fenced funding – to local authorities for the enhancement of services to allow carers to take a break from caring. The grant will total £140 million for England over the next 3 years – £20 million in 1999/00, £50 million in 2000/01, £70 million in 2001/02. Local authorities will need to assess the needs of carers in their area for services of particular types. These services may be many and varied, including domiciliary and sitting services that give the carer a short - break, or longer breaks or holidays. Local authorities could use a checklist of questions in making their assessment.

25. The Government will make it a condition of receipt of the new special grant for carers that local authorities review, with other agencies and especially the health service, their provision of services to give carers a break from caring. They will be required in the first year of the grant explicitly to involve and consult carers and their organisations on the appropriateness of current provision and the possibility of greater diversity. Where evidence shows that existing services meet the needs of carers, these should be enhanced. Where more diversity is needed, and especially a wider variety of services at different times of the week and at weekends, authorities must plan how to stimulate provision of such services.

26. In providing or developing the provision of short breaks for carers, the empowerment of the carer should be a key aim. What carers want most of all during a break from caring is that their relative is well cared for and secure. But the carers' voice is often not heard, and their own needs can be overlooked. Carers' needs should be considered on an individual basis and they should have choice about the type of services designed to give them a break which they would like, and about the timing of the break.

## II The Bill

This section outlines some of the main points in the Bill. It does not cover every detail.

### *Clauses 1-5 and 7 deal with carers aged 16 or over looking after an adult*

#### *Clause 1 deals with assessments*

Clause 1 (1): This requires local authorities to carry out an assessment of the carer's ability to provide, and to continue to provide care, if the carer asks the local authority to do so. The person being cared for must be someone for whom the local authority could provide community care services [see Part I B of this paper for an outline of community care services] but the assessment of the carer is not related to an assessment of the person being cared for. This is a departure from existing legislation [see Part I A of this paper].

Clause 1 (2): This enables local authorities carrying out a carer's assessment under this Bill to take into account an assessment under the *Carers (Recognition and Services) Act 1995* in so far as it considers it material to do so [see Part I A of this paper]

Clause 1(3): This excludes people providing care under a contract or as volunteers for a voluntary organisation from the definition of carer, which is similar to previous legislation [see Part 1 A of this paper]..

Clause 1 (4): This enables the Secretary of State in England and the National Assembly in Wales to give directions about the way an assessment is to be carried out.

Clause 1 (5): This says that subject to such directions, the assessment is to be carried out as the local authority considers appropriate.

Clause 1(6): This defines voluntary organisation as in the *National Assistance Act 1968*. Section 64 of that Act says *voluntary organisation* means a body the activities of which are carried on otherwise than for profit, but does not include any public or local authority.

#### *Clause 2 deals with services for carers*

Clause 2 (1): This requires the local authority to consider the assessment; to decide whether the carers has need that could wholly or partly satisfied by services that the local authority could provide; and, if so, whether or not to provide services to the care. This goes beyond existing legislation in that it provides for services to the carer [see Part 1 A of this paper]. Examples that have been mentioned in Government statements include mobile telephones and taxi rides.

Clause 2 (2): This defines the services as those which a) the local authority sees fit to provide and which will, in the authority's view help the carer in providing care for the person being

cared for. It says that the services can take the form of physical help or other forms of support.

Clause 2 (3): This says that although the service is provided to the carer, it can take the form of a service delivered to the person cared for if it is a community care service. But if it is provided to the person cared for, it must not include any services of an intimate nature.

Clause 2 (4) : This says that Regulations may make provision about the definition of "intimate nature".

***Clause 3 deals with vouchers:***

Clause 3(1): This provides for Regulations to make provision for the issue of vouchers by local authorities. Vouchers are a new provision that appear to correspond to the idea of a credit for carers for carers referred to in the *National Strategy for Carers Report* [see Part I A].

Clause 3 (2): This defines vouchers as documents issued to the person being cared for where the local authority has agreed with the carer that it would help him/her is s/he took a break. It would enable the person being cared for to secure services that would otherwise have been provided by the carer. These services would take the form of temporary community care services [see part I B].

Clause 3 (3): This specifies some points that the Regulations may provide for, that is: for the value of the voucher to be expressed in terms of money or of the delivery of a service for a period of time or both; for the service or service provider or arrangement under which the service is provided to be approved by the local authority; for the vouchers to be issued to the carer or the person cared for; for a maximum period during which a service can be provided against a voucher.

Clause 4: This amends the *Carers Act* so that an assessment under that Act can take an assessment under this Act into account. Where the question of providing a service to the carer under this Bill or to the person cared for under community care legislation arises, it requires local authorities to decide under which provision it is going to provide the service and who to provide it to, the carer or the person cared for.

***Clause 5 and 6 deal with direct payments***

Clause 5: This amends the *Direct Payments Act* so that Direct Payments can be provided instead of services to carers provided under Clause 2. [See part I B of this paper for a discussion of Direct Payments]

***Clause 6 deals with direct payments and vouchers for parents of a disabled child and 16 or 17 year old disabled children***

Clause 6: This amends the *Children Act 1989* so that direct payments can be made under that Act instead of services that would have been provided under Section 17 of that Act.[ See Part I C of this paper]. It provides that the direct payment must not be used to buy services from certain people (who are to be prescribed in Regulations). It also provides for Regulations to exclude long-term residential care from direct payments. [See part I B of this paper]. It also provides for Regulations for vouchers, similar to those provided for by Clause 3, to parent carers of a disabled child in order to secure services under Section 17 of the *Children Act 1989*. [See Part I C of this paper]

### ***Clause 7 deals with charging***

Clause 7: This provides for services for carers under the Bill to be included among those for which local authorities can charge under the *Health and Social services and Social Security Adjudications Act 1983 Section 17*. [ See Part I B of this paper]

### ***Clauses 8-11***

Clause 8 deals with minor and consequential amendments; Clause 9 makes financial provision; Clause 10 deals with interpretation and Regulations; and Clause 11 deals with the short title, commencement and extent.

## **III Responses to the Bill**

Due to the short time between publication of the Bill and the Second Reading, few organisations had had time to respond at the time that this paper was being written. Below are summaries of views of organisations received in the Library (listed in alphabetical order by name of organisation).

### **Association of Directors of Social Services**

The Library has not received their views but they were quoted in the journal *Community Care*, which said that social services directors were anxious that councils could face a sharp rise in claims without additional funding. The journal said that Andrew Cozens, spokesperson for the Association, called to the £140 million Carers Grant from Government to local authorities for be increased so that local authorities could cope with the demands of the Bill. It quoted him as saying that in many local authorities fewer than 10 per cent of eligible carers were getting a care assessment.<sup>59</sup>

### **Carers National Association**

The CNA welcomed the Bill as an important step forward. It said that the Bill would give families more choice and flexibility to arrange the types of services that they need. It was

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<sup>59</sup> “Carers Bill adds to cash worries”, *Community Care* 13-19 January 2000

concerned that carers should not be charged for services that were designed to assist and support them in their caring role. Carers saved social services departments millions of pounds every year by providing unpaid care. CNA did not think that it was equitable to expect carers to pay additionally for services as well as having to give up their own time to provide informal care. It was also concerned about the amount of funding available not only for carers but also for services for people being cared for. In particular, it argued that if carers had more confidence in the services provided to disabled and elderly people, carers would feel happier about taking a break.

### **Council for Disabled Children**

The Council said that all its member organisations warmly welcomed the Bill and the proposal to extend direct payments to disabled children and young people and their families. There were a number of points on which they would like clarification, for example: if young disabled people received direct payments in their own right, how would the balance between parents' and young people's wishes and feelings be balanced? Parents might need respite care for their own survival but a young person might not wish to use available services. It argued that the development of a proper advice and advocacy service was essential. Another concern was whether there would be enough services for people to buy.

### **Mencap**

Mencap welcomed the Bill and the fact that it legally recognised the role of carer but was concerned that it did not give carers a right to respite care. It also welcomed the extension of direct payments. It was concerned that no additional resources were being allocated for respite care (additional to those already announced) as a major problem at the moment was the lack of choice for respite care. It also said that there many issues to do with vouchers that would need clarification as the details were not in the Bill.

### **National Centre for Independent Living**

The NCIL said that there was much in the Bill to be welcomed. In particular it had recommended direct payments for 16 and 17 year olds. Greater flexibility in the services arranged would benefit everyone. However, a core purpose of the *Direct Payments Act* had to been to increase independence by giving disabled people more control over the way that community care services were delivered. Any extension of direct payments to other groups must not undermine this basic principle for disabled people. Payments to carers must therefore not take away choice or control from disabled people. The fact that carers could not get Direct Payments for any service of an intimate nature for the disabled person was a partial safeguard against disabled people being coerced into taking care situation not of their choosing. But it needed to be buttressed by firm commitments to principles of independent living whenever Direct Payments were offered. Many of the conflicts between carers and disabled people arose because no appropriate service was on offer.

**RADAR**

RADAR said that the Bill was encouraging in that it offered direct payments to disabled people of 16 and 17 and it also gave more choice to parents of disabled children. However, there was a danger that conflict would arise between the carer and the person for whom the care was being provided. It was crucial that there should be clear policy guidance about how such conflict would be resolved and that this guidance should be uniformly applied by local authorities.